“how do you make leukaemia visible? Well how do you?”: Jo Spence’s photofantasy as a participatory artistic method

Lizzie Merrill

PhD

University of York

Centre for Women’s Studies

March 2025

Abstract

This study examines the artist Jo Spence's *The Final Project* (1991-1992) and the visual outcomes of a workshop based on Spence's method of photofantasy, held with participants, which produced 32 artworks. It explores how photofantasy expresses the embodied experiences of people who have had cancer. Developed following Spence's leukaemia diagnosis in 1990, photofantasy involves collaging through "sandwiching slides together and making camera double exposures" (Dennet in Lee 2013, 9). Her collaborator, Terry Dennett, recalled the effects of her leukaemia, noting that it made her "less mobile" and "sapp[ed] her energy", leading Spence to realise that "her health was no longer good enough for her to engage directly in photography" (Dennet in Spence 1995, 222) as she had done previously. In response, Spence adapted her practice, using photofantasy to continue artistic production despite her physical limitations.

While *The Final Project* has been critically framed as a meditation on death (Boyer 2016, Lee 2013), this study challenges that interpretation, presenting photofantasy as a rich site for the exploration of illness experience. Many of the physical challenges of Spence's leukaemia, namely lowered immunity and exhaustion, are experienced by other cancer sufferers because of the effects of their disease/treatment. Photofantasy uniquely addresses these constraints, allowing artistic engagement without extensive movement or direct self-representation. Its collage-based nature enables the reimagination of photographic realities, allowing the creator to reinterpret their lived experiences. It also allows meaning to emerge as the practice unfolds, without requiring a predetermined concept. Thus, photofantasy offers a unique insight into aspects of the experience of cancer patienthood that are inaccessible through language alone.

Through visual analysis and auto-theory, this study is grounded in the lived experience of cancer. It shows how Spence and participants used photofantasy to reclaim agency, challenge dominant cancer narratives and expand visual metaphors of illness.

Contents

Figure List

Figure 5.7. Fairy's Workshop Artwork.

Figure 5.8. Opal's Workshop Artwork.

Figure 5.9. Helena's Workshop Artwork.

Acknowledgements

To Clare Bielby and Boriana Alexandrova, thank you for challenging me, supporting me and showing me what being part of feminist academia is all about. I am incredibly lucky to have been able to learn from you both and to have your ongoing encouragement. I do not take for granted how much time and care you've afforded me and this project – it has made it all possible!

To Francesca Lewis, thank you for being a huge source of inspiration as well as for being my co-supervisor for a time. Your scathing notes in the library's copy of *The Wounded Storyteller* offered me comic respite even on my most miserable days.

To my participants, I am so thankful for your openness and willingness to share your experiences with me. My time running the photofantasy workshops was some of my favourite in academia. Your creativity has given me so much to work with, I can only hope that I have done justice to your creations.

To my mum and my nana, thank you both for your uncanny ability to bring me back to reality and for telling me you knew I could do this, which made it impossible for me not to. I owe you everything.

To Jess, Erlina and Beca thank you for hanging around, always checking-in and reminding me there's more to life than all of this.

To Daisy and Maddy, I cannot thank you enough for every elongated meeting, every WhatsApp moan and every listening ear you've leant me. I am in awe of you both and my PhD would not have been the same without you.

To Ollie, thank you for living this process alongside me, for weathering every bad mood, every off day and every knock in confidence. You're the safest place I know.

To Marbles, Ozzie and Fred, this thesis was in your furry hands all along. You were there looking up at me when I thought I just couldn't write another word, your little wet noses prodding me when I thought I was losing my mind. You'll never know all the joy you've brought me.

Author's Declaration

I declare that this thesis is a presentation of original work and I am the sole author. Part of Chapter 1, "A Feminist Participatory Practice: My Methodological Approach", was presented at two conferences, Sisterhood in Action at the University of York (2024) and the Interdisciplinary Bodies conference at Brunel University (2024). In addition to this, I developed an exhibition based on this project titled "Photofantasy", that was held at Four Corners Gallery in Bethnal Green, London from 12th-15th June 2024. From this exhibition, I published an article titled "Photofantasy: A Curatorial Essay" on The Polyphony (2024). Aside from these instances, this work has not been presented or published elsewhere. This work has not previously been presented for a degree or other qualification at this University or elsewhere. All sources are acknowledged as references.

Introduction

A Wellcome Introduction to Jo Spence

As is sometimes the way with things that prove to be deeply formative, I came upon Jo Spence's work with little idea of the impact it would have on the trajectory of both my life and my research. In December 2019, as a master's student, I was recommended the *Misbehaving Bodies* exhibition. It was being held at the Wellcome Collection, London and promised to explore artistic representations of chronic illness and death. As someone interested in the intersections between art and death studies, I was sold when I learned that the exhibition featured visual artist Oreet Ashery's exploration of her father's death, alongside several video works addressing chronic illness and dying in the digital age also by Ashery. I was aware that the exhibition also included the works of Spence, an artist who documented her experience living with breast cancer, but this was of less interest to me. As Ashery was a visiting professor at my university at the time, I was intrigued by the prospect of seeing her films – as well as the possibility of interviewing her for my thesis – so I planned my trip.

Walking into the exhibition, I made a beeline directly for Ashery's video installations. Sitting on a bear-shaped beanbag, I watched each of her videos from start to finish, certain that this was going to be the focus of my upcoming MA thesis. Afterwards, I walked around the rest of the exhibition, predominantly consisting of Spence's panels from the projects *The Picture of Health* (1982-1986) and *Cancer Shock Photonovel* (1982). This was my first encounter with Spence's work. Born in 1934 in London, Spence was a photographer, writer and cultural worker. Having begun her photographic career as a wedding photographer in 1967, she transitioned to pursue documentary photography in the 1970s, motivated by her Marxist, feminist political beliefs,. Spence was a founding member of two photography collectives, the Hackney Flashers collective (1974) and the Polysnappers (1980). She also, alongside long-term collaborator Terry Dennett founded the Photography Workshop Ltd, an open resource that promoted photography as a tool for empowerment and liberation. Spence's earlier works, *Beyond the Family Album* (1979) and *Remodelling Photohistory* (1980-1982) focussed on exploring the construction of photographic histories. However, in 1982, Spence was diagnosed with breast cancer and the focus of her work shifted. Her subsequent works *Cancer Shock* (1982) and *A Picture of Health* (1982-1986) focussed on Spence's concerns regarding her health and her treatment regimens. Her approach within these projects involved both documentary style self-portraiture and a practice of "phototherapy" that Spence developed alongside fellow artist Rosy Martin.

Phototherapy consisted of performatively restaging personal narratives to reclaim agency over these encounters. Despite initial hesitation from the public towards her overtly personal work on cancer, Spence's efforts from 1982 to 1989 ultimately established her as an advocate for women's health empowerment and breast cancer activism. The *Misbehaving Bodies* exhibition focussed largely on the selection of work Spence made following her breast cancer diagnosis.

I was not an unbiased viewer of Spence's work. In May 2005, at the age of nine, I was diagnosed with Acute Myeloid Leukaemia. After a pain in my hip had become severe almost overnight, I was taken to my local general practitioner. Unsure exactly what was going on with me, he suggested that I be transferred to a nearby hospital for X-rays and blood tests. This confirmed the last thing that anyone had expected: my blood counts were abnormal, indicating that I had leukaemia. I spent the next 6 months at Great Ormond Street Hospital undergoing several courses of chemotherapy treatment. Despite having been in remission for over fourteen years at the time I first encountered Spence's work, this experience was not rooted in my distant past. I was still receiving yearly check-ups and consultant visits, as well as bi-yearly echocardiograms to monitor the potential long-term effects of chemotherapy on my heart. As Arthur Frank suggests, people who have had cancer that has been successfully treated can find themselves existing in "remission society", wherein they are well but "obligations are never again what used to be normal". They are ever changed by their disease (2013, 9). Because of this, I found myself experiencing intense feelings towards Spence's work.

In the panels on display at the *Misbehaving Bodies* exhibition, Spence wrote about rejecting chemotherapy and a mastectomy (opting instead for the less invasive lumpectomy) and choosing to manage her condition on a survival regimen consisting of a juicing diet, Chinese medicine and acupuncture. Her vehement rejection of the very medicine that had saved my life triggered something in me. As a child, I had internalised the belief that medical recommendations were a kind of gospel that we could not risk deviating from, so Spence's disobedience seemed incomprehensible to me. Years of medical supervision had moulded me into the "good patient" [1], someone who placed absolute trust in my doctors. Spence's rejection of Western medicine didn't feel, to me, like the empowering act of agency she believed it to be.

[1] A "good patient" is categorised as someone who is compliant, sycophantic and coping positively (McCreaddie and Wiggins 2009).

This feeling imploded when I found out, within the exhibition, that in 1990, Spence was also diagnosed with leukaemia. As I walked around the exhibition once more, I settled on a piece where Spence was wearing a black swimming costume, floating on her back with arms outstretched (see Figure 1.1). As this piece comprised two photographs overlayed, Spence appeared to fade into both a field and a pool simultaneously. The caption next to it read: "After being diagnosed with leukaemia in 1991[2] [Spence] made a series of photo fantasies that reflected on representations of death and depicted her body returning to nature". The series that this work came from was called *The Final Project,* and it was very different to Spence's earlier bodies of work. Rather than using a method of documentary style photography or phototherapy, it comprised a practice of photofantasy. Following her leukaemia diagnosis in 1990, Spence's reduced physical capacity led to the creation of this entirely new artistic practice, whereby the artist collaged old images and negatives from her archive to create entirely new yet reminiscent artworks. The purpose of this method was to allow Spence to continue creating visual works that expressed "the stories and actions in her mind" (Dennett in Lee 2013) while managing the exhaustion brought on by her cancer, reduced access to the outside world and her changing bodily appearance.

Figure 1.1. Jo Spence *The Final Project*, 1991-1992. From the Jo Spence Memorial Archive, The Image Centre.

Two aspects of this image unsettled me deeply. First, I struggled with why leukaemia was being framed only in the context of death, while Spence's breast cancer had been curatorially explored through the lens of identity. The curatorial caption to Figure 1.1 was focused exclusively on "representations of death". This marked a very clear distinction between Spence's earlier work which had explored representations of illness, identity and the changing body. In addition, Figure 1.1 was the only piece from *The Final Project* represented in the exhibition, so its fleeting mention reinforced this idea that *The Final Project* had little to

[2] This date is incorrectly recorded in the exhibition. Spence was diagnosed with leukaemia in December 1990.

contribute to understanding illness experience. Any sense of identification I had felt with Spence over our mutual diagnoses quickly disappeared as the curation of her work confined this project to a study of death. The nuance with which she had once explored illness was gone, replaced by a singular focus that felt reductive. Second, I was troubled by how Spence chose to respond to her illness. As she said, "If you deviate one iota from the path of chemotherapy, everybody, literally everybody, thinks you're stark raving mad" (1995, 215), and I was no exception to this. The exhibition detailed how Spence had stabilised her breast cancer naturopathically and I (correctly) assumed that she had tried to do the same with her leukaemia. I was not used to seeing anything but gratefulness for treatments like chemotherapy and for medical professionals. But if Spence rejected the very treatment that had saved my life, what did that say about the treatment? Had my gratitude for being alive blinded me to the many unpleasant aspects of my treatment that I was in no way grateful for? Her defiance only magnified my compliance, making my own powerlessness painfully clear for the first time. Even though I was a child when I experienced cancer, I hadn't seen myself as powerless before, nor blinded by my gratitude. So, it felt as though Spence and I couldn't coexist. I decided to scrub Spence's work from my memory, to forget that it existed and to leave the exhibition. It felt so oppositional to everything I had experienced.

Try as I might, this determination lasted only a couple of days and my desire to forget was sharply overtaken by a desire to answer some of the questions I had. I opted to revisit the exhibition and give myself another chance to connect with Spence's later work. Having seen all the work on the walls already, I sat at the table in the centre of the exhibit that supported piles of various books on both Spence and Ashery. I first opened *Jo Spence: The Final Project* (2013), a book edited by Louisa Lee that holds several essays on and images from *The Final Project* (1991-1992). Within this book I saw images of surgery, oversized needles, blood cells, hospital beds and vials of medicine. I saw things I knew and recognised – a visual language of illness similar to the one I had experienced myself. Lee's book was comprehensive; it covered several aspects of this project, ranging from Spence's thoughts on dying to her research into Mexican death rituals and Day of the Dead[3]. However, the overall framing of Spence's work in this book mirrored what I

[3] Day of the Dead (Día de los Muertos) is a Mexican holiday honouring deceased loved ones, traditionally celebrated on November 1st and 2nd. Families and friends gather to pay their respects, often creating altars (ofrendas), a central practice of the holiday. In *The Final Project*, Spence explored the tradition of altar-making, while also incorporating skeleton motifs into her work, which have been interpreted as reflecting Mexico's embrace of the skull as a symbol of "the nothingness and insignificance of human existence" (Paz 1990, 93).

had seen on the walls of the exhibition: that *The Final Project* was "both an exploration and confrontation of mortality" (Epps in Lee 2013, 79).

This interpretation continued to unsettle me. While *The Final Project* was emphasised as an exploration of death, Lee's book presented works for which I felt a personal affinity. Within several of her works, Spence had captured a feeling that was uncannily familiar to me, as someone who had lived with the same disease for a period of time. What I felt connected to in the images reproduced in Lee's book was, however, not being represented in the printed essays nor in the *Misbehaving Bodies* exhibition. Despite our oppositional approaches to treatment, there was something unique about my and Spence's experience of patienthood that *The Final Project* was silently representing. Though Spence's experience was terminal, I did not see her work as being solely about death or dying. My discomfort with Spence's work began to shift: it was not the images themselves that unsettled me, but rather how they were being exhibited and critically received. This realisation planted the seeds of my research, sparking a critical re-examination of Spence's works from 1991-1992 alongside my own reflections on cancer and patienthood.

Not merely a question of reframing

This project was driven by the desire to unpack what exactly in Spence's images felt uniquely familiar to me, as a someone who has experienced leukaemia, and to explore the ways in which the visual can express the experiences of people who have or have had cancer. As my engagement with Spence's work was heavily affected by my own experiences of cancer, I recognised that this project in part would also require me to re-examine my own relationship with medical treatment. For this reason, I opted to approach the project from an autotheoretical lens that employed my own lived experience as a tool for understanding and theorising. With this framework, I set out to develop a new analysis of *The Final Project* – not to simply reframe Spence's work in theoretical analysis but to extend its application in a practical way. In order to do this, I drew on Spence's history of developing her photographic practices into participatory workshops.

At an event entitled "Jo Spence: Fairytales and Photography",[4] Patrizia Di Bello, Marina Warner and Rosie Martin discussed how, in 1982, when Spence started "A Picture of Health", she was

[4] Held on the 30th March 2023, at the Centre for British Photography in London.

making work about her cancer experience at a time when very few others felt able to make work about their cancer. Spence was not the sole pioneer of this kind of work, but her approach and her desire for visibility during critical illness were undeniably radical. This radical approach was something that Spence sought to share. Hatherley states, "As a student, a workshop organiser, an educator and collaborator [Spence's] work was always conducted in the collective spirit of radical shared empowerment" (Hatherley 2020, 21). Spence toured with her own exhibitions, offering critical talks and cultural workshops. Not only did Spence seek "to portray suffering and the world of the sick person, to convey and exemplify something about her life and the experience of living it" (Bell 2006), but she continually encouraged her audiences to do the same through artistic means. Spence's cultural workshops taught tools and methods for using photography for expression.

Susan E. Bell writes that Spence "wanted her works to encourage her audiences to incorporate artistic images into their own experiences" (Bell 2006). Not only did Spence see her workshops as encouraging the use of art for expression, but she saw her own photographic images as exemplifying something about illness that could resonate for others in a similar situation. In her article, "Identity and Cultural Production" (1990), Spence wrote that "my current work could be called 'photography plus therapy' – for myself as well as with a cross-cultural range of clients – unpicking the threads of our own repressed histories" (Spence 1995, 133). Spence discusses how she adapted her practice of phototherapy to support people, through creativity, who are "like [her]self - part of the 'invisibly ill'" (Spence 1995, 133). This work involved "the joint production of visual and verbal signs, fantasies and memories (through snapshots, studio camera work and client drawings)" (Spence 1995, 134). Where Spence called her work "photography plus therapy", it appears that Spence's primary focus was on the visual representation of internal thoughts/feelings, and the therapeutic aspect came once these had been pictured. Jan Zita Grover writes of the practice of phototherapy that, "Spence work[ed] with clients to picture their shame, their points of resistance, so that these are concretized and can then be discussed and worked through after phototherapy ends" (Grover 1990). Therefore, similar to many arts and health practitioners, Spence championed the benefit of visual methods when trying to illustrate experiences of illness with her workshop audiences.

Despite developing many of her artistic methods into workshops, there is no record of photofantasy having been trialled in such a way. From 1991-1992, Spence was suffering with/from the effects of her leukaemia and an outcome of this was that audience engagement with her practice, through cultural workshops, became impossible for Spence to pursue.

Spence's focus while suffering with leukaemia became improving her condition, documenting her day-to-day life and exploring the fantasies in her mind. As photofantasy was developed in response to the constraints of Spence's illness, namely her reduced mobility, I theorised that it could be a useful tool for others to explore their experiences of cancer. In addition to this, Dennett has described *The Final Project* as "unfinished" (Dennett in Spence 1995, 222), highlighting Spence's desire for it to be continued through further critical engagement. With this in mind, I saw the development of photofantasy workshops not only as a way to continue *The Final Project* but also as an opportunity to generate further ideas and diverse perspectives on cancer experiences.

The intention behind this workshop was to allow my participants to explore their experiences of cancer through visual means, using Spence's practice. Each workshop was led one-to-one between the researcher and one of five participants, all of whom had personally experienced cancer. The participants ranged in age from thirty-six to seventy-seven. The workshops involved a brief introduction to Spence's work and *The Final Project* in particular, led by the researcher, followed by around two hours of artmaking in the style of Spence's practice of photofantasy, based on our experiences of cancer. This involved creating collages from magazines, newspapers and various other printed materials, (including personal images, if participants had chosen to bring these to the sessions). Although incredibly similar to collage, a key distinction between the practices is that photofantasy focusses specifically on the reshaping and reinterpretation of participants' visual history. It involves repurposing images (especially those which consist of personal photographs and medical imagery) to construct new visual meanings. I provided prompts for these sessions (see Appendix 1), again based on Spence's practice, but participants were free to make art about whatever aspect of their cancer experience they desired. I made art alongside the participants also, and throughout the sessions we would break to discuss what we each had made. These discussions were recorded and, alongside the artworks that emerged from these sessions, have formed the data for this project. I will go into greater detail regarding the workshop design and participant recruitment, among other methodological considerations, in the next chapter.

I have chosen to structure this thesis as follows: Chapter 1 outlines my methodological approach, providing a clear framework for how this study will be conducted. Chapter 2 introduces my new interpretations of *The Final Project*, establishing a foundation for my analysis. Chapters 3, 4, and 5 build upon this by examining *The Final Project* alongside the artworks created during the workshops. Given that there is currently no analysis of *The Final*

Project that specifically considers its exploration of illness experience, it was crucial to first establish how Spence's practice allows for such an exploration. This framework then serves as a launching point for discussing what the workshop artworks reveal about cancer experience. Chapter 2 introduces two central research questions:

- What does *The Final Project* (1991-1992) convey about the experience of living with leukaemia?
- In what ways does the practice of photofantasy enable Spence to communicate her lived experience of cancer?

By answering these two questions, I am setting the scene for the possibilities of Spence's work and her unique artistic practice to communicate illness experience. As I go on to analyse *The Final Project* and the workshop artworks in light of one another, three further questions come into play:

- What does the method of photofantasy communicate about cancer experience?
- How does this new knowledge expand our understanding of *The Final Project*?
- How can the practice of photofantasy support the recovery of agency within medical encounters?

My aims in answering these questions are: to provide a new interpretation of *The Final Project* that foregrounds its engagement with illness experience rather than solely its representation of mortality; to explore the ways in which photofantasy functions as a creative method for communicating the complexities of living with cancer; to demonstrate how participatory photofantasy workshops can serve as a method for people with cancer to visually articulate their experiences, offering an alternative to verbal or written narratives; and to investigate how photofantasy can help reclaim agency within medical encounters by allowing participants to reshape and reinterpret their own cancer narratives through artistic means. Through this project, I aim to expand existing scholarship on Spence's later work, positioning *The Final Project* as a significant contribution to both academic and wider public discourse on illness representation. In addition to this, by mobilising participatory methodologies, this project aims to establish photofantasy as a powerful tool for self-expression and empowerment for people navigating the complexities of cancer. This in turn seeks to demonstrate the usefulness of visual research methodologies in exploring experiences of illness and expressing the nuances of cancer experience.

Situating my research within the existing terrain

Illness Narrative and Autotheory

Several medical humanities scholars have made a case for the ways that verbal language can support people expressing their experiences of illness. The medical humanities is an interdisciplinary field that explores the intersection of health and the humanities, often including the study of literature, philosophy, history and art. Generally, in a similar way to disability studies and feminist theory, the medical humanities focus on the lived experience of illness, with a view to foster empathy and critical thinking in medical practice. A key aspect of the medical humanities is illness narrative study, which refers to the way people articulate their subjective, lived experience of disease, distinct from the clinical definitions of illness. Illness narrative study is developed from narrative theory which principally posits that "we are *homo narrans,* or storytelling animals hard-wired to make sense of experience through the temporal processing of narrative cognition; that this mode of thinking enabled us to construct a coherent self-identity" (Mäkelä and Dawson 2022). As Stella Bolaki describes in *Illness as Many Narratives: Art, Medicine and Culture* (2016), "illness stories or narratives have been seen as giving expression to the subjective or lived experiences of a particular disease or condition, which is distinct from the clinical definition of disease" (3). In recent years, Bolaki perceives that illness narratives have "grown exponentially" (4) while also having "garnered positive attention" for their "contribution to narrative medicine" (5). An example of this can be seen in the article *From Particularities to Context: Refining Our Thinking on Illness Narratives* (2017). In this piece Annie Le, Kara Miller and Juliet McMullin reflect on how the illness narrative "The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures" (1998) has become a teaching tool to improve "cultural competency" amongst medical students.

The usefulness of illness narratives has also been theorised by a number of further scholars, for example Arthur Frank (1995/2013), Anne Hunsaker Hawkins (1993), Thomas Couser and Nancy Mairs (1997) and Rita Charon (2006), each of whom have adopted methodologies centred around the study of illness narratives. In *Reconstructing Illness: Studies in Pathography* (1993), Hawkins explores how illness is constructed and represented through personal narrative. Similarly, Charon explores the importance of understanding and integrating patients' personal stories into medical practice in her book *Narrative Medicine: Honouring the Stories of Illness* (2006). One of the most renowned explorations of illness narrative, however, is Frank's *The*

Wounded Storyteller (1995/2013). In this book, Frank addresses the importance of creative expression through storytelling for people dealing with illness, while drawing on his own lived experience of being diagnosed with cancer. He identifies three fundamental types of illness narrative: restitution, chaos and quest. Restitution narratives explore illness in anticipation of returning to health, chaos narratives explore illness as a state of ongoing suffering without clear respite and quest narratives consider how illness can lead to personal transformation. Frank incorporates the work of various authors as well as the personal stories told to him by people he has encountered throughout his life who are dealing with illness. Through this, he argues that by turning their diseases into stories, people begin a wider process of healing.

This practice of writing about personal experiences with illness, especially cancer, has also been an important topic in feminist writing. One of the most well-known examples is Audre Lorde's *The Cancer Journals* (1980), in which she reflects on her experience with breast cancer and its impact on her identity. By interweaving journal entries with theory, Lorde was one of the pioneers of writing about cancer from a personal perspective. This approach - interweaving personal narratives with critical analysis – continued in feminist literature, notably in Eve Kosofsky Sedgwick's essay "White Glasses" (1992). In this piece, which I will go on to discuss in relation to my methodological approach, Sedgwick examines her own cancer alongside her friend Michael Lynch's AIDs diagnosis, considering illness' implication for gender and sexuality. These works by Lorde and Sedgwick laid the foundation for the literature to which Jo Spence contributed. Several of Spence's essays engaging with her artistic practice and her experiences of cancer were published in *Putting myself in the picture: a political, personal and photographic autobiography* (1986) with many more being published posthumously in *Cultural Sniping: the art of transgression* (1995).

While earlier feminist writings such as these often engaged with autobiography and personal narrative, this gradually evolved into autotheory - a genre that merges personal narrative with critical analysis. One of the first scholars to engage with this form was Jackie Stacey in her book *Teratologies* (1997), which follows the academic's experience of ovarian cancer. Stacey describes her book as one that "crosses the boundaries between the personal and the academic, the autobiographical and the theoretical" (1997, ix). This intersection between cancer experience and autotheoretical writing has continued to be built upon throughout the last 20 years. A further, significant example is anthropologist, Lochlann Jain's *Malignant: How Cancer Becomes us* (2013). In this text Jain explores various aspects of their life with breast cancer, using these experiences to theorise the broader cultural dynamics surrounding cancer.

One of the most recent examples of cancer experience in autotheoretical writing is Anne Boyer's *The Undying* (2019). In this work, Boyer reflects on her experience of breast cancer while weaving together criticism of capitalism and the medical industry, alongside her own narrative of bodily and spiritual regeneration

Scholars in the field of disability studies, much like in feminist theory, have also engaged with autobiographical experiences in their generation of theoretical writing. This approach has emphasised the importance of self-representation and agency within the field. Rosemarie Garland-Thomson highlights that many of the field's leaders "have come into disability studies by coming out as people with disabilities themselves" (2017, ix). This can be seen in the writing of Laura Hershey, Alison Kafer, Alice Wong and Ashley Shew, each of whom has drawn on their lived experience of disability in their work (Hershey 2005, Kafer 2013, Wong 2020, Shew 2022). In addition to engaging through a lived perspective, several disability studies scholars have engaged with disability theory through a second-hand lived perspective. Faye Ginsburg, Rayna Rapp and Lennard J. Davis have addressed disability through the experiences of their family members (Ginsburg and Rapp 2013, Davis 1995). Just as feminist theory underscores positionality in knowledge production, disability studies centres lived experience as a fundamental aspect of its scholarship. The intersections between disability theory and feminist theory are thus evident in the works of Lorde, Spence, Sedgwick, Stacey, Jain, and Boyer, who each write about their lives while navigating disabling physical conditions.

The importance of acknowledging one's positionality was addressed by Spence, who when reflecting on the ways knowledge about cancer is produced, criticised both the medical field's objectification of patients and academic discourse's tendency to theorise bodies from an outside perspective. Spence wrote that, "if I was sick of medical people who viewed me as only an object of study or a treatment, I was equally sick of academics within my own discourse who wrote theories of the representation of bodies without in any way seeming to inhabit their own" (1995, 130). In this, she highlights how academic analysis can risk the same detachment as clinical medicine, reinforcing the need for lived experience as a counterpoint. Each of the examples I've explored, from within the Medical Humanities, Feminist writing and Disability Studies, actively challenge the detachment of disembodied perspectives through the incorporation of personal lived experience. Elizabeth Anderson argues that "the central concept of feminist epistemology is of situated knowledge: knowledge that reflects the particular perspectives of the knower" (Anderson 2000). Thus, my own project follows the same tradition of integrating personal experience into scholarly inquiry. By adopting a feminist standpoint

epistemology, I will embed my autobiographical and autotheoretical perspective throughout my analysis ensuring that I do not replicate the academic tendency Spence critiques, whereby theories about the representation of bodies are produced from an unembodied perspective.

Patient Testimony and the Deficiency of Language

Much like the examples I've offered in feminist theory and disability studies, in the medical encounter, experiences of illness are most-often communicated verbally. There is the initial consultation when one visits the doctor and all the conversations with medical personnel that follow, in the form of (what is often termed) patient testimony, about what the experience entails. By patient testimony, I am referring to moments where we try to express our symptoms and their effects with as much clarity as possible to healthcare providers or medical professionals. As verbal language and discussion are the typical means for expressing experiences of illness in the medical setting, it is easy to fall into common tropes when talking about our bodies or our symptoms. For example, terms like "shooting pain", "burning sensation", "lightheaded" and "dull ache" all illustrate experiences that could differ greatly from person to person, depending on how we've come to understand them. Beyond this, certain aspects of the experience of illness cannot be adequately expressed through words. Virginia Woolf, in *On Being Ill*, asserts that "among the drawbacks of illness as a matter for literature there is the poverty of the language. English which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and the headache" (Woolf 2021, 43-44). Woolf addresses how "language at once runs dry" when attempting to express pain or symptoms. In this essay, Woolf is attempting to establish illness as a serious subject for literature, however, she simultaneously makes a case for the deficiency of language when trying to express the nuances of different experiences of illness.

Understandably, personal written expressions of illness, like those I have mentioned, are far removed from expressions of patient testimony within the medical encounter, not in the least because there are differences in intention between the two. Patient testimony is primarily for diagnostic purposes, whereas personal writing can reflect creative self-expression. Despite this, the language we use to explain our illnesses in patient testimony, which is often rooted in common analogies and cliches, can become one to fall back on when trying to express our experiences of illness outside of the medical setting. Angela Woods addresses how patient testimony relies on a "very specific kind of storytelling" that is dependent on detachment and minimised distress (Woods 2012b). Woods suggests that in order to have one's condition taken seriously and to have your account believed to be reliable, one must detach from one's own

experiences and minimise their distress when expressing them. When offering patient testimony, the "good patient", categorised as someone who is compliant, sycophantic and coping positively (McCreaddie and Wiggins 2009), is often praised by the healthcare provider. This privileges compliance, gratitude and positivity as primary vehicles for expressing and understanding our illnesses. Thus, these traits of the "good patient" are often perpetuated when one expresses illness in verbal form.

In the article "Rethinking Patient Testimony in the Medical Humanities: The Case of *Schizophrenia Bulletin's* First Person Accounts" (2013), Woods addresses the importance of clarity, non-fantastical language and linearity when people with schizophrenia construct their patient testimonies. In this example, Woods explores patient testimony expressed in the form of written accounts of schizophrenia, published in the *Schizophrenia Bulletin*, a journal targeted at mental health professionals. Woods suggests that "the absence of playfulness, irony, fantasy, figurative language, the appearance of other narrative voices, non-linear structures, and visual or typographic innovation" is imperative for the account to not be considered "mad writing" (Woods 2013). Similar rules would seem to apply across all patient testimony; in order to be considered a reliable narrator of your illness in a medical setting and thus be offered the correct care, your testimony must adhere to the set of rules that Woods outlines.

Therefore, when verbalising illness, even outside of the doctor's office, people can often continue to express their experiences as "conventional, linear narrative" that has "the form and logic of a story" (Woods 2011). Woods addresses the dangers of relying on narrative in general as the sole expression of illness experience in her essay "The limits of narrative: provocations for the medical humanities" (2011). Woods makes reference to philosopher and literary critic Galen Strawson's suggestion that "there are deeply non-Narrative people and there are good ways to live that are deeply non-Narrative" (Strawson 2004). In line with this suggestion, illness experience can be understood as resisting narrativity. Strawson's notion of a "non-Narrative" way of living is very familiar to the experience of those who are unwell. Whether living day-by-day, awaiting information about your condition, or losing hours of the day to feelings of exhaustion, there can be many gaps in our memory and a sense of fragmented experience when recalling our illnesses. Consequently, attempting to impose a coherent narrative on these fragmented experiences can feel forced and can fail to reflect the disjointed and uncertain nature of living with illness.

This can be seen to align with Woods' criticism of Frank's work. While Frank proposes that verbal narrative, specifically, is necessary "in order to recover the voices that illness and its

treatment often take away" (2013, xx), Woods has addressed the restrictiveness of Frank's way of thinking in her article "Beyond the Wounded Storyteller: Rethinking narrativity, illness and embodied self-experience" (2012a). Woods addresses how the expression of illness experience need not be restricted to verbal or written narrative, pointing out that: "narrative does not have a monopoly on expressivity. Although many people do not believe themselves to be artistically gifted or particularly creative, medical humanities researchers and arts-in-health practitioners have shown that experiences of distress and of physical vulnerability can be brought to life and given shape in a wide variety of media". Woods' writing appears to mark an evolving trend within the medical humanities towards acknowledging the capacity for artwork and visual images to express that which cannot be expressed in words. For this reason, my project does not rely solely on verbal expressions of illness experience and has incorporated the creation and discussion of visual images as a mode of expression.

Visual Arts and Expression

As noted, Woods has called for medical humanities scholars to consider the importance of alternative methods for expressing illness, asserting that "the visual arts, [sic] also reminds us that language is not the only medium for communicating matters of medicine, health, and illness… creative processes structured around images, visual symbols, and spatial composition can have profound therapeutic effects as well as produce powerful aesthetic works" (Woods 2011). In addition to this, Woods has emphasised the importance of exploring modes of expression that do not rely solely on the narrativization of our experiences, writing that, "narrative returns us again and again to structure, coherence and unity… What place is there for formlessness, for meaninglessness, for silence" (2013, 125). For Woods the visual arts offer a mode of understanding illness experience that can resist narrative linearity whilst still engaging with the regenerative nature of expression. By narrative linearity, I am referring to narratives that implement chronology, clarity, and are often expressed through "the form and the logic of a story" (Schechtman 1996).

The benefit of engaging with visual arts as a mode of expression has been further explored by Bell in her chapter "Seeing Narratives" from the book *Doing Narrative Research* (Andrews, Squire and Tamboukou 2013, 142-158). She explores "how and why" scholars within the medical humanities are studying visual narratives, suggesting that "people are able to make statements with images that cannot be fully made with words or quantified with numbers". This appears in reference to Michael Rich's suggestion that images capture aspects which words cannot, "elements such as body language, direction of gaze, or the nuances of human emotion"

(Rich 2002). For Rich, images offer an insight into, or a snapshot of, a moment, from which we can infer relations between their subjects. Through body language, spatial arrangement and other coded elements, images give a sense of their subject's relations as well as how these relationships operate.

These scholars have not necessarily dismissed the significance of verbal expressions of illness; rather, they have shifted toward embracing a diverse range of modes of expression to capture a more comprehensive representation of lived experiences. This can be seen in Bolaki's *Illness as Many Narratives* (2016), where she emphasises the importance of an approach to illness narratives that embraces the diverse ways they might be expressed. She explores photography, artists' books, performance, film and theatre to demonstrate the various forms in which these narratives can emerge. In doing this she has argued "for the importance of attending to the many narratives of illness, in all the different meanings of this phrase, and of engaging with a wide range of media and methods to forge more explicit and critical links between the arts, cultural studies and medicine so as to ensure that the medical humanities does not degenerate into a narrow discipline" (2016, 23). Beyond ensuring that the medical humanities as a field remains broad, Bolaki's approach acknowledges how certain experiences might resist verbalisation and instead require alternate methods of expression to be engaged with or expressed.

Thus, I align myself with Bolaki in situating this research at the intersection of visual and verbal modes of expression, with a view that recognising a multiplicity of methods is essential and of incredible value for capturing the complexities and nuances of lived experience. As addressed, I provide a visual analysis of the photofantasy works, exploring how images function as a means of articulating experiences of illness, while, at the same time, also engaging with verbal discussions of these works and the experiences of illness they draw upon. My approach does not seek to deny or diminish the value of verbal modes of expression. Rather, it demonstrates the importance of recognising and integrating alternative, non-verbal forms of communication, highlighting that there are additional unique benefits to visual expressions of illness that should not be ignored or undervalued.

Photovoice and Photography: an uncomfortable history

In research that utilises participatory visual methods to explore illness experience, the practice of photovoice (often also referred to as Participatory Photography or PP) has been used repeatedly (several examples include: Hoover and Studts 2024; Polo et al. 2020; Hirsch Yi, Kim

and An 2016; Morrison and Thomas 2014; Poudrier and Mac-Lean 2009). As a practice Photovoice involves taking photographs to document personal experiences and perspectives, which are often then discussed with a second party; it can also involve writing from these images. Photovoice has been described as a way for individuals to express their experiences, perspectives, and daily lives through a combination of photographs and written narratives (Wang, Burris and Ping 1996). Jennifer Poudrier and Roanne Thomas Mac-Lean address how the practice "prioritizes participants' knowledge as a vital source of expertise" and aims to capture their "viewpoint" through the practice (2009). Meanwhile, Laura S. Lorenz[5] has highlighted how the practice involves generating "visual metaphors" as "vehicles for voice" (2010).

In addition to research on photovoice and cancer experience, numerous studies have used photovoice as a means through which to explore a wide range of health and illness experiences. A notable example is Lorenz's study, "Visual metaphors of living with brain injury: exploring and communicating lived experience with an invisible injury" (2010). In this research Lorenz uses photovoice with people who have experienced brain injury as a tool to communicate their lived experiences. In doing this, Lorenz demonstrated how photovoice can be a useful form of expression, particularly when verbal communication is limited or unavailable. She suggested that:

> the cognitive challenges related to brain injury require a creative approach to eliciting survivors' perspectives on their experience of illness, healing and health care. The solution used in my study was photovoice, which involved putting cameras in the hands of brain injury survivors and asking them to reflect on their lives, take photographs of their situations and use their images to represent their lived experience with brain injury. (Lorenz 2010)

In this specific case, where people with brain injury found expressing themselves through verbal language challenging, Lorenz introduced a visual language to broach this barrier to expression. Lorenz has argued that, "visual metaphors of the survivor's journey are a personal expression of voice" (Lorenz 2010), thus, the camera becomes a mouthpiece for expressing thoughts, feelings and ideas. Studies like this have highlighted the importance of employing specialised visual imaging practices, like photovoice, particularly when exploring alternative modes of expression for people facing barriers to verbal communication.

[5] Lorenz is both a scholar and co-founder of Photovoice Worldwide, an organisation that helps both individuals and organisations to employ and practice photovoice effectively.

As Lorenz suggests, photography "has served as a powerful tool for understanding people's lives [and] illuminating experience with health and illness" (2010), which explains its repeated use by individuals with a variety of health issues. However, there are ethical complexities attached to employing photography as a medium for patient representation and expression, based on its fraught history. Neil Gibson highlights this history, stating that: "The practice of using photography as therapy dates back to the 1850s when Hugh Welch Diamond applied photographic processes to document and highlight the different strains of mental illness he encountered among female patients" (Gibson 2017). Diamond believed that by capturing a person's appearance in a photograph, he was revealing "a window into their character" (Gibson 2017). This approach exemplifies a voyeuristic, clinician-centred method of photography that contrasts sharply with the more patient-centred approaches used today. While Gibson acknowledges that Diamond's early use of photography with patients has evolved significantly throughout the 20th century (Gibson 2017), the historical tendency toward clinician-centred practices continues to influence how photography is used in medical settings. This history raises important considerations for approaches like photovoice, where placing the camera in the hands of the patient seeks to shift the balance of power in visual representation.

Moreover, in the history of photography and medicine, allowing patients to use a camera to express themselves has not been a primary focus. Erin O'Connor has addressed how several decades after its conception in 1839, photography became a popular tool for medical practitioners to document diseases by taking photographs of their patients (1999). As she notes, the problematic nature of capturing what "disease *is*" arose with this practice, for clinicians could only document that which is "superficial", i.e. "pathology as surface" in photographs (O'Connor 1999). As well as being focused on the superficial or visible/obvious symptoms of disease, medical photography rendered "the person incidental to the portrait" by "taking illness as its subject" (O'Connor 1999). This history of objectifying the patient in medical photography persists in modern clinical practice. Whether for disease monitoring or later diagnosis, the bodies of patients are still regularly imaged by physicians in clinical settings. Although the images are now taken with informed consent and in an environment that usually considers the patient's dignity, the diagnostic information from these images, alongside bloodwork and other tests, is frequently trusted in lieu of patients describing their symptoms. Moreover, in the UK, these images are not released to patients and require a written request, suggesting that the patient does not own them. The nature of reducing a person and their symptoms to a photographic image perpetuates the objectifying history of clinical photography, even if the patient is now treated with greater respect during the imaging process. Thus, the

fraught history of medical photography can be seen to create difficulty when turning to the photographic medium, as a means for exploring patients' own perspectives on their illness experience.

A Unique Approach

Even though the practice of photofantasy engages with photographic images and thus can also be tied to the ethical complications of photography in clinical practice, I argue that it employs a unique approach that seeks to disable the existing power differentials present in clinical photography. While medical images and notes in the UK are largely controlled by the medical institutions that produce them, in the second chapter of this thesis, I argue that Spence's photofantasy works offer a compelling counterpoint by reclaiming these images for personal exploration and self-representation. By invoking the aesthetics of medical imaging within her works, Spence transformed these clinical records into artworks that better reflected her lived experience of illness. She engaged with medical imagery in a playful and exploratory way, using photofantasy to challenge the authority of clinical photography and to regain a sense of autonomy over her body. This act of creative intervention was not only a means of resisting the objectifying nature of medical photography but also a way to reimagine the patient's role in their own medical narrative. It is, in part, this reparative potential that drew me to explore photofantasy as a method within my research. Where conventional medical photography prioritises the clinician's perspective, Spence's practice of photofantasy challenges this by putting the medical image back into the hands of the patient/artist. This is why, as I will go on to discuss in my methodology, in the participatory workshops I gave participants the opportunity to bring their own medical images and medical notes to create collages from these. This aspect of photofantasy demonstrates how intervening with photography and photographic images offers the capacity to disrupt and distort existing dimensions of power. Where the pre-existing medical image can demonstrate the objectified body, Spence's collage-based works reinterpret the medical image, reinforcing Spence's persisting identity.

Similarly, while photography has proven a valuable tool for capturing certain aspects of illness, it poses significant challenges when attempting to represent the experience of *invisible* illnesses. By invisible illnesses, I am referring to conditions which are not visible on the surface of the skin but perhaps can be located with medical imaging tools. Spence herself came to realise this difficulty when faced with the invisible illness leukaemia, an illness that lacked the visible markers she had previously documented in her work. Following her breast cancer diagnosis in 1982, Spence had photographed her cancerous breast before and after surgery,

using the camera as a direct means of engaging with her changing body. However, leukaemia presented an entirely different set of representational difficulties – there was no such visible part of her body which captured the "location" of her illness. Faced with this challenge, Spence was forced to move beyond literal photographic representation and instead explore more symbolic and metaphorical ways of visualising her illness experience. This shift underscores a critical limitation of photography: while it may capture external realities, it can prove challenging when used to capture internal or unseen experiences. Photofantasy, by contrast, allows for active intervention in photographic images, which makes it possible to articulate aspects of illness that remain otherwise unseen.

Furthermore, photofantasy as a practice overcomes several barriers to photography that living with cancer can present – barriers that many photovoice studies do not account for. Dennett has discussed several of the symptoms that Spence experienced as a result of her leukaemia, noting that: "[the] characteristic feature [of leukaemia], a proliferation of immature white cells and a reduction in the red cell count, would progressively reduce the supply of oxygen to [Spence's] brain, slowing down its functions, eventually robbing her of her most prized possessions, her sharp wit and critical power of thought and, above all, making her less mobile and sapping her energy". This impact became evident when Spence attempted to take photographs in a cemetery. Dennet notes that the experience "made [Spence] realize that her health was no longer good enough for her to engage directly in photography" (in Spence 1995, 222). Spence's situation reflects broader challenges that many people with cancer face: limited physical mobility, exhaustion, and isolation due to immunosuppression from both the illness and its treatments. The inability to leave home or engage in physically demanding activities can restrict access to traditional photographic opportunities. Additionally, beyond these physical constraints, Spence also struggled with body image, a common issue for cancer patients. Dennett recalls that by 1991, Spence's physical appearance no longer aligned with the mental image she held of herself, and when she attempted self-portraiture, she was confronted with what she described as her "withering image" (Spence 1995). This reflects what Michelle Cororve Fingeret, Irene Teo, and Daniel E. Epner (2014) identify as a "critical psychosocial issue" for cancer patients, as bodily changes such as weight loss, scars, hair loss, and medical devices can deeply affect self-perception. For individuals who experience distress in seeing their altered bodies, self-focused photography may feel more alienating than empowering.

Thus, photofantasy as a participatory method, not only builds upon existing photovoice studies by enhancing our understanding of photographic images as a tool for expressing illness but also

addresses several overlooked challenges of the medium, providing a more inclusive and adaptable approach to self-representation. For people who are immunocompromised or immobile there are a limited selection of images that it is possible to capture from one's hospital room or bedroom. With photofantasy, by using pre-existing printed media – archived personal photographs, magazines, and other images – participants can construct visual narratives that go beyond the spaces to which they are confined. This ensures that people who are homebound or experiencing fatigue can remain creatively engaged. Additionally, photofantasy offers a way to explore self-representation without confronting the body's present appearance. Where Spence found self-portraiture distressing due to the contrast between her current and remembered self-image, photofantasy allowed her to work with past images that aligned with her self-perception. By collaging older photographs, she could visually embody an identity that felt more authentic to her than the physical changes imposed by leukaemia. In this way, photofantasy is able to grant agency over one's representation, offering a means to engage with personal history without being confined to the realities of illness. Beyond facilitating self-expression, photofantasy also enables individuals to reimagine aspects of their lives through creative manipulation. Unlike conventional photography, which captures a fixed reality, photofantasy allows for the transformation of images, inviting participants to construct alternative worlds and meanings. This aligns with Spence's reflections on fantasy's significance in her life after her leukaemia diagnosis – she noted a newfound appreciation for fantasy films and the role of imagination in coping with illness (Spence 1995, 217). Photofantasy, as a method, embodies this desire for imaginative escape. Rather than recording snippets of reality, it allows for active re-creation, offering individuals a space to reconstruct their experiences on their own terms. By integrating these elements, photofantasy expands upon photovoice methodologies. It provides an adaptable, empowering mode of visual storytelling that accounts for restricted mobility, body image concerns, and the emotional need for imaginative self-representation.

Photofantasy and Collage-Based Methods

As addressed, the version of photofantasy I employed within the participatory workshops was very similar to collage-making. Thus, my research engages with the use of collage in participatory practice also. The use of collage-based methods to support the expression of cancer experience has received far less attention than studies into photovoice. Nevertheless, there has been a lot of research into using collage as a participatory research method in various other social settings (for example: de Rijke 2024; Abranches and Horton 2024, Yuen 2018). Lynn Butler-Kisber in *Qualitative Inquiry: Thematic, Narrative and Arts-Based Perspectives* (2018), has

addressed how collage can operate as a qualitative research method. She notes that collage "engenders" a "sensory or embodied response" (Butler-Kisber 2018). This is in relation to the tactile nature of collage-making, as well as the physicality of cutting, tearing and pasting images, which arguably evokes something "sensory or embodied", both when creating and viewing/experiencing the works. The process of making, as well as a sense of the maker, are incredibly present in the finished work through the torn pages and cut-out images that comprise it. Lawrence S. Rainey has also commented upon this, suggesting that the fragmentary nature of collage allows for "a single coherent picture [to give] way to relations of juxtaposition and difference" (Rainey 1998) which in turn allows "the fragments [to] both work together or in opposition to produce new connections and illuminating ideas" (Butler-Kisber 2018). In Rainey's account, it is the abstraction of existing images to create new ones that allows for connections to be made and thoughts to be elucidated. It appears that in collage, the photograph or image alone is not enough; meaning emerges when it is altered, built upon and layered.

Further to this, Butler-Kisber suggests that "the use of metaphor", when choosing images to represent ideas and instances, as well as "the gaps and spaces within a collage reveal both the intended and unintended" (Butler-Kisber 2018). This is achieved by layering, altering and re-organising images, revealing a multi-dimensional way of viewing the artwork. This notion of "intended and unintended" re-emerges in the way that collage works are created. As collages are made by recontextualising pre-existing images created for another, potentially unrelated purpose, the collage-maker often approaches the meaning of their collage as one that is flexible and heavily guided by what is available to them. Brandon Williams suggests that the process of collage-making takes place through a less "conscious control over what is being presented" which in turn allows for "greater levels of expression" and "greater areas for examination and subsequent clarification" (Williams 2000). Williams suggests that collage-making rarely begins with a clear objective in mind and instead develops as images are discovered and added to the piece. Abstraction is at work in the process of collage-making, to allow for connections to be made between images that are both conscious and unconscious. Thus, meaning is produced throughout the process of collaging, without a sole focus on a singular intended outcome. This can be seen as particularly significant for people navigating the challenges of critical illness, as it removes the pressure to articulate a clear narrative or intention from the outset. Rather than needing a reason or purpose to begin the practice, this can develop organically, guided by the resonance of found images.

This aspect is further highlighted by Bulter-Kisber, who suggests that in collage, intuition and experimentation drive the process. Unlike traditional written narratives, which often follow a structured progression from idea to expression, collage operates in reverse. Butler-Kisber writes that:

> In linear, written texts, the author works from the ideas to the feelings or from the 'head to the heart'. In collage the opposite is true. The creator seeks the fragments and glues them together to express a feeling or a sense of an experience or phenomenon rather than a particular idea. She works from the 'heart to the head'. (Butler-Kisber 2018)

This reversal of the conventional creative process highlights the ways that collage resists narrativity and allows meaning to emerge organically. Carol A. Mullen suggests that this intuitive, experimental method of working allows space for "reseeing, relocating and connecting anew" (1999). Thus, in collage making, confusion and ambiguity are often embraced, with the collage-making process simultaneously helping to unravel complex ideas and feelings.

In addition to this, the way that collage can be seen to reflect the disjointed experience of cancer has directly been referenced by Patricia Lobo, in her article "Collages for Cancer" (2016). In this piece, Lobo reported on the work of Astrid Brousselle, a researcher who collaborated with collage-based artist Anouk Sugàr to turn research findings on early cancer diagnosis into art. In relation to this research, Sugàr proposed that collage allows for its makers to reflect on the uncertainty, insecurity and the general "mind-fog" that is often present when diagnosed with an illness. Patricia Lobo addresses how Sugàr uses collage to explore "the period of uncertainty between first noticing something might be wrong and the moment when people decide to see the doctor" (Lobo 2016). Sugàr stated: "I used collage because it is a spontaneous medium; it's not something forever embedded. This portrays the mind-fog experienced when people know there's something wrong with them. There's insecurity and fear that is not always rational, and collage displays this sometimes erratic behaviour" (cited in Lobo 2016).

Each of these examples, which highlight the unique properties of collage, reinforce my decision to use photofantasy as a participatory method. As photofantasy is collage-based, it similarly allows meaning to emerge in a fragmentary and non-linear way. This approach enables people to explore narrativity or non-narrativity according to their own preferences. Frank theorises that storytelling is what repairs the disorientation of being diagnosed with an illness, suggesting that narrativity is a necessary measure for repairing our lives and expressing experiences of illness (Frank 2013, 3). However, as I will explore throughout this thesis, "repair" need not be regarded

as the sole function of instances where people express their experiences of illness. While narrative frameworks may offer stability and coherence, they do not always capture the full spectrum of lived experience, especially when that experience is marked by uncertainty or fragmentation. Instead, non-linear and multi-layered modes of expression, like collage and photofantasy, create a space where these more elusive, ambiguous or even contradictory aspects of illness can be articulated. By embracing the disorder, fluidity, and multiplicity inherent in both art and illness, photofantasy allows for expressions that go beyond traditional storytelling, shedding light on the invisible, the unspoken and the ineffable dimensions of living with illness.

Collage, and by extension photofantasy, can therefore appear to be uniquely attuned to expressing certain experiences of illness, for it does not require the artist to impose clarity or coherence onto their experience. Instead, collage embraces confusion, fragmentation, and fluidity, allowing meaning to emerge organically. Frank highlights how illness can disrupt people's "sense of temporality", as "what tomorrow may have in store for the body is unknown" (Frank 2013, 55). This lack of certainty and the sudden disruption that illness can cause means that knowing what to make art about or to write about can be a barrier to trying. The open-ended nature of collage, however, provides an alternative – one in which the creator can piece together symptoms, sensations, thoughts and feelings, without needing to have a clear idea of what they are working towards. By allowing for spontaneity, reinterpretation and meaning to emerge through association, photofantasy offers a method of expression that mirrors the lived reality of illness, accommodating its unpredictability.

In addition to this, I propose that photofantasy enables a more embodied expression of the experience of illness. As a method, it mirrors how Frank describes illness in *The Wounded Storyteller*. He explains that:

> stories [of illness] are told in conditions of fatigue, uncertainty and sometimes pain, and always fear that turn the ill person into what Ronald Dworkin describes as a "narrative wreck"... Almost every illness story I have read carries some sense of being shipwrecked by the storm of disease, and many use this metaphor explicitly. Extending this metaphor describes storytelling as repair work on the wreck.
>
> The repair begins by taking stock of what survives the storm... Disease happens in a life that already has a story, and this story goes on, changed by illness but also affecting how the illness story is formed. (Frank 2013, 54)

What Frank describes is a scenario where illness has created a rupture in the life of the unwell person, where their life post-diagnosis is no longer the same as what existed before. The term "narrative wreckage", then, exists to explain how, when recalling this experience in narrative, people may feel the need to collect the fragments of their life prior to illness to reconstruct their lives as they exist now. However, while Frank emphasises narrative as the means of this reconstruction, I argue that meaning making does not have to be limited to storytelling. This process of collecting fragments is applicable in a very literal way to photofantasy as a practice. Little by little, images are added and combined to create something that is different and new but made of fragments that existed before. As a practice it can thus be seen to mirror how we experience illness, embracing the fragmentary nature of recollection and memory. This, as I will explore in Chapter 2, opens up space for non-narrative modes of meaning-making that acknowledge ambiguity and disruption rather than seeking to resolve them.

A Gap in the Literature on Spence

My research, as it relates directly to Spence's practice and artmaking, will contribute to a significant body of work on the artist and her expressions/explorations of illness. Scholars such as Susan E. Bell and Stella Bolaki have examined Spence's works from 1982-1989, particularly in relation to how they communicate the lived experience of illness (Bell 2002, Bolaki 2016). In her book *Illness as Many Narratives* (2016), Bolaki discusses the photograph "Property of Jo Spence?" (1982) considering how it serves as a powerful exploration of bodily autonomy and identity in the face of medical objectification. Bolaki's analysis aims to demonstrate how Spence's photography functions as an expression of her illness narrative. Similarly, Bell, who sought to expand the study of illness narratives beyond merely textual forms, explores the photograph "Mammogram" (1982) in her article "Photo images; Jo Spence's narratives of living with illness" (2002). In this text, Bell explores how Spence's work critiques the objectification of women's bodies by medical practices, aligning this analysis with the wider argument of the article which centres on the potential for photographic narratives to complicate and enrich understandings of illness experience beyond verbal or textual accounts. These studies demonstrate the broader critical engagement with Spence's breast cancer projects as a means of articulating illness experience. Further to this, several additional critical reflections cover Spence's breast cancer projects in a similar way, for their depiction of illness experience (Bolaki 2016, DeShazer 2013, Dennett, Radley and Bell 2011, Tembeck 2008, Bell 2002, Dykstra 1995).

However, there is a gap in the literature focussed on Spence. The same level of critical attention as was afforded to Spence's breast cancer works, has not been afforded to her later work. As

outlined, in 1990 Spence was diagnosed with leukaemia, marking another significant shift in her artistic practice. Spence produced a few projects in the period 1991-1992, however the primary body of work is *The Final Project*. This series has largely been analysed in terms of its engagement with death. For instance, *Jo Spence: The Final Project* (Lee 2013) compiles various critical perspectives, with the central argument being that "*The Final Project* is both an exploration and confrontation of mortality" (Lee 2013, 79). Anne Boyer, in her article *The Kind of Pictures She Would Have Taken* (2016), suggests similarly that "In this late work, it's almost like what Spence is doing is teaching herself a dialectical mode of dying". Boyer's article goes slightly further than others in extending this discussion, for Boyer goes on to propose that "the impossibility of representation that leukaemia presented… in fact presented a new potential for a mode of understanding the political beyond the modes of self and self-representation that had determined her earlier work". However, aside from Boyer's nod towards the potential of *The Final Project* to generate new modes of understanding, there remains no scholarly text that explicitly examines *The Final Project* in terms of illness experience.

The perception that *The Final Project* lacks engagement with illness experience can be linked to Spence's departure from self-portraiture following her leukaemia diagnosis, as well as her incorporation of skeletal imagery and symbolic motifs in place of her own body. In her breast cancer projects, Spence had used her body as a site to represent her struggles with illness, engaging with questions of autonomy and medical authority. With leukaemia, however, physical constraints made the use of her body in photography increasingly difficult. Boyer (2016) argues that this shift marked a rupture in Spence's artistic identity – from the politically engaged "cultural sniper" to a terminal patient. Spence herself expressed a sense of withdrawal, stating in an interview with Jan Zita Grover that she was finished with "go[ing] like an Amazon into the lion's den over and over again in order to be politically useful" because it was "too time-consuming and too conflictual" (Spence 1995, 217). While this statement has often been read as an admission of artistic disengagement, it more accurately reflects a transformation in both her artistic and political approach. Rather than signalling the abandonment of the practice of making art about illness experience, Spence's adoption of photofantasy suggests an adaptation to new constraints. Johanna Hedva's "Sick Woman Theory" (2016) explores how illness imposes barriers to conventional approaches, arguing that political resistance can take internalised, embodied, and often invisible forms. Spence's later work can be understood in this context: unable to physically stage self-portraits, she turned to photofantasy as an alternative artistic method. In contrast to the assumption that *The Final Project* no longer engages with Spence's illness experience, her engagement can be seen to persist – though in a less overt, more

introspective form. By constructing symbolic, imaginative images, she processes her own changing body and the realities of terminal disease, reframing artistic production as a means of embodied resistance.

My thesis seeks to address this critical gap in scholarship on Spence's work from 1991-1992. Firstly, I will offer a critical re-examination of *The Final Project* by considering it through the lens of my own experience of leukaemia, bringing an embodied autotheoretical perspective that has not yet been applied. By engaging with Spence's photofantasy works alongside my own recollections, I will explore how these works articulate the experience of illness in ways that have been overlooked. This includes the introduction of several unpublished works into scholarly discourse for the first time. Through my archival research, I uncovered a number of previously unexamined materials that expand the critical conversations surrounding *The Final Project*. Beyond this, my research is the first to offer an account of the development of photofantasy into a participatory artistic practice for people who have been diagnosed with cancer. As highlighted earlier, Dennett suggested that "the methods that [Spence] had started to evolve also had important implications for photography". However, she "did not live to explore these new paths, that is left for those who follow her" (Dennett in Spence 1995, 223). This statement underscores the open-ended potential of photofantasy – a practice that, while foundational to *The Final Project*, remains largely unexplored. By facilitating workshops with five participants who have experienced cancer, I investigate how photofantasy can serve as a tool for reflection, allowing people to reshape and reinterpret their illnesses through artistic means. This participatory element extends Spence's legacy, transforming her final method into a collective practice that promotes agency and self-expression in ways that traditional photography or verbal storytelling may not. Additionally, my methodology is innovative in its fusion of autotheory with visual analysis. By using my own lived experience as a framework for interpretation, I not only offer fresh perspectives on *The Final Project* but also recontextualise Spence's practice within contemporary studies of illness. In doing this, I position photofantasy as a significant yet underexplored mode of meaning-making. This approach allows me to expand on critical understandings of how non-linear, multi-layered forms of artistic expression can capture the complexities, ambiguities and contradictions of living with illness – dimensions that more conventional narrative frameworks may struggle to accommodate. In doing this, I hope to illuminate new dimensions of Spence's artistic legacy and further establish her works from 1991-1992 as a vital site of inquiry.

Cancer Studies

This research exists at the intersection of various disciplines and can be seen to carve out its own space in relation to these. In particular, it builds on a growing trend within Disability Studies to unite considerations of chronic illness and disability. Traditionally, Disability Studies has been shaped by the social model, which distinguishes between impairment and disability. According to this model, people may have impairments, but these are not the source of disability. Rather, societal barriers such as inaccessible environments, discriminatory attitudes, and systemic exclusion cause people with impairments to be disabled. Hanna Bertilsdotter Rosqvist, Hisayo Katsui and Janice McLaughlin have addressed how "medical sociology for a long time 'owned' chronic illness", while "disability studies instead looked at impairments, which may be associated with chronic illness, but not necessarily" (2017). In recent years, however, this distinction has been increasingly challenged. Even though the idea that "chronic illness is a major cause of disability" was outlined by Susan Wendell in 2001, Nicole Brown and Jennifer Leigh have expressed how both chronic illness and disability have been regarded as distinct experiences in much of disability studies scholarship (2020, 6).

My study does not suggest that chronic illness and disability are interchangeable. Rather, it builds on Wendell's argument that there is significant overlap in how these experiences are lived, even if they are classified differently. Cancer serves as a key example of the gap in the literature created by not addressing this overlap between disability and chronic illness. While cancer is legally recognised as a disability under the UK Equality Act, many individuals with cancer do not identify as disabled. Moreover, the disabling effects of cancer can often be temporary – for example, during treatment or in response to pain and mobility limitations. In my own case, cancer confined me to a wheelchair for a period due to hip pain, yet this experience was not permanent or representative of a fixed disabled identity. Similarly, while cancer is sometimes classified as a chronic illness, it does not always fit neatly within this definition, which typically applies to long-term conditions requiring continuous management. Although I experienced a prolonged period of chronic unwellness while hospitalised for leukaemia treatment, I do not fall within the conventional category of "chronic illness". Rather than attempting to fit cancer into one category or the other, my project argues that cancer exists at the intersection of disability and chronic illness, embodying aspects of both while resisting full alignment with either. This hybrid positioning has been largely overlooked in the existing scholarship. Where Rosqvist, Katsui and McLaughlin have taken a huge step towards uniting the fields of disability studies and chronic illness research in the Scandinavian *Journal of Disability Research* by focussing Volume 19, Issue 1 on explorations of chronic illness within disability

studies, they have not specifically addressed cancer in relation to this research. My project seeks to fill this gap by connecting disability studies research with lived experiences of cancer. In Chapter 4 for example, I apply theories of crip time to cancer experiences, introducing a new concept I call *Cancer Time*, which captures the unique temporal disruptions faced by those living with cancer.

This research, which blends artistic practice, patient experience and critical theory can be seen to contribute to a broader discourse that might be termed "Cancer Studies". While there is no universally recognised "Cancer Studies" discipline within the humanities in the way that Disability Studies or Gender Studies exist, there is a growing body of interdisciplinary scholarship, which I have highlighted, that critically engages with cancer from cultural, social and artistic perspectives. However, much of this research is subsumed under broader categories preventing a sustained engagement with cancer as a unique site of inquiry. By centring cancer as the subject of this critical investigation, this study helps to create a more focussed engagement with the disease. It does so by building upon and extending approaches from within the Medical Humanities, Disability Studies and other interdisciplinary fields and applying them specifically to the experience of cancer. This project thus not only responds to gaps in existing literature but also actively contributes to defining cancer as a critical field of study within the humanities.

Thesis Overview

In Chapter One, "A Feminist Participatory Practice: My Methodological Approach", I map the intersections of my creative approach. I begin by outlining my how I employed a Feminist Standpoint Epistemology, expressing both the benefits and drawbacks of such an approach. From this I explain my workshop design, addressing how Feminist Participatory Action Research was a key inspiration to my methodological considerations. I then go on to explain the decisions I made around my participant recruitment, the collage making sessions and important ethical considerations in relation to my project. Finally, I address my theoretical approach through Eve Kosofsky Sedgwick's essay "White Glasses", articulating how I integrate autotheory and visual analysis to engage with both Spence's work and the artworks produced in the workshop.

In Chapter Two, "The Final Project and Photofantasy: An Investigation of Leukaemia", I examine works from *The Final Project,* uncovering new perspectives that challenge prevailing interpretations of this work as solely an exploration of death. By revisiting these pieces through

the lens of my own experience of leukaemia, I reveal a counter narrative that demonstrates how several of Spence's works offer insight into her lived experience of disease. Drawing on the metaphor of the zombie, I explore how Spence's work visualises leukaemia not as an endpoint but as a state of transformation. This metaphor captures the reality of living with a disease that alters both the body and one's sense of self. Next, I examine the emergence of medical imaging aesthetics within *The Final Project,* focusing on Spence's use of skeletons and internal body imagery. I consider how these visual elements reflect an exploration of bodily interiority and the process of integrating illness into one's sense of self, as well as a reclamation of agency over the body in the face of medical objectification. Through this re-examination, I aim to shed light on the radical potential of *The Final Project*, creating a jumping off point for the chapters that follow.

In Chapter 3, "Cutting, Slicing and Pruning", I explore how these actions emerge within the practice of photofantasy as tools for exploring and expressing experiences of cancer. I begin by examining the parallels between the surgeon and the collage-maker, drawing on the work of artist and pioneer of photomontage, John Heartfield. By connecting Heartfield's ideas to Spence's practice, I consider how she engaged with her own photographs, in the practice of photofantasy, as though performing a form of surgical intervention. Extending this analysis to the workshop artworks, I investigate how reframing the artist as a surgeon facilitates a reclamation of agency. This shift not only empowers participants but also creates a safer space for recreating or reimagining instances of powerlessness in the medical encounter. Finally, I explore how the physical acts of cutting and slicing bodies are metaphorically transformed through ideas of pruning and gardening. In this analogy, the plant or tree comes to act as a stand-in for the person with cancer, highlighting both the dehumanisation patients may experience and the ways surgical interventions, though often perceived as acts of care, can also be experienced as forms of bodily violence.

In Chapter 4, "Strange Temporalities and Cancer Time", I examine how the experience of cancer profoundly reshapes one's perception of time. Drawing on Alison Kafer's concept of "crip time" from *Feminist, Queer, Crip* (2013), alongside the work of Carmel Cardona and Taey Iohe, I develop the notion of "Cancer Time" – a framework that reflects the disrupted, non-linear, and often surreal experience of time during cancer experience. I begin by exploring the role of water and liquid, both as metaphors for time and as recurring elements in several artworks. This leads into a discussion of liminality and ghostliness, considering how cancer experience can feel like an existence in suspension – a kind of purgatory. Drawing on Kathy Charmaz's reflections on

illness-induced time shifts and Jo Spence's photofantasy work, I explore how the figure of the ghost symbolizes this in-betweenness, as well as the erosion of identity in the face of cancer's strange temporalities. Finally, I examine how bodies are depicted as both decaying and fruiting, engaging with fungal imagery. By drawing on the symbolism of mushrooms, I extend Abi Palmer's notion of "mushroom time," reinterpreting it to highlight the hidden potential within liminal states of being. Through these explorations, I argue that Cancer Time is not a singular or universal experience but multifaceted. It challenges linear understandings of time, offering instead a tapestry of disruption, suspension and reimagination.

In Chapter 5, "Hybridity and a Fusion of Parts", I explore how cancer experience can affect one's embodied sense of self. By focusing on the various physical alterations that people with cancer can undergo, I explore how the cancerous body can be understood as a hybrid – an assemblage of parts brought together through medical interventions. I begin by introducing the metaphor of the body as patchwork, considering how surgical repairs, the insertion of medical devices and other bodily alterations can disrupt one's perception of the body as a unified whole. Drawing on my workshop participants' reflections, I explore how the patchwork metaphor serves not only to highlight fragmentation but also to acknowledge the presence of trauma within "repaired" bodies. Building on this, I engage with cyborg theory and the writings of Jay Baglia to suggest that the cyborg offers a powerful metaphor for understanding the cancerous body. Finally, I explore how the practice of photofantasy has provided participants with a means to capture and reconcile their hybrid realities. Through collaging and creative expression, they have been able to represent their hybrid bodies – not as fragmented or broken, but as collages that reflect both loss and adaptation. Photofantasy thus becomes a space for reimagining the self, where hybridity is embraced as part of an ongoing process of identity formation.

Chapter 1: A Feminist Participatory Practice: My Methodological Approach

In this project, I sought to explore the ways in which Jo Spence's artistic practice of photofantasy can express the experiences of people who have had cancer. I focussed on analysing Spence's *The Final Project* alongside the artworks created in workshops based on Spence's photofantasy method, held with five participants. The purpose of these workshops was to create visual artworks that explored and captured experiences of cancer. One of the focal concerns I wanted to address in this research was the theoretical universalisation of cancer experience. This was not only with the view of challenging the dominance of biomedical knowledge in representations of healthcare but also to reconsider the conventional modes used to express illness. In the introductory chapter, I examined how relying on certain forms of media to represent cancer can lead to broad generalisations, often overlooking the nuances of individual experiences. As Angela Woods asserted, modes of expression that exist outside of verbal narrative are the key to revealing deeper representations of people's lived experiences (Woods 2011). With this in mind, my project aimed to investigate cancer patienthood from a creative perspective, using visual imagery to challenge and resist the creation of further overly generalising narratives.

I approached my research from a feminist standpoint epistemology, this was with the view of acknowledging that it emerged from my own experiences of leukaemia diagnosis and treatment. Based on this perspective, and using a participatory action research approach, I actively took part in the photofantasy workshops, creating artworks alongside participants. Throughout these sessions, participant and researcher engaged in discussions about how our thoughts and memories had influenced what we were making, as well as our mutual experiences of cancer. Thus, my autobiographical perspective was embedded in both the data collection as well as the analysis. The conversations held with participants during the workshops were used to contextualise my visual analysis of the workshop artworks, as were my own experience of leukaemia patienthood. This was with the intention of developing an embodied analysis that remains rooted in lived experience.

In this chapter, I begin by outlining my feminist epistemology, which has guided the development of this project from the moment of its conception. From this, I will explore how the participatory aspect of this project was conceived of, as well as how participatory action research shaped my approach to these sessions. Following on from this, I outline the design of

my participatory workshops going on to discuss the recruitment process I followed, including the ethical considerations involved in working with people who have experienced cancer. Finally, I will examine the theoretical grounding for my approach. My own autobiographical input into the project, rooted in my personal experience of leukaemia, formed an integral part of both the data collection and the analysis. Thus, this will form a key component of my methodological approach, as will the discussions I had with participants during the workshops, which explored how their memories and thoughts shaped their artistic choices.

Feminist Standpoint Epistemology

To challenge both biomedical and universalising representations of cancer experience, my research centres on the lived perspectives of Spence, my participants and myself. This has relied on a feminist standpoint epistemological approach, which has historically foregrounded the situated knowledges of people whose experiences are often marginalised or overlooked. By prioritising these personal, subjective experiences, I aimed to disrupt dominant discourses surrounding illness and embodiment, instead emphasising the diverse and unique realities of people affected by cancer.

A feminist standpoint requires the acknowledgement, as outlined by Caroline Ramazanoğlu and Janet Holland, that "feminist researchers, as knowing subjects, are deconstructed, unstable and diverse" (2002), meaning they occupy a specific relation to the research they undertake. This perspective challenges traditional notions of objectivity by recognising that knowledge is shaped by the researcher's social, historical and political positioning. Donna Harraway's metaphor of the greasy pole, which represents the slippery path to pursuing feminist knowledge, addresses this point, illustrating how the pursuit of an "enforceable, reliable account of things" is contingent on an awareness of one's situated knowledge as well as the "partial visions" that this affords (1991, 188). She critiques the idea of a neutral, detached observer and insists instead on "the embodied nature of all vision", which emphasises that knowledge production is always partial and shaped by the researcher's lived experiences. This leads to what Harraway terms "embodied objectivity", a model that does not abandon the pursuit of knowledge but rather demands reflexivity, accountability and an explicit recognition of positionality throughout the process of knowledge production. By adopting such an approach, feminist standpoint epistemology challenges dominant, supposedly universal narratives and instead foregrounds the value of diverse situated perspectives in knowledge production.

However, there have been criticisms to the feminist standpoint perspective. As D. Millen has explains, feminist standpoint theory "draws on Marxist ideas about the role of the proletariat to suggest that women, as an oppressed class, have the ability to not only frame their own experiences of oppression but to see the oppressors – and therefore the world in general – *more* clearly" (1997). From this perspective Millen warns that feminist standpoint theory "marginalises other oppressive struggles in its over-riding focus on womanhood", which in turn risks the generation of new hierarchies of oppression (1997). It is for this reason that my approach to adopting a feminist standpoint epistemology also employs an intersectional approach to feminism. Intersectionality, first coined by Kimberlé Crenshaw in 1989, addresses how different aspects of a person's identity, such as race, class and disability, can combine to create varied experiences of privilege or oppression. Thus, when considering the marginalised perspectives explored and expressed within my study, this is with an awareness that such perspectives do not denote a perspective devoid of privilege. Rather, each individual within my study is engaged in a complex entanglement of different privileges and oppressions that affect both their perspective and their experiences differently.

Moreover, in light of several of the critiques of feminist standpoint theory, Susan Wendell, in her book *The Rejected Body* (1996), addresses a mode through which she can avoid "making the same mistakes" with "people with disabilities" as have been made with the category "women" in adopting a feminist standpoint epistemology (70). One of the key strategies she identifies for doing this is rejecting the assumption that "people with disabilities identify with all others who have disabilities or share a single perspective on disability (or anything else), or that having a disability is the most important aspect of a person's identity or social position" (70). In other words, Wendell highlights the need to not generate universalising (and generalising) claims from what are subjective and individual positions. Even though people may occupy the same category of oppression, their relations to it and within it are often extremely different. Further to this, Wendell also acknowledges that it is impossible to have "an accurate understanding of what it is to be disabled until we hear from everyone who is disabled" (72), reiterating again the fact that a feminist standpoint epistemology provides access to partial realities and experiences rather than whole or objective ones. This leads Wendell to her conclusion that:

> I do not want to claim that all people with disabilities, or all women with disabilities, have the same epistemic advantages, or that they all have the same interpretation of their experiences, or even that they all have similar experiences… I do want to claim that, collectively, we have accumulated a significant body of knowledge, with a different

> standpoint (or standpoints) from those without disabilities, and that that knowledge, which has been ignored and repressed in non-disabled culture, should be further developed and articulated. (73)

In this, Wendell highlights both the limitations and the values of adopting a feminist standpoint epistemology, particularly in relation to experiences of disability and healthcare. She positions it not as a means of asserting a singular, authoritative perspective but as a foundation through which marginalised experiences can be recognised, developed and meaningfully articulated.

By adopting a Feminist Standpoint Epistemological approach, the trajectory of my research was ultimately reshaped. In the early days of this project, it was originally conceived of as a close reading of Spence's *The Final Project* through an autotheoretical lens with no participatory component or direct engagement with other individuals. However, attending the Arts Health Research Intensive (2022), run by the Arts Health Early Career Research Network, prompted me to critically reflect on my methodological choices. I recognised the ambition I had for my research to contribute to a deeper understanding of the nuances of cancer patienthood, yet my initial approach remained constrained by the perspectives of Spence and myself alone. Conscious that no study, regardless of its scope, could fully capture the vast and varied realities of cancer I was hesitant to move beyond my original focus. However, recognising that all knowledge is situated and partial, I felt a growing desire to amplify multiple positions and perspectives in my exploration. This recognition ultimately drove the evolution of my project, leading me to integrate the perspectives of participants whose lived experiences further enriched the study's exploration of cancer experience.

Workshop Design

As noted, the workshops consisted of participants trying out the practice of photofantasy on a one-to-one basis, alongside me, the researcher. To do this, the participants and I created individual collages around our experiences of cancer. Initially, I opted to recruit between four to six participants for this would generate around sixteen to thirty participant artworks alongside the same number of researcher artworks. Participants were provided with a brief presentation on Spence's *The Final Project*, by the researcher, to begin with, and offered artistic prompts (see Appendix 1) based on Spence's practice which they could engage with when collage-making. An example of this is: "try to express, using images, how you visualised your cancer". The prompts were offered as entirely optional. If participants had a clear idea of what they wanted to create,

they were encouraged to go with this. Available to participants was a table of magazines, newspapers, glue, tape and pens. Participants could also choose to bring their own collage materials if they liked. This was mentioned in the information sheet, shared with participations to determine if they wanted to take part in this project (see Appendix 2). The idea behind participants being able to make art with their own photographs or medical images was to adopt a further element of Spence's practice, where the artist used old images of herself in her work.

During the collage making, the participants and I discussed what their collages were trying to communicate, the ideas that they were exploring and how their experiences of cancer were influencing the making. The discussions we had during the workshops were recorded and transcribed to be used for context when analysing the participants' artworks in this study. Two weeks after these sessions, participants were asked to complete a brief written survey which gave them the opportunity to express any further thoughts/feelings that they had experienced regarding the artmaking sessions (see Appendix 3). I considered that following these artmaking sessions, participants might have felt that there were aspects of their experience that they did not get the chance to express during the workshops, or aspects of their works that they had come to understand differently. These subsequent reflections provided further context in my analysis of the artworks. There were three forms of data generated by the participatory sessions: the original artworks created (both by the researcher and participant); the conversations during artmaking (which were recorded and transcribed); and the submitted responses from the post-workshop survey regarding participants' thoughts. Each of the five participants, alongside myself, produced two to five artworks per session. This has resulted in thirty-two artworks overall, which act as a continuation of Spence's unfinished *The Final Project*. By engaging the voices of five other people who have experienced cancer patienthood, and of course myself, my aim has been to illustrate a broader (although by no means completely representative) series of expressions of cancer experience. Analysing Spence's works, alongside those produced in the workshops inspired by her practice, offers an insight into how the practice of photofantasy can be applied more broadly. It also offers a unique exploration of illness experience that resists the confines of linear narrative, embraces fragmentation and captures aspects of illness that can often remain unspoken or hard to articulate.

Participatory Action Research

A further challenge arose, however, with regard to gaining access to my participants' marginalised experiences in a meaningful way that did not risk reproducing the same structures of power that I sought to dismantle. This was one of the focal reasons that I adopted a methodology that involved Participatory Action Research (PAR). PAR is defined as a research approach that examines how participants actively engage in collaborative, action-oriented projects that reflect their knowledge (McIntyre 2008). McIntyre describes PAR's approach in more detail as: "characterized by the active participation of researchers and participants in the coconstruction of knowledge; the promotion of self- and critical awareness that leads to individual, collective, and/or social change; and an emphasis on a colearning process" (McIntyre 2008). As it involves participants in the co-creation of knowledge, PAR has often been utilised to represent marginalised voices/perspectives, like that of the critically unwell person. McIntyre argues that "feminist-infused PAR projects" are, as Lynn Reinharz suggests, "[m]aking the invisible visible, bringing the margin to the center" (McIntyre 2008; Reinharz 1992, 248). This is achieved, as Brett G. Stoudt addresses, through the creation of safe spaces that avoid exploitation, within which meaningful relationships between researcher and participant can be built (2007). This relies on creating an environment that challenges the power structures present in research, pushing for "minimized power gaps" between researcher and participant (Stoudt 2007).

When mirroring this in my study, I sought to create a research environment that allowed participants to feel involved as co-contributors, rather than objectified by the researcher working alongside them. The purpose behind this was to acknowledge their expertise, bring together different specialisms and to create an environment that welcomed differences in opinion (Flower and Kelly 2020). A key factor in establishing this supportive space was my insider positionality. As someone who has also been diagnosed with cancer, I share a social identity with my participants, which I believe helped establish a sense of relatability and trust. However, the insider position is not without its challenges. As Danielle Berkovic, Darshini Ayton, Andrew M. Briggs, and Ilana N. Ackerman (2020) caution, participants may become "tense and closed off" when they realise that the researcher occupies the same position as them, as this can undermine the "perceived neutrality of the interview, potentially creating distrust" (2020). To mitigate this risk, I was upfront about my positionality from the outset, making it clear during the recruitment process rather than revealing it only in the workshop sessions.

Beyond positionality, I further cultivated a collaborative and non-hierarchical research space through the structure of the workshops, which involved collective artmaking. In line with McIntyre's notion of "active participation of researchers and participants in the construction of knowledge"(2008), I created work alongside my participants, ensuring that every activity I invited them to engage in was one I undertook myself. This approach struck me as a kind of co-learning process, whereby both parties shared knowledge to further explore and develop our understanding of our experiences of cancer. Essentially, I intended to be an active participant in the research sessions as much as a researcher; I also hoped for there to be an equilibrium between participants' contributions and my own. As sessions developed, I noticed the value this brought to the sessions. I found participants asking me questions about my work in a similar way that I had questioned them and this greatly fuelled our workshop discussions. Moreover, our creative exchanges became a source of mutual inspiration. I found that both participants and I frequently drew from each other's work with recurring discussions, symbols and imagery often reappearing across multiple pieces. Ultimately, it was imperative to me that the data collection process fostered open dialogue about cancer experiences, with both researcher and participant contributing equally. This was why applying the PAR principles of collaborative knowledge production and fostering a non-hierarchical research environment was essential in generating research that meaningfully engaged with the marginalised experience of cancer patienthood.

There have, however, been criticisms to participatory research, with Kelly and Flower noting that the widespread nature of participatory methods can lead to a kind of participatory fatigue, whereby participants perform their responses in line with the needs of the researcher (2020). They also highlight that others, namely Bill Cooke (2001) and Harry Taylor (2001), have perceived participatory methods to be exploitative as they can extract local knowledge to further research agendas, with little benefit for those involved. Rather than viewing these challenges as a reason to avoid participatory methods, however, I instead saw them a reason to engage more thoughtfully with participatory practices. Where some participatory research can risk performativity, I sought to create genuine, reciprocal exchanges with my participants. Similarly, rather than merely extracting knowledge from participants, I hoped that the participatory practice would have tangible meaning for them. In doing this, I aligned with Bradbury's assertion that action research should generate "practical knowledge that is useful to people in the everyday conduct of their lives" (2015). Moreover, given PAR's deep intertwinement with "civil rights and anti-racism movements, feminisms, community development and so on" (Reason and Bradbury 2007), choosing such an approach for my study was both a methodological and

an ethical choice whereby I sought to acknowledge the responsibility of research to not just study marginalised experiences but to actively engage in reconfiguring the structures that shape them.

Recruitment

Although I have theorised that photofantasy is tailored to suit several of the challenges of cancer patienthood, I made the decision to recruit participants for this study who were no longer in active treatment for a cancer diagnosis. I did not want any discussions had as part of the workshops, or during reflections on Spence's work or the lived experience of cancer patienthood, to affect treatment decisions in any way. Also, having never trialled this artistic method with participants before, it would have been unethical to approach those who were experiencing invasive treatment and critical illness with an untrialled workshop. Therefore, I chose to conduct this study with people who are living with/managing their cancers, as well as people who are in remission. I did not want to restrict discussions of cancer to only those who have been "cured". Additionally, I was wary to restrict my study to only those in remission, for I risked promoting the idea that seeking a "cure" is always the only admissible route for those experiencing the illness, when many people are living with and managing cancer day-to-day.

I recruited participants in a number of ways. Initially, I began recruitment using a gatekeeper organisation, Pauls (a UK-based cancer support charity). I felt that this method of recruitment was necessary as a step to mitigate the risks of emotional harm done to my participants, as Pauls offers therapeutic support to people who have been diagnosed with cancer. I understood that recruiting participants from within a cancer charity would reduce the diversity of my study group, as it would be based on those who had both material and cultural access to this charity and its support. Access to this charity could be determined by proximity to certain Pauls centres, access to a vehicle to travel to these centres, good support networks for referral to this charity and other variables. However, I felt that having access to specialised services to help manage wellbeing would better equip participants to discuss aspects of their diagnoses and reduce risk of emotional harm during the study.

When recruiting through Pauls, my recruitment poster (see Appendix 4) was shared on their centres' notice boards. My recruitment poster asked for anyone interested in taking part to send me an email. I opted to recruit participants of any gender, who were over eighteen years of age, who have been diagnosed with cancer and who were at a reasonable distance from their initial

diagnosis. I judged “reasonable distance” on a case-by-case basis, from the individual details shared by those who got in touch with me via email. Unfortunately, I had no one get in touch in response to the noticeboard. At this time, Pauls were not able to share my recruitment poster digitally (via email or to their social media), which I believed would otherwise have garnered greater interest. Therefore, I began recruiting by sharing my recruitment poster to my own personal Twitter (now X) account. When participants from outside of Pauls got in touch via email, I directed them to several wellbeing resources (see Appendix 6). I also outlined from these resources that I had partnered with Pauls, signposting them as a useful charity for participant wellbeing. I recruited two participants through an open call on my personal Twitter account. Further to this, I contacted “Bowel Cancer Support Group UK” and “Cancer Survivors and Supporters”, two community groups based on Facebook, who shared my open call also. I recruited two further participants this way. I contacted Testicular Cancer UK and Womb Cancer Support UK on Twitter, who shared my recruitment poster to their Twitter accounts. I did not recruit anyone this way. I got in touch with Blood Cancer UK by messaging their CEO, Gemma Peters, on Twitter. Blood Cancer UK, then, shared my open call with their patient ambassadors via a mailing list and I recruited a further participant this way. The participants I recruited each contacted me via email, from the promotional poster that I had shared. At this point, I provided those who contacted me with an information sheet (see Appendix 2) to inform them of all aspects of the study. Following this, if anyone was interested in taking part, I asked, via email, for information regarding their age, dates of diagnosis and dates of treatment (if received). This information was requested to judge eligibility for the project. If those who contacted me were eligible, I shared a consent form (see Appendix 5). I recruited eligible participants in order of those who returned a consent form to me first.

One of my participants had been diagnosed a year and a half earlier. This was the most recent diagnosis I accepted for the study and my decision was based on the fact that this participant had been out of active treatment for four months. Four out of the five participants had been diagnosed in excess of eight years prior. I opted for those who had been diagnosed less recently as I was wary of conducting a workshop with participants who potentially had a lot of unprocessed thoughts and feelings regarding their diagnoses. It was my hope that people with reasonable distance from their initial diagnosis would have had more time to come to terms with this. The ages of the participants ranged from thirty-six to seventy-seven. I had hoped for a range of different ages when recruiting participants to offer a variety of perspectives, so this range was in keeping with my intentions. I also recruited only women for this study. This was not my initial intention; I had wanted to recruit a gender-diverse group of participants, so that I

could analyse gender-based differences in participants' experiences. However, only one prospective male participant got in touch with me, eventually opting not to take part.

In addition to this, at the recruitment stage, one of my participants, Opal, made me aware that she was an artist and had made work throughout her cancer diagnoses. We discussed briefly how this might affect the outcomes of the workshop, but I was keen from the beginning not to restrict her access on this basis. As I will touch on in the chapters that follow, I found with the session held with Opal, that the discursive aspect of the photofantasy workshop was equally if not more powerful than the artistic side of the practice. This is perhaps because Opal had already, using similar practices to photofantasy[6], explored her experience of cancer creatively.

The Collage-Making Sessions

I met with participants on a one-to-one basis, in a place that they felt comfortable, either at home or in a public place, like a co-working space. When working in a public place, I looked for food/beverage shops that had space for artmaking, were quiet enough to conduct interviews, were ideally close to green spaces for breaks if necessary and that were happy for me to conduct my research on site. It was my stated preference that these sessions would normally happen in a public place, local to participants, for this provided the greatest level of safety, comfort and convenience for both parties. However, if participants preferred to have a workshop where personal information could be shared in greater privacy or if they were unable to attend a public place for any reason (i.e. being immunocompromised, physical disability, medication schedule, etc.), workshops were conducted in the participants' homes. I conducted three workshops in public, one at a participant's home and one at the home of a mutual contact of mine and the participant's. The workshops conducted in public were still held in relatively private spaces. In all three public spaces, we had a private room to ourselves. The workshop that took place at a participant's home was held in private, with a large workspace. The workshop conducted at the home of a mutual acquaintance allowed full privacy and a large workspace also. All of the workshops had been planned to take place over a two-hour period, except for the workshop in a participant's home. I was invited to join this participant for lunch and, as a result, I spent four hours with them. Given the intimate nature of the information that was being shared between participant and researcher, I felt that rejecting this invitation and restricting the session to the two-hour intended time slot would have risked applying too rigid

[6] In one of her pieces, Opal had even created a collage using her medical notes.

(and clinical) an approach to what was intended to be a collaborative creative method, promoting non-hierarchical communication and understanding.

Meeting with one participant for a longer period of time allowed for very rich and exciting conversations about cancer patienthood and artmaking. The richness of these conversations certainly revealed that the conversational aspect of these sessions was as, if not more, powerful than the artmaking for some. In the days that followed this session, I did however find myself feeling quite drained. The sessions that ran for two hours certainly allowed for concentrated discussions about art and patienthood, while minimising the risk of exhausting the participants and the researcher. Despite finding the longer session incredibly fruitful, if conducting these further, I would encourage workshops to run within a more rigid time frame.

Prior to commencing the workshops, I had a strict plan for how the time during these sessions would be divided. I had planned a ten-minute information sharing session on Spence's *The Final Project* to begin the workshops. Following this, I had planned two short five-minute art making sessions, followed by two ten-minute making sessions and a final fifteen-minute making session. Each of these were separated by breaks and there was a thirty-minute buffer, in case participants or the researcher needed to take time out. By initially keeping art-making sessions short and building up to a longer thirty-minute period of artmaking, I intended for participants to feel gradually introduced to the practice. It was also my aim that by informing participants about the structure of these sessions beforehand, it would reassure them and allow them to feel prepared for what was to come.

In practice, the sessions ran very differently. From the first session, I realised that five minutes was not long enough to produce a collage, as it took several minutes to find images from the materials. Therefore, instead of a range of different timed sessions in each workshop, I followed the participants' lead on how long they needed to produce each collage. I tried to work at the participants' speeds and remained attuned to when they appeared ready to end each making session. I then offered breaks and continued only when participants felt able. As a result of this flexibility, some making sessions ran for fifteen minutes, while others lasted twenty-five to thirty minutes. This is why different numbers of artworks were produced in each workshop.

The workshops all began with a ten to fifteen-minute introduction to Jo Spence's artistic practice and *The Final Project*. This was intended to introduce participants to Spence's artistic practice, methods and ideas. I took the same book to each workshop: *Jo Spence: The Final Project*, edited by Louisa Lee (2013). I encouraged participants to look through this book, which

shows numerous images from *The Final Project*, while I gave the presentation. I created an information sheet on Spence that I read from and offered to participants to read along to. This introduction to Spence gave information regarding her artistic practice, how it changed with her cancer diagnoses and how her approach to artmaking was informed by her breast cancer and leukaemia. It also outlined the ideas behind photofantasy as a method and why Spence adopted it.

Following this, I reiterated to participants that we were going to be creating collages that engaged with our experiences of cancer. I provided participants with a sheet of prompts that I had created based on Jo Spence's practice (see Appendix 1). These prompts were designed to encourage participants to reflect on their experiences of cancer, using some of Spence's methods. Two examples were:

- Thinking of a moment during your experience of cancer, create a fantastical representation of this time.
- Find a substitute self in the materials as a starting point. This self can be you now or you at any point following your diagnosis. Begin adding to and collaging around this self. (Spence's use of "substitute selves" in photofantasy was outlined in the prior presentation).

The first prompt invites participants to consider their cancer experience in a fantastical way, as Spence did throughout *The Final Project*. The second prompt invites participants to use Spence's method of substituting images of herself with masks, figurines or other figures. It was my intention with each of the prompts to draw on a different aspect of *The Final Project* and Spence's practice while artmaking at this time.

We spent between fifteen to thirty minutes on each collage. This was guided by participants and how long they desired to spend on each collage. I verbally checked in with participants throughout the collage making process with regard to how much more time we would need and was also led by participants' cues, for example if they would slow with artmaking or sit back/pause and looking at their page. We then spent around five to fifteen minutes discussing what we had just made, with researcher and often participant asking questions of the completed works. Following this, I would check-in with participants, asking whether they needed to pause for refreshments or a break. Once we had either taken a short break or confirmed that the session would continue, artmaking resumed. We continued this process until the end of each session, with all but one session lasting two hours.

Ethics

To carry out this research, I was granted full ethical approval from the University of York's Economics, Law, Management, Politics, and Sociology Ethics Committee (ELMPS) in September 2022, prior to commencing fieldwork in December 2022. To apply for this approval, I completed a form where I detailed the measures taken to ensure both my safety and that of my participants. However, as the study progressed, my ethical considerations evolved and extended beyond the initial requirements of the ethics form. I will thus go into some detail in this section regarding several of the most significant ethical considerations that arose throughout my research. I will cover the involvement of vulnerable people in my research, the discussion of sensitive topics, managing the risk of emotional distress, protecting the physical health of both participant and researcher, participant anonymity, the use of personal images and doing research with participants I know.

One of the major ethical considerations of my project was the vulnerability of the participant group that I was working with. Even though I opted to minimise the risk of the study affecting treatment decisions by working with people no longer in active treatment for their cancers, I was open to recruiting people who had opted not to treat their cancer or had a terminal diagnosis. As mentioned, I made this decision because restricting my study to those in remission would have risked presenting a narrow and singular experience of cancer. However, working with people who are terminally unwell or living with cancer presents several additional ethical concerns. I was aware that taking part in research can be burdensome, especially for people who are already unwell, and I was incredibly wary of causing any kind of emotional distress for my participants. Additionally, obtaining informed consent can be far more challenging if someone is unwell and this is even further complicated when someone might be in a state of declining health as their capacity for offering informed consent can change (Verceles and Bhatti 2018). Ultimately, because of this, I had to consider each prospective participant on a case-by-case basis. If, based on factors such as their distance from diagnosis or treatment, or the progression of their illness, I felt that participation in the study could pose a risk to their well-being, whether physically or emotionally, I would have considered them ineligible to take part.

As it happened, I was only contacted by people who were in remission for their cancers as prospective participants. However, I had already carefully considered how I would approach recruiting participants who might be classified as vulnerable, including those who were terminally ill or had chosen to decline treatment. These ethical considerations remain crucial

for any future iterations of this study. I had a thorough informed consent process for taking part in the study that involved providing clear accessible information about the study and allowed ample time for participants to review this and ask questions before consenting. I was also able to make this information available in multiple formats where necessary. Additionally, where participants might have been at risk of declining health, I was prepared to check for ongoing consent at multiple stages of the research process, as I recognised that participants' emotional readiness could change over time. In the context of seeking informed consent among critical care patients Catherina Chenaud, Paulo Merlani and Bara Ricou note that when consent is "given at the very beginning of a study" it "cannot ensure the protection of the patient throughout the whole study by itself" (2007) as aspects can be easily forgotten when people are in critical conditions. In addition to this, I implemented a clear opt-out policy, that allowed participants to withdraw their participation in the study up to one month following their individual participatory workshop having taken place. By putting these measures in place, I aimed to strike a careful balance between ensuring that the experiences of people living with cancer were represented in my study, while also prioritising my ethical responsibility to protect vulnerable participants from harm.

Another significant ethical concern in my study was the discussion of sensitive topics. Since cancer itself formed the entire basis of my research, this required extensive consideration. While participants gave their informed consent to take part in this study and acknowledged that they were aware of its focus and its themes, I recognised that their feelings towards this could change and shift as the study progressed. As Martyn Hammersley and Anna Traianou address, obtaining consent "does not rule out the requirement that a researcher must evaluate what would count as an invasion of privacy, and whether this is warranted" (2016). To accommodate this, I designed the workshops to be largely participant-led in terms of discussion topics. In the information sheet, I made it clear that: "The study encourages its participants to only discuss elements of their diagnosis and cancer experience that they feel comfortable doing so. Therefore, any discussions had as part of this study will be guided by topics that participants desire to explore. You will not have to talk about anything you do not want to". In practice, this meant fostering organic discussions with participants about their artworks, including their use of symbols, images, colour, which allowed them to lead into discussions of their cancer experience at their own pace. As a researcher, I was careful to avoid asking direct questions about people's cancer experience unless they had already introduced the topic themselves. Additionally, as mentioned, I incorporated several planned breaks throughout the workshops

and regularly checked in with participants to ensure they were comfortable continuing, offering extra breaks as needed.

The discussion of sensitive topics was closely tied to another key ethical consideration: manging the risk of emotional distress for both my participants and me. While my approach to the discussion of sensitive topics helped mitigate this risk, I also implemented additional safeguards. As noted, I had a designated gatekeeper for the study who was familiar with my project and listed in the information sheet (see Appendix 2) as a source of emotional support for participants. Alongside this I also provided a number of additional resources for emotional and therapeutic support (see Appendix 6). When it came to managing my own emotional well-being, I maintained regular discussions with my supervisors, who provided encouragement and support. At several points, I found it necessary to step away from my research for a few days, and they reassured me that this was both appropriate and necessary. In addition to this, I accessed the University of York's mental health services on a number of occasions throughout my study. Ultimately, managing my emotional distress was a constantly evolving process that required a lot of mindfulness, self-awareness and compassion for my own capabilities.

Further to managing mental wellbeing, I was also incredibly mindful of protecting the physical wellbeing of both myself and my participants throughout the participatory workshops. As I was planning these workshops in mid-2022, concerns about the spread of Coronavirus remained prevalent. All of my participants had been diagnosed with cancer, so I was acutely aware that many of them could have compromised immune systems, making them more vulnerable to illness. In my own case, following treatment, I was informed that any previous immunity that my body had built up was likely wiped by my chemotherapy. Based on this, I took particular care when organising in-person sessions to minimise any potential health risks. Given the nature of my study, it would not have been feasible to conduct remotely, as it would have significantly hindered the participatory art-making process. Therefore, I implemented several precautions to ensure that in-person sessions were as safe as possible. I was clear when organising sessions with participants that it was possible to facilitate workshops in participants homes where it would support their wellbeing. I made this decision with the understanding that public spaces can pose unnecessary risks for people who are immunocompromised. My primary approach to safeguarding participant's health involved carefully monitoring of my own well-being to avoid exposing my participants to illness. In the three days leading up to meeting with each of my participants, I took a lateral flow test to check for Covid-19. Additionally, I remained vigilant that I didn't have any manifesting cold or flu-like symptoms when attending workshops in person. If I had exhibited any signs of illness, I would have looked to reschedule sessions.

As my work dealt with sensitive topics and personal information, a further key ethical concern of my project was ensuring the anonymity of my participants. To protect their identities, I asked each of my participants to choose their own pseudonym, which I have consistently used throughout the course of my research. While anonymity is typically a straightforward ethical consideration, in this project, it raised questions about whether it allowed me to appropriately credit participants for their creative contributions. This issue became particularly relevant in an exhibition that I organised, which showcased the works produced during the participatory workshops alongside several of Spence's pieces, borrowed from the Jo Spence Memorial Library Archive. The exhibition titled "Photofantasy" ran from 12th-15th June 2024 at Four Corners Gallery in London. The possibility of holding an exhibition was mentioned in the information sheet I initially provided to my participants, with a clear statement that if I proceeded with it, I would seek their explicit consent again. In line with this, in February 2023, I provided an additional consent form to my participants (see Appendix 7) to ask whether they were happy for their works to be part of the exhibition. I followed guidance from the Centre for Women's Studies departmental representative from the ethics board to ensure this process adhered to ethical standards. During these discussions, the question of crediting my participants arose. It became clear that it was impossible to both retain anonymity and fully credit my participants by name. While I valued the importance of giving credit for their contributions, protecting their anonymity took precedence. Each of my participants had shared a lot of their personal health information with me, which has been detailed in this thesis. Since there are published records of the exhibition, crediting my participants by name would have made them identifiable within this thesis. To address this, I specified in the exhibition consent form that, in keeping with the wider project, participants would remain anonymous in the exhibition. At the same time, I sought to ensure that participants felt recognised and valued in other ways. I invited participants and their friends/family to attend at a private view of the exhibition and made sure to personally thank each of them for their contributions. Additionally, at this private view, it was possible for participants to take credit for their own work if they wished, which some chose to do in conversations with family and friends. Since there are no written records of these personal acknowledgements, there was no risk of compromising anonymity within my study.

Moreover, since participants were invited to incorporate personal images, medical scans, or medical notes into their artwork, I had to carefully consider how this might pose a risk to their anonymity. While, in practice, nothing actually needed to be redacted or removed from the artworks to protect participants' identities, I had initially intended to remove any identifying information from personal images or medical notes if necessary. However, I was the only person

to include personal images in the art making, which I was very comfortable doing. Among my participants, Opal was the only person who chose to incorporate some of her medical notes into her artwork. Fortunately, these notes did not contain any details that compromised her anonymity, so redaction was not needed. Beyond preparing to redact sensitive information from artworks, if necessary, I also offered participants the option to exclude their works from being reproduced in this thesis. Although all participants consented to having their artwork included, I was prepared to verbally describe their artworks instead of printing them if preferred. This additional safeguard ensured that participants retained full control over how their contributions were represented while maintaining their privacy.

The final key ethical concern that arose during my research was the question of doing research with people I already knew. At the point that my recruitment transitioned from using a gatekeeper to an open call on social media platforms (Facebook and Twitter), I discussed with my supervisors the possibility that people within my personal or social circles, potentially even friends, might express interest in taking part. To ensure ethical integrity, we decided that if this should happen, I would assess each case individually with my departmental ethics representative. Ultimately, only one of my participants was someone I had a prior connection with, though this was as a friend of a friend, rather than a direct acquaintance. They were made aware of my study through a mutual friend and got in touch regarding participation as a result. While having pre-existing friendships with my participants could have raised further ethical concerns, particularly regarding bias and the ability to maintain professional boundaries, I determined in consultation with my departmental ethics representative that in this specific instance no additional ethical measures were required. Since my relationship with this participant was not one of close personal friendship, it did not compromise the integrity of my research or raise concerns about coercion or undue influence.

Theoretical Framework

After completing the artmaking workshops, I was left with an extensive and at times seemingly limitless collection of data to work with for this project. The workshops had generated thirty-two visual artworks alongside five audio recordings, which I transcribed into five text-based documents. In addition to this body of work produced by participants, I also conducted research into Jo Spence's archives, accessing over fifty pieces from *The Final Project*. Given the sheer volume of material, my initial approach was to categorise the works thematically. I

identified recurring motifs, such as expressions of self, place, and power to explore/observe commonalities across different pieces. This process helped me determine how certain works might enter into dialogue with one another. I applied the same method to the transcribed workshop discussions and Spence's autobiographical writing, looking for thematic overlap.

A key consideration in my analysis was the nature of the workshop-generated artworks. As these were created through exchanges between researcher and participant, I did not treat them as fixed, standalone objects. Rather, I chose to view them as traces of a broader, dynamic and collaborative process of meaning-making. Based on this, I afforded equal significance to both the verbal discussions and the physical artworks when interpreting the workshops' outcomes. I adopted a similar perspective in my engagement with Spence's works, recognising them as processual rather than static representations of meaning. Spence's works from 1991–1992 were created during a period of profound physical limitation due to her illness. As she grappled with leukaemia, the constraints on her artistic practice became starkly apparent. In Spence's own words, following her diagnosis, she expressed uncertainty about her ability to continue creating: "It feels at this point as if I will never do anything again" (Spence 1995, 217). My approach, therefore, is to consider the works Spence was able to create as traces of her lived experience with illness - fragments through which meaning can be drawn out and explored.

As part of this study, I integrated my own experiences of leukaemia into my research, adopting an autotheoretical approach. Lauren Fournier defines autotheory as "the integration of theory and philosophy with autobiography, the body and other so-called personal and explicit subjective modes. It is a term that describes a self-conscious way of engaging with theory" (2021, 7). In my case, this approach involved drawing direct connections between my personal experiences alongside those of Spence and my research participants. By doing so, I made explicit how my own subjectivity has influenced the interpretations and meanings I draw from these works. Fournier further emphasises that autotheory is "as much a wrestling with, and a processing of, discourses and material realities of theory… as it is an invoking of oneself as an integral part of theorizing" (2021, 15). In this sense, my work does not simply apply theory to personal experience, but rather engages in an ongoing, reflexive negotiation between the two. By acknowledging my own embodied knowledge, I position myself not as an objective observer, but as someone whose lived experience is integral to the research process itself. I actively engage my lived experience as a means of theorising and generating meaning within my research. At times, this has taken the form of brief recollections from my treatment, offering moments of personal reflection that illuminate broader theoretical discussions. In other instances, I have

simply drawn attention to the ways in which my own experiences have shaped my interpretations of the material. Through this process, my lived reality does not function as an anecdotal aside but rather as a critical lens – one that deepens and complicates my understanding of the artworks, texts, and conversations that form the basis of this study. It was neither possible nor desirable to separate my positionality and lived experience from this project, as they were fundamental to its very conception. My initial encounter with Spence's work at the *Misbehaving Bodies* exhibition was profoundly shaped by my own experience of cancer. The emotional and intellectual responses I had in that moment were inseparable from my personal history with illness. As the project developed, my experiences continued to shape my engagement with the material, influencing both my analytical framework and the ways in which I related to Spence's artistic practice.

I am coming to understand my experience of leukaemia patienthood as a kind of shared vision that allows me to expand the cultural understanding of Spence's images. I have developed this idea through Eve Kosofsky Sedgwick's essay "White Glasses" (1992). For Sedgwick, the object, "white glasses", begin as a material appendage that she appreciates and desires, first spotted on a friend: "the first time I met Michael Lynch, I thought his white-framed glasses were the coolest thing I had ever seen" (Sedgwick 1992). As Sedgwick begins to discuss Lynch's AIDS diagnosis and eventually her own breast cancer diagnosis, her essay articulates the moments where both Sedgwick and Lynch's experiences of health interweave and surpass one another in terms of severity. Sedgwick writes of the "white glasses": "so often I feel that I see with Michael's eyes – not because we are the same, but because the same prosthetic device attaches to, extends, and corrects the faulty limb of our vision" (Sedgwick 1992). The idea that these "white glasses", which the pair now both own, cause Sedgwick and Lynch to see from one another's eyes develops into a metaphor for their shared experience of existing as queer bodies in a heteronormatively centred healthcare system. This becomes clear when Sedgwick articulates how AIDS and breast cancer both expose markers of gender and sexuality that prove difficult for both her and Lynch. Where these glasses are described as a "prosthetic device", they become more of a prosthetic knowledge that is adorned through a shared experience of queerness and ill health.

When viewing Spence's images, I imagined myself possessing a similar metaphorical appendage that allowed us to share in understanding the works from a specific viewpoint: that of leukaemia patienthood. Despite our vastly different lives, both Spence and I share access to this understanding as well as a capacity to recognise elements unique to the experience of

leukaemia. Beyond Spence and I, my research participants were also part of this shared vision; they too in a sense wore "white glasses" through their individual experiences of cancer. It was through the collective perspective of me, Spence and my participants that new layers of meaning were able to be drawn from Spence's work, shaped by our overlapping experiences of illness.

When travelling between the different repositories for Spence's work, I noticed in particular how my autotheoretical approach was shaping my research experience. I visited the Jo Spence Memorial Library Archive (at Birkbeck, University of London), the Women's Art Library (at Goldsmiths University), the Richard Saltoun Gallery, the Centre for British Photography (housing the Hyman Collection), the Tate Modern and Britain, as well as the Wellcome Collection. Further to this, I also accessed the Image Centre's (Toronto, Canada) digital archives. What struck me most throughout my archival research was the scattered nature of Spence's archive. Her materials were not distributed in a logical or linear way as each institution seemed to hold a small selection of works spanning multiple projects, with parts missing or being held elsewhere. As a result, my experience of encountering Spence's work was inherently fragmented. With each visit, I felt that I got marginally closer to puzzling together a representative understanding of her work. However, upon reflection, my research did not fit together neatly quite like a puzzle. This has led me to conceive of my process more like constructing a mosaic, whereby I have gathered fragments of Spence's artistic practice and writing, layering them together with each archival visit. Yet, this process has not resulted in a linear or complete representation of Spence's work. Instead, my understanding has been shaped by how I have pieced these fragments together, informed by my own perceptions, interpretations, and positionality. Even the metaphorical cement that binds these pieces – what gives structure to my understanding – is infused with my autobiographical perspective. The connections I have drawn between Spence's work and her writings are not neutral but shaped by my lived experience and my subjective lens. This approach only deepened with the introduction of my participants' workshop artworks. These creations added further layers to this evolving mosaic. Their contributions became new fragments, expanding and complicating the picture, reinforcing that any attempt to represent Spence's work – or the experience of illness – remains partial, subjective and fluid.

In addition to adopting an autotheoretical approach, a further aspect of my methodology is visual analysis. My visual analytical methods involved a mixed approach that integrates techniques from semiotics, metaphor analysis and narrative analysis. The intention behind this

mixed approach was to allow me to examine different layers of meaning within both Spence and my participants' artworks. I have understood the artworks as constructed representations, shaped by cultural, historical and personal contexts, rather than direct reflections of reality. Thus, to analyse these works, I focused on their formal elements, including composition, layering, and the use of imagery. I paid particular attention to the process of collaging – cutting, assembling, and reconfiguring parts of negatives to create final compositions. By exploring how images are altered and combined, I aimed to uncover the visual languages developed by Spence and my participants to express their lived experiences.

The semiotic approach that I employed in my visual analysis related to how signs and symbols emerged within the artworks. By identifying recurring motifs, colour choices, spatial arrangements and the relationships between visual elements, I explored how meaning was constructed and communicated. This approach also allowed me to consider how participants and Spence drew upon broader cultural and medical iconography - such as medical imagery, fragmented bodies or objects associated with care and treatment – to reconstruct their visual narratives. In addition to this, I have paid particular attention to the construction of metaphor within the works. As George Lakoff and Mark Johnsen address in *Metaphors We Live By* (1980), "the human conceptual system is metaphorically structured and defined". They propose that metaphors are not just linguistic devices but rather that they shape the way that people think and understand the world - where we might think in abstract terms, these are understood through metaphor. Thus, by focussing on the construction of metaphors within the artworks, I began to tease out the abstract patterns of thought that shaped both Spence and my participants' understandings of illness. Further to this, I have employed elements of narrative analysis within my visual methodology. While traditional narratives are often structured through language and chronology, visual storytelling operates through composition, sequence and association. Narrative analysis thus allowed me to explore how both Spence and my participants used visual elements to construct, disrupt or resist narratives of illness, recovery and identity. By combining semiotic, metaphor, and narrative analysis, my visual analysis moved beyond simply describing what is depicted in the artworks. Instead, I considered how meaning is constructed, what cultural and personal frameworks inform these representations, and why certain visual choices emerge in expressions of illness. This multi-layered approach allowed me to explore both the individual and collective dimensions of cancer patienthood, positioning visual art as a powerful means of articulating experiences that resist straightforward verbal narration.

In my second chapter “The Final Project and Photofantasy: An Investigation of Leukaemia”, I present a visual analysis of Spence’s *The Final Project* that embeds my own auto-theoretical experience of leukaemia patienthood within the discussion. I examine the visual metaphors, symbols and narratives that emerge within Spence’s images (from 1991-1992) and contextualise these in light of my own experiences and understanding. My analysis builds on Spence’s current work, using it to contribute to our cultural understanding of cancer experience. Currently, no dedicated analysis exists that focusses specifically on *The Final Project* as an expression of leukaemia patienthood, making this investigation a crucial starting point for my thesis. By beginning with Spence’s work, I intend to establish a framework that will inform my later analysis of the artworks produced in the participatory workshops. This initial discussion will act as a conceptual basis that will be expanded upon in the following chapters. In Chapters 3-5, I will continue to integrate analyses of Spence’s works alongside analysis of the workshop artworks, examining them in dialogue with one another to develop deeper insights into how cancer was experienced and explored by my participants. The chapters are structured around key themes that emerged across both Spence’s art and the participant-created works. This thematic approach has allowed me to explore Spence’s legacy of photofantasy and *The Final Project,* while also considering how contemporary experiences of illness can be articulated through visual expression as well as understood and conceptualised in new ways.

Chapter 2: The Final Project and Photofantasy: An Investigation of Leukaemia

> *"Now that I have leukaemia, the language that worked with breast cancer doesn't seem, applicable… I'm spending my time trying to decide what story my illness is telling me" (Spence 1995, 215-6)*

In 1982, Jo Spence was diagnosed with breast cancer, prompting the creation of some of her most acclaimed works. Both the series *Cancer Shock* (1982) and *A Picture of Health* (1982-1986) expressed various facets of her experience of illness through documentary photography – from encounters with medical authority to staged self-portraits reflecting her feelings regarding surgery. During this period, Spence was also developing a practice alongside fellow artist Rosy Martin that the pair called phototherapy. Spence wrote that phototherapy involved "the joint production of visual and verbal signs, fantasies and memories (through snapshots, studio camera work and client drawings)" (Spence 1995, 134). Whether working directly with Martin or her various clients, Spence used phototherapy to explore visual representations of internal thoughts and feelings.

However, in 1990, when Spence was diagnosed with leukaemia, her practice shifted significantly and so too did its public reception. Although Spence continued to make work, initially pursuing her prior practices of documentary photography and phototherapy, she realised quickly that the exhaustion her disease presented would prove a challenge to her original practices. From this conflict between the unwell body and her photographic practice, Spence developed a new artistic method, Photofantasy, which consisted of collaging old images from her archive to create entirely new scenes. Its purpose was to allow Spence to continue creating visual works that expressed "the stories and actions in her mind" (Lee 2013) while living with exhaustion, reduced access to the outside world and her changing bodily appearance as a result of her disease.

Spence created *The Final Project* (1991-1992) while living with leukaemia, just as her works from 1982–1989 reflected her experience with breast cancer. However, as I have addressed, *The Final Project* is rarely acknowledged as expressing Spence's experiences of illness or patienthood in the same way. Where Spence's earlier works have been understood as creating "photographic narratives of her experiences with illness, medicine, and alternative healing practices" (Bell 2002,11), *The Final Project*, has instead been described as "address[ing] her imminent death" (Johnson 2016) or allowing the artist to teach "herself a dialectical mode of dying" (Boyer 2016).

This scholarly focus on death has been reflected in exhibitions that have included works from *The Final Project* too. Spence's work in the Wellcome Collection's *Misbehaving Bodies* (2019-2020) exhibition, discussed in the introductory chapter to this thesis, was accompanied by various curatorial captions, with one (hung aside an image from *The Final Project*) reading: "after being diagnosed with leukaemia in 1991 [Spence] made a series of photo fantasies that reflected on representations of death and depicted her body returning to nature". There appears to have been an acceptance that *The Final Project,* unlike Spence's earlier work from 1982-1989, is not so much about representing illness as it is about representing death.

Part of the difficulty in understanding *The Final Project* as representing Spence's experience with leukaemia as illness can be seen to come from conflicting views about her body's altered capacity for political engagement following her leukaemia diagnosis. Susan E. Bell wrote when considering Spence's work generally that: "Spence's photographs reflect a central tenet of the second wave of feminism that the personal is the political" and that this is explored through both Spence's body and her experiences, as captured within her photography (2002, 11). However, when Spence was diagnosed with leukaemia, she ceased photographing her body for her work, and her primary vehicle for politics disappeared. There are very few photographs of Spence from the period while she was living with leukaemia. In fact, the gap between one taken in 1991, and a further taken in late spring or early summer of 1992 (which pictures the artist in bed at the Marie Curie Hospice in Hampstead, looking considerably frailer than in previous images) reveals a stark contrast in Spence's appearance. Reflecting on this substantial gap in Spence's photographic record, Anne Boyer wrote that that "Spence, who had documented her own image through a politicised mode of self-portraiture she called 'phototherapy', seems to have turned into someone else without warning, leaving no photographic record that would bridge the gap between Spence the sniper and Spence the terminal cancer patient" (Boyer 2019). The term "sniper" or "cultural sniper" captures the way that Spence shot and exposed issues in culture. This role of sniper is captured most famously in a photo taken of Spence in pantyhose, with a slingshot, war paint, and bared teeth, which is printed on the cover of *Cultural Sniping: The Art of Transgression*, a book of essays by Spence that was published posthumously. Where Boyer aligns the figure of Spence "the cultural sniper" with the "politicised mode of self-portraiture" that the artist embraced, it is implied that Spence the "terminal cancer patient" who no longer approaches art in the same way perhaps also has an altered engagement with politics. This has led some to perceive *The Final Project* as depoliticised entirely.

This prevalent assumption began with Spence herself. The less assertive artistic approach that Spence adopted (consisting primarily of photofantasy) was expressed by the artist as de-politicised. When talking of her artistic practice in an interview with Jan Zita Grover from 1991, Spence said "I *used* to be a political self linked to issues of class and poverty and childcare, gender definitions" (1995, 217) (emphasis added). Her phrasing and framing of her political activity in the past tense, implies that she was no longer involved in politics in the same capacity by 1991. As referenced in the introductory chapter, Spence also explained that she was no longer willing to repeatedly throw herself into challenging and politically charged situations, as it was both too demanding and too exhausting (Spence 1995, 217). She asserts further that her approach to artmaking with leukaemia is one that avoids "being politically useful" for she is no longer a "political self". However, this interpretation raises questions about how involvement with politics might evolve in the face of illness. As Boyer highlights, "dying from disease, or at least certain types of diseases, is an experience that can appear fundamentally unavailable to the available politics" (2016).

Johanna Hedva has written on the difficulties of nurturing the unwell body and one's politics simultaneously, as well as how the unwell body can make certain political activism unavailable. When reflecting on how their chronic illness made it impossible to attend the Black Lives Matter protests in 2014, Hedva wrote, "How do you throw a brick through the window of a bank if you can't get out of bed?" (Hedva 2022). This question forms the basis of Hedva's "Sick Woman Theory", an essay discussing the difficulties of certain political actions when facing chronic illness. A central concern for Hedva was the difficulty of being physically present in spaces of activism, like rallies and marches, when her body made it impossible to be so. Although not an identical concern, there is similarity here with Spence's struggle. Spence's familiar method of artmaking/political activism became unavailable to her when the constraints of her unwell body made it impossible to appear in her photography in the same way. Of her practice from 1991-1992, Terry Dennett wrote that Spence did not appear in her work as she had before, because "two photographic sessions in a cemetery made her realize that her health was no longer good enough for her to engage directly in photography" (in Spence 1995, 222). As Hedva found her illness inhibited her from protesting in the street, Spence's body and the constraints of its illness inhibited her capacity for generating artwork – her primary tool for political commentary.

As noted, it was from the challenges posed by Spence's illness that photofantasy as a method emerged. In a sense, photofantasy became an accessible accommodation that removed some of the barriers inhibiting Spence. Where photography was too physically demanding, requiring

movement in public spaces and a well and able body, photofantasy required only one's hands and could be conducted from a fixed, private space. However, the physical constraints of Spence's illness, combined with the intensive regimens of care required to sustain her, persisted as a barrier to production. She expressed to Grover in the interview cited above: "it feels at this point as if I will never do anything again except look after myself" (Spence 1995, 217). These intensive routines consumed significant time and energy, leaving Spence with less opportunity to create art or make explicit political statements through her work. In an interview with David Hevey, Spence acknowledged the dual challenge faced by those with impairments: "it is a struggle both to maintain our bodies and get the struggle heard" (*Spence in* Hevey 1992). Consequently, rather than using self-portraiture to deliver direct political commentary on healthcare and autonomy as she had in the 1980s, Spence focused on producing whatever art she could, whenever she could.

This tension between Spence's physical limitations and artistic production is central to understanding *The Final Project*. With much of her time consumed by the demands of caring for her diseased body, Spence's art can itself be seen as an extension of this practice of care. Each of her pieces appears part of a coping strategy for coming to terms with her diseased body. Of her practice, Spence stated "this time around, I'm spending my time trying to decide what story my illness is telling *me* rather than trying to impose a narrative onto other people that I still don't even understand myself" (1995, 216). With each of her collaged pieces that explore her body in various scenes and scenarios, it can appear that Spence is enacting this process of discovery that she mentions – of trying to uncover the narrative of her disease. Thus, rather than interpreting the works from *The Final Project* as objects with intended meanings, they can instead be understood as traces of Spence's lived experience, with each piece reflecting her negotiation of the boundaries and challenges of terminal illness and revealing different aspects of her embodied struggle.

In this context, the political engagement that emerges from *The Final Project* is very different to the public activism and explicit critique that Spence employed in the 1980s. Instead, it reflects a more personal and embodied form of resistance. Through artmaking as a tool for self-discovery as well as her radical care practices, Spence reveals the previously hidden realities of her illness. Thus, when Hedva suggests that "Sick Woman Theory is an insistence that most modes of political protest are internalised, lived, embodied, suffering, and no doubt invisible" (Hedva 2022), *The Final Project* becomes a focal example of such embodied forms of protest. As Spence visualises her struggles, articulating the internal transformation her disease had

caused she helps redefine political resistance for people who are unwell, disabled or otherwise restricted by the constraints of their bodies. Thus, in this chapter, I will argue that *The Final Project* surpasses the narrow interpretations often ascribed to it. Instead, I will propose that it offers a nuanced exploration of Spence's experience with illness. Through this lens, I will examine several works from *The Final Project*, uncovering new perspectives and interpretations.

I will begin by addressing the dominant narrative that has confined *The Final Project* to a specific corner of Spence's oeuvre – that it is focussed on exploring Spence's death. Through both archival research and my own lived experience of leukaemia, I will demonstrate how counter narratives can be seen to emerge from this body of work. By producing images in which her body or face were superimposed onto unexpected and often surreal environments, Spence imagined multiple scenarios and fantastical narratives around her experience of leukaemia. Several lesser-discussed pieces from *The Final Project* can provide an insight into how Spence experienced both the hospital and medical supervision during her disease. Building on this, I will explore how Spence incorporated slides of blood cells into her compositions, layering them over images of her face and body. By positioning the cells so that they actively disrupt and interact with these images, Spence can be seen to allude to the personal transformations her leukaemia has caused. Out of these transformations the figure of the zombie can be seen to arise as a metaphor for Spence's embodied experience. Beyond representing the effects of several symptoms of Spence's illness, I will assert how this metaphor challenges traditional Marxist readings of the zombie, reframing it as a symbol of resilience and of a politics rooted in care. Finally, I will look at several works from *The Final Project* that incorporate overlayed skeletons and skulls – often interpreted as symbols of decay. Rather than reinforcing themes of deterioration, I will demonstrate how these elements can instead be understood as appropriating the aesthetics of medical imaging, which in turn allowed Spence to reclaim agency within the medical encounter. Beyond this assertion of agency, I will explore how these works also explore the strangeness of the internal body, prompting us to reconsider how art can reimagine and expand our understanding of the human body.

Revealing a counter narrative

In addressing some of the alternative approaches to *The Final Project,* I would like to note the impossibility of ascribing any singular interpretation to the series. As well as the subjectivity of art in all its forms, *The Final Project* is not held in any singular archive or collection and thus is

nearly impossible to view in its entirety. I have visited various repositories for Spence's work across London to try and access this series: the Jo Spence Memorial Library Archive at Birkbeck, University of London; the Women's Art Library at Goldsmiths, University of London; the Richard Saltoun Gallery; the Centre for British Photography (housing the Hyman Collection); the Tate Modern and Britain; as well as the Wellcome Collection. Beyond this, I have also accessed the Image Centre's (Toronto, Canada) digital archives, which house the majority of Spence's work pre 1990. With each of these visits, my interpretation of *The Final Project* continued to shift. In part, I want to make explicit that the interpretation that one might have regarding the series can depend entirely on which works (from each collection) one has access to. Thus, while my interpretation is formed from considerable archival exploration, there are still further unseen images from *The Final Project* that could continue to shape discussions regarding this body of work.

Figure 2.1. Jo Spence, *The Final Project*, 1991-1992.

With that in mind, I'd like to address one of the most widely circulated works from *The Final Project*. As discussed in the introductory chapter, Figure 2.1 shows Spence's outstretched body fading into a pool/field. This piece was produced by layering two photographs together, one of Spence floating in a pool wearing a black swimsuit and another of a large farmer's field. The outcome of combining these images is much as one might expect: a slightly confusing image where the ground appears to be both earth and water, with Spence's fading body as the centre point. This image not only serves as the back cover of Spence's posthumously published book *Cultural Sniping* (1995), but it also features as the header image of a *Guardian* article about *The Final Project* (Johnson 2016). In addition to this, it was the only piece from the project included in the *Misbehaving Bodies* exhibition at the Wellcome Collection (2019–20). As a result, this image has frequently been cited as evidence supporting interpretations of *The Final Project* as an exploration of Spence returning her body to nature or preparing for her imminent death. In

Samantha Johnson's article in the *Guardian*, for example, this image is captioned: "Spence was thinking more poetically about death" (Johnson 2016).

While Figure 2.1 can be associated with the idea of Spence returning her body to nature, there are multiple other works within this series that convey distinctly different meanings. Where Spence imagined her body floating over a field in this particular image, it appeared in various other locations also: lying across a surgeon's table, atop a rocky beach; impaled on a prickly cactus; fading into a weathered stone. Each setting expresses a distinct aspect of Spence's lived experience with leukaemia and goes far beyond "thinking more poetically about death". While several images from *The Final Project* that I go on to explore later in this thesis could illustrate this point, I'd like to offer the example of Figure 2.2. In this piece, Spence overlays a similar image of her floating body, but the surrounding environment shifts dramatically. Instead of blending with a natural landscape, her body floats over a setting reminiscent of a hospital. The scene includes weighing scales or a blood pressure reader, several vials of medicine, clinically white cabinets and large industrial sockets. These sockets remind me of those which would power the various machines that supported me while I was receiving treatment. Although Spence's body is still reclined, suggestive of fatigue and weakness, this backdrop paints a very different picture to that of Figure 2.1. It is no longer possible to read the image as Spence returning her body to nature. Figure 2.2 instead tells the story of a body lost within the machines and mechanisms of the hospital.

Figure 2.2, Jo Spence, *The Final Project*, 1991-1992.

As Spence changes the backdrop upon which her floating body is superimposed, the meaning of the image, as I see it, is drastically altered. Unlike Figure 2.1, Figure 2.2 appears to speak to the feeling of being within the hospital – often reclined, subjected to various medical processes, and existing within a carefully controlled environment. The scales represent the close monitoring of weight, while the vials of medicine can be seen to represent the treatments that are offered to return the body to a state of equilibrium. Where Spence appears floating in the centre of the image, she can be seen as suspended within the hospital scene, reliant on each of

these processes to live. As the overlaying of the two images blurs the edges of Spence's body, her form can be seen to fade into the clinical surroundings. Through this effect, Spence is made only partially visible and somewhat ghostly. This can make it seem as though the artist is partially existing and partially fading from existence. Although the symbol of the ghost can hint at a kind of death, it can also be seen to suggest the artist's lingering presence within the hospital, as though she haunts it. For anyone who has spent extended periods of time in a hospital, the feeling of merging with the room or the room becoming an extension of oneself is deeply familiar. After days on end spent in the same environment, it often no longer feels like a temporary space one inhabits. For me, especially at points where I was less mobile, I felt more like a piece of furniture within the room than a person. Where Figure 2.1 conveys themes of escapism and freedom, Figure 2.2 captures the restrictive and surreal nature of spending prolonged time in clinical spaces, underscored by the enclosed and cluttered backdrop Spence has chosen.

As I will go on to explore in Chapter 4, both Figures 2.1 and 2.2 reflect ideas about liminality. As the body is suspended in the scene, it captures the suspension of time and self often felt during life with a serious illness. While Figure 2.1 has been interpreted as a depiction of Spence's preoccupation with death during *The Final Project*, viewing it alongside Figure 2.2 allows for an alternative interpretation to emerge. This perspective suggests that Spence is not only contemplating mortality but also exploring the transformation of her body beyond its connection to nature. Rather than focussing solely on her terminal prognosis, she is addressing broader dimensions of her experience with leukaemia.

A further example of Spence superimposing her body over different backdrops can be seen in Figure 2.3. This piece is held as part of Richard Saltoun's private archive and was made accessible to me on request. It is one that I have not otherwise seen elsewhere and so has not contributed to existing literature on *The Final Project*. In this image, Spence pictures herself fading over an image of a sharp, prickly cactus. The fact that the image used is a close-up of the plant makes the cactus spikes appear magnified, making them

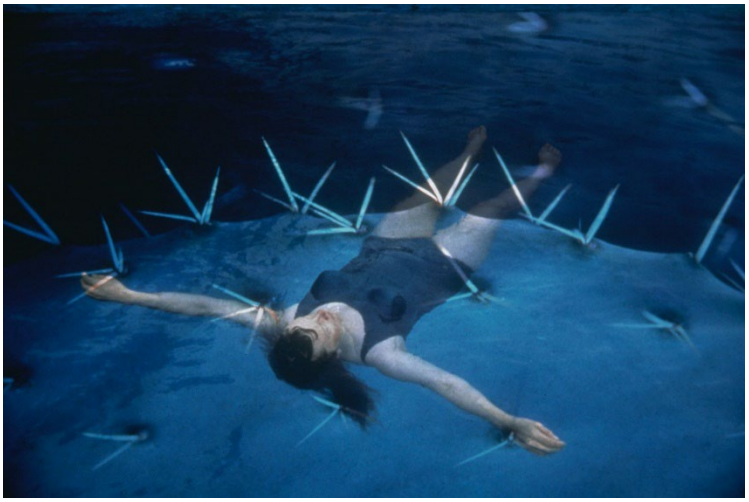


Figure 2.3. Jo Spence *The Final Project*, 1991-1992.

seem more threatening to Spence. Through the placement of her hands and arms, Spence looks as though she has been impaled by the cactus, reminiscent of stigmata. While this might hint at a connection to crucifixion and its biblical associations, the piercing of flesh makes explicit Spence's physical pain and discomfort. The cactus spikes visually evoke sensations of being pricked, stabbed, or impaled, and for me, they immediately call to mind medical needles. They were a daily presence for testing my blood and even arose in a much larger and more menacing way when I had my bone marrow harvested. The feeling of waking up after the surgery and being so acutely aware of where the needles had been inserted at the base of my back is one that I can recall vividly. This sensation of being repeatedly poked, prodded and pricked by medical staff is a shared experience for many diagnosed with cancer, and the cactus spikes surrounding Spence resonate as a representation of this clinical pain. Beyond this, Figure 2.3 metaphorically highlights the physical injuries scattered across Spence's body, creating the impression of painful, bloody wounds. If the spikes are not interpreted as direct references to medical interventions, they may instead be seen to symbolise the broader physical suffering tied to Spence's leukaemia diagnosis. Joint and bone pain, common symptoms of the disease, especially in its later stages, are subtly alluded to in the shadows at the base of the cactus spikes. These shadows, darker at the centre and fading outward, can be understood to mimic the feeling of pain radiating outwards from a central point, spreading across Spence's body.

Thus, as Spence superimposes her floating body over various backgrounds and landscapes, she can be seen to create quite drastically different scenes by making relatively minimal changes. Each subtle recontextualisation of her body, through the altered landscapes, radically transforms the meaning of her work, offering new perspectives on her experience with illness. I will revisit this selection of images (that depict Spence's floating body) in later chapters, to uncover further insights into the artist's life with leukaemia. Beyond Figures 2.1, 2.2 and 2.3, Spence's body also appears suspended over both a surgeon's table and a weathered stone covered in lichens[7]. These examples, along with the previously discussed images, reveal a narrative far beyond those which have emerged already – of *The Final Project* as an exploration of or preparation for death. Instead, a more nuanced interpretation of Spence's work can be seen to emerge, challenging the limited scope of existing analyses.

[7] Lichens are an organism produced by a symbiotic relationship between fungi and algae.

The Zombie and Transformation

As well as layering her floating body over various backdrops, Spence explored the layering of cancer cells over several different images of herself. This can be seen in Figure 2.4, one of the most direct examples of Spence exploring the clinical aspects of leukaemia within *The Final Project*. The work is comprised of two images layered into one "whole". In the base image, Spence, standing in an orange summer dress on what appears to be a sunny day, casts a playful shadow against a wall. On top of this image, a slide of blood cells under a microscope is layered. While some of these cells are healthy, the larger, less uniform cells pictured represent Chronic Lymphocytic Leukaemia blasts (the mutating blood cells found in Spence's bone marrow). The artist and her shadow, with wispy hair and arms outstretched, are engulfed by the cells. Through its arrangement over Spence's figure, this overlayed image alters the shape of her body: as well as her figure being widened, the shadow she casts is elongated and the boundaries of her body, previously clear, are now extended. The disruption that the overlaid slide of cells visually presents to the original image can be understood to represent the intense way that Spence's life and body have changed as a result of her disease. Further to this, the blood cells that have been introduced form a barrier between the artist and the viewer, distorting her before us.

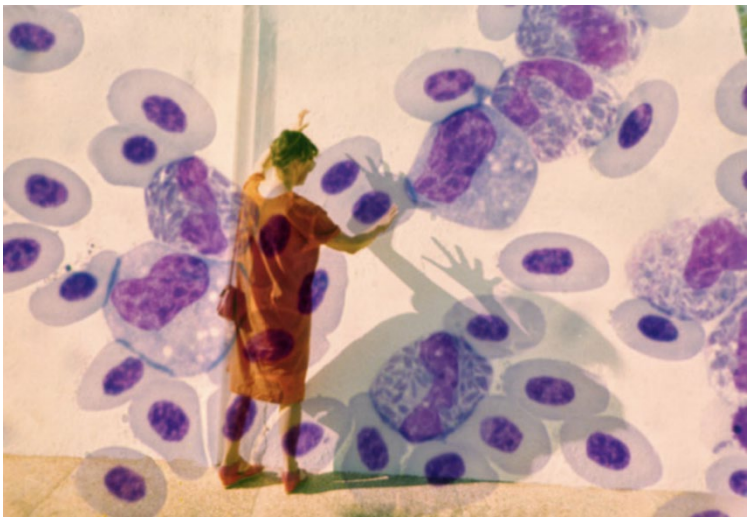


Figure 2.4, Jo Spence *The Final Project*, 1991-1992.

As Spence's gaze in this image is focussed on the cells in front of her, she almost looks as though she is examining them. The blood cells, spread across the wall, for this reason can appear to be reminiscent of a conspiracy board or murder map, often seen in popular culture when detectives piece together unsolved mysteries. These boards are covered with pinned information and lines connecting clues, mirroring the arrangement of the cells on the wall. The way that the cells have grouped together makes it appear almost as though Spence is drawing connections between different pieces of information. Meanwhile, her raised arms, close stance, and focused gaze give the impression that the artist is puzzling out a solution, deeply overwhelmed by the sheer volume of information. For this reason, Figure 2.4 can be understood as speaking to a moment that Dennett described when discussing *The Final Project,* whereby,

following her diagnosis, Spence sought information about her disease, researching "into the clinical aspects of leukaemia" (in Spence 1995, 221). In the same way that the cells obstructing Spence's body can be read as representative of her disease taking over her life, they can also be seen to represent the whirlwind of available information about leukaemia and the rabbit hole of information searching that Spence was lost within.

W. Karnilowicz discusses the experience of information searching in relation to their own diagnosis of cancer, writing that: "my experience of diagnosis and the first thought of being 'diseased' led to a motivated, compulsive and focused investigation of everything that was prostate cancer" (Karnilowicz 2011). Such an investigation is not uncommon; Boyer too writes of this experience: "a newly diagnosed person with access to the Internet is information's incubant. Data visits like a minor god. Awake, we pass the day staring into the screen's abyss, feeling the constriction of the quantitative, trying to learn to breathe through the bar graphs, head full of sample sizes and survival curves, eyes dimming, body reverent to math" (Boyer 2016, 22). Although, the internet was not available in such a capacity to Spence from 1990-1992, a similar process of researching can be seen to take place within her work. Where Boyer found herself "staring into the screen's abyss," Spence stares into her blood cells, scrutinising them for answers.

This process of searching within cells or statistics for information can be understood to mirror the daily monitoring of disease progression that takes place in hospital through one's bloodwork. I recall meticulously tracking my own bloodwork each day. Nurses would draw blood samples every morning, and by midday, I would have a detailed breakdown of my blood cell counts. This cycle of having my blood collected, waiting for results, charting the numbers and observing any fluctuations filled my days. This constant awareness of blood cells that I recall can equally be seen in Figure 2.4. As Spence stares at the wall covered in her cells, a similar sense of investigation is evoked, where the artist focuses on these microscopic details that signify so much. For those living with leukaemia, the pervasive presence of blood cells in their perception of the body and self is profoundly familiar. Beyond merely tracking the progression or improvement of the disease, bloodwork results dictate what one can or cannot do. After chemotherapy, I experienced neutropenia multiple times, a condition that meant my neutrophil count had become dangerously putting me at a heightened risk of infection. This directly impacted my daily life, restricting where I could go or who I could interact with. I was no longer able to leave the ward, visit the hospital school, or have certain visitors. Figure 2.4

captures the overwhelming presence of blood cells in the life of the person with leukaemia as well as their relationship, which shapes the boundaries of one's existence.

In addition to their propensity to shape and guide what one is able to do with their day, the blood cells can be seen to lead to another transformation in Spence's work. Where Boyer describes herself as "information's incubant", she introduces the idea of being incubated, grown and transformed through the search for information regarding her condition. By overlaying a slide of cells in Figure 2.4, Spence can be seen to similarly suggest that researching into her condition, as well as the nature of her disease, has begun to reshape and transform the artist into something new. This is apparent in the way that the blood cells interact with Spence's body and shadow. As her body casts a shadow on the wall before her, it creates a new outline that is widened and tilted. In this shadow, Spence's arms and fingers are extended, which creates a sense of her reaching for something. The stance that she adopts here draws connotation to the zombie which as a monster has been symbolised through the visual of a reaching hand (Lauro 2017, 1). Although Spence's creation of this zombie-like shadow could be perceived as playful, the introduction of the overlaid slide of blood cells to Figure 2.4 draws attention to the presence of disease within Spence's body. Any sense of playfulness is thus diminished by the overwhelming threat of these cancerous cells. This can appear to suggest that the zombie connotation which emerges within the image is not necessarily as light-hearted as it may seem but instead alludes to the embodied transformation that Spence is experiencing.

Figure 2.5. Jo Spence, *The Final Project*, 1991-1992.

The zombie is a repeated motif in several of Spence's works and can equally be seen in Figure 2.5, which also employs the overlay of blood cells. In this image, Spence appears dressed in white, with a bridal veil in her hair, she holds her head in one hand with her eyes closed and her expression oscillates between exasperation and fatigue. The slide of blood cells is faintly visible over the image, suggesting the presence of illness, which contextualises her expression. The hand cradling her head reflects her pain or exhaustion, while the faded quality of the image – caused by the cell overlay, evokes sensations of dizziness

or nausea. In both Figures 2.4 and 2.5, the overlay of cells creates a sense of Spence's disease proliferating across the compositions, while the sense of sickness expressed through Spence's body amplifies the connection to the zombie figure.

Where Spence's works can be seen to liken her to a kind of zombie, this figure can be understood to serve as a metaphor for the profound disruptions caused by leukaemia, where one's identity becomes intertwined with the physical effects of the disease. The zombie, a figure caught between life and death, captures Spence's embodied experience of living through the symptoms associated with leukaemia. When discussing the effects of Spence's leukaemia, Dennett highlighted its defining characteristic – the excessive production of immature white blood cells and a decrease in red blood cells. The impact of this was a limited oxygen supply to Spence's brain that impaired her cognitive function, affected her mobility and led to severe fatigue (Dennett in Spence 1995, 222). This experience of being robbed of energy and cognitive function are particularly related to the zombie. The zombie usually represents a change in pace and is often associated with slow and lurching movements. As David McNally writes "they move slowly and clumsily" (in Lauro 2017, 124). Where zombies have been known to move without use of certain limbs or with gaping wounds spread across their body, their condition is most often marked by a reduction in mobility, as Dennett describes Spence having experienced. Further to this, Lars Bang Larsen describes the zombie as "a body that is rotten but reactive, oblivious to itself yet driven by unforgiving instinct" (in Lauro 2017, 157). While this description is not entirely applicable to Spence, there are parallels in the way her illness impaired her behaviour. Like the zombie, she can be seen as functioning on a reduced cognitive capacity and existing in a more instinct-driven state. The zombie thus can be seen as a metaphor for the physical transformations that Spence's body experienced as a result of her leukaemia.

Martin O'Brien, a visual artist who explores living with the chronic illness cystic fibrosis in his work, has also found a deep connection with the figure of the zombie, going so far as to self-identify as one. In his article reflecting upon his commissioned work *Taste of Flesh/Bite Me I'm Yours* (2015), O'Brien writes:

> The zombie is both human and nonhuman animal; it is both dead and alive; it is something to both fear and pity. It offers a useful metaphor for thinking about being in the world with a chronic illness in which the relationship with death is keenly felt as a way of life. (O'Brien 2016)

For O'Brien, the zombie serves as a potent metaphor for chronic illness experience, embodying a liminal state of being simultaneously alive and dead, while also eliciting both "fear and pity". This idea of the zombie representing a state between life and death demonstrates a further way that the monster can be applied to Spence's experience, given the nature of her terminal diagnosis. In addition to the liminality O'Brien ascribes to the zombie on the basis of its existence between life and death, the mindless, mechanical behaviour of the zombie can equally appear to attest to Spence's experience. She has noted numerous times that leukaemia required an intensive focus on personal care. As the artist engages in these repetitive practices of care day-in and day-out to sustain her unwell body, Spence can appear to take on a role like that of the zombie, existing on autopilot only to sustain herself.

Figure 2.6, Jo Spence, *Epic Journey,* 1991-1992.

These mindless, repetitive acts of care can arguably be seen in Figure 2.6, a photofantasy piece titled "Epic Journey" (1991-1992) from Spence's Leukaemia *Diary* series[8]. Where it appears in *Cultural Sniping: The Art of Transgression* (1995, 224), the caption to this piece reads: "A page from Jo's on-going documentation of her survival programme."[9] *Epic Journey* is a key example of Spence's artistic exploration of living with leukaemia as well as her survival regimens. From top to bottom, the artwork features a series of photographs that

[8] Although this work was not taken from *The Final Project,* it was produced at the same time (1991-1992) and used the same method of photofantasy, whereby Spence layered multiple photographs together. It is the only image from the period that I have found that uses these same practices. For this reason, I have included it within this analysis.

[9] The full image caption reads:

> Jo Spence/David Roberts, 1991-1992
> *Epic Journey* (from the *Leukaemia Diary* series)
> A page from Jo's on-going documentation of her survival programme.

The suggestion in this caption is that Figure 2.6 was part of a broader project titled the *Leukaemia Diary* series. This was of great interest to me for such a series would exemplify Spence's artistic interest in detailing her life with leukaemia. However, despite extensive archival research, I was unable to locate additional images from the series. Patrizia Di Bello, archivist of the Jo Spence Memorial Library Archive, confirmed that Spence maintained diaries throughout her life. Nevertheless, no further materials documenting her leukaemia were accessible beyond Epic Journey.

document the artist's daily activities. The top two images depict Spence tending to and harvesting her homegrown herbs. The central image shows her relaxing in the bath while reading a book. On either side of this central image are two photographs of Spence knocking on the door of the Samaritans. Finally, the bottom images portray her seated at a table, counting her various medications. Each image very clearly illustrates the point Spence makes in the interview with Grover, where she says, "it feels at this point as if I will never do anything again except look after myself" (1995, 217). Figure 2.6 appears as a visual reflection of the various tasks of care that punctuate Spence's day. From nourishing her body with organic food, to managing medication to spiritual support, leukaemia for Spence appears to mean an intensification of her regimens of care.

At the Jo Spence Memorial Library Archive, there is a physical photo album that appears closely linked to this piece. I first noticed the link because it contained the same image of Spence counting her medication as appears in Figure 2.6. In addition to this, I noticed one further image of Spence standing in front of a printed article titled "Epic journey into a wild and unfamiliar world". This article was written by Hugo Davenport about the 1988 film *Time of the Gypsies*. Although there appears little link between the film, which depicts a young Romani man navigating life with magical powers, and Spence, the notion of an "Epic Journey" clearly resonated with the period of life that the artist felt she had entered, as this appears to be the namesake of Figure 2.6. In addition to these images, the photo album holds various photographs of Spence's daily care routines: she is pictured standing naked and brushing her body with an exfoliating brush, sleeping beneath a patchwork blanket, meditating at the bow of a boat and drinking while gazing longingly out of a bedroom window. Spence has captured, in each of these images, the reality of her day-to-day life. Every photograph, which range from moments of rest to the meticulous management of medications, can be understood as testifying to Spence's ongoing negotiation of life and care amid a terminal diagnosis, as well as her desire to document this process.[10]

[10] Discussions with Patrizia Di Bello (archivist of the collection) revealed the challenges of accurately dating this album. Although it is unclear whether one of the photographs was part of an earlier project taken during Spence's breast cancer (1982-1989), I have dated two others as being taken far later. The first photograph shows Spence slumped over a table, covered in a blanket. This image appears in *Jo Spence: The Final Project* (Lee 2013) alongside a collection of other works from the period 1991-1992. In addition to this, there is a further image of Spence stood in front of the printed article 'Epic journey into a wild and unfamiliar world', the film associated with this review was released in the UK in November 1990, just a month before Spence's leukaemia diagnosis. Thus, at least two photographs in the album likely belong to her visual documentation of life with leukaemia.

Rather than using these images individually as statements about the excessive care that the cancerous body requires, Spence's organisation of them in Figure 2.6 can be seen to emphasise the demanding nature of living with leukaemia. Unlike Figures 2.1-2.4, which layer one image on top of another, *Epic Journey* is a collection of images, each of which, when put side-by-side, build on the overall meaning of the piece. The cyclical arrangement of the photographs can be seen to suggest the relentless repetition of Spence's daily care activities. Through the composition of images that mirror and repeat each other, the piece can be seen to suggest that the artist is trapped in an endless loop, forced to repeat these activities unendingly. This repetitive cycle of activities of care is essential for sustaining Spence's life and in this aligns with the zombie even further. As a being, the zombie is often imagined as endlessly performing mechanical, survival-driven actions. Thus, where Spence combines images in Figure 2.6, these photographs come together to create a sense of relentless busyness, imbuing the work with a dynamic, animated quality. The combination of movement and monotony enhances the metaphor of Spence as a zombie, embodying the unceasing and intensive routines necessary for her survival.

If we see Spence as becoming a kind of zombie within her work, she can be seen to reframe the zombie as a Marxist metaphor. Jose Alvarez Lara and Abigail Muller note that "before George Romero forever transformed the genre in 1968" with the film *Night of the Living Dead*, "zombies were portrayed as colonial or postcolonial individuals who, robbed of mind and soul, endlessly toiled for the monetary gain of a master that usually manufactured them through voodoo rituals" (2023, 397-8). This portrayal reflects the origins of the zombie in the Haitian *zombi*, a figure enslaved through sorcery to labour without autonomy (Lauro 2017, ix). From this context, the zombie emerged as a Marxist metaphor for the worker who mindlessly produces for their master. However, the zombie's metaphoric ties to capitalism go beyond just this. In his article 'The Zombies of Karl Marx: Horror in Capitalism's Wake' (2018), Tyler Malone outlines the zombie's Marxist metaphors:

> The zombie as Marxist metaphor is a tripart image: the zombie simultaneously represents capital itself (which, zombie-like, lives only by consuming living labor), the capitalist worker (for the enslaved living labor becomes a zombified living dead), and the everyday consumer (who, trapped in this system, consumes in response to the thing that is consuming it, continuing the cycle endlessly). The point is that capitalism, which, in this scenario, we could call "zombie patient zero," is responsible for infecting both

> worker and consumer, and they thereby perpetuate the epidemic by fulfilling their function in and for the system.

Malone's interpretation highlights the zombie's association with enslavement, contagion, and the inescapable cycle of consumption. Each of the three zombies that Malone considers are driven by capitalism or entrapped within its systems.

Spence, however, transforms this narrative. The zombie she embodies is not controlled by capitalist forces but instead guided by her own will and the imperative to sustain herself. When interviewed by Grover, as noted in my introductory chapter, Spence highlighted that she was moving away from the sphere of art and cultural work to which she had previously dedicated her life and that instead she felt she would "never do anything again except look after myself" (1995, 217). Choosing to step away from artistic production to instead focus on "look[ing] after" herself indicates a significant shift away from capitalist notions of productivity. Unlike Malone's "capitalist worker," Spence's care work is uncompensated, self-directed, and explicitly detached from the goal of returning to productivity for capitalism's benefit. Through this reframing, Spence creates a powerful counter-metaphor. She also resists the capitalist devaluation of bodies that cannot produce. In this sense, Spence's work can be seen to reclaim the zombie as a figure of power, highlighting the strength found in a politics of care and asserting that survival itself is a radical act of resilience.

Hedva asserts that "the most anti-capitalist protest is to care for another and to care for yourself" (2022). This perspective stems from the notion that, under capitalism, care is valued only to the extent that it enables continued work and production; any care beyond this is considered excessive and unnecessary. Even care deemed necessary under capitalism – such as that which turns unwell bodies into productive ones – is often invisible. Against this backdrop, Spence's response to her leukaemia diagnosis stands out as a deliberate rejection of the demands of production. Where Spence states that she will no longer be returning to "the lion's den" as she once did "over and over again" (Spence 1995, 217) she appears to acknowledge and shift away from the self-exploitation she associated with her earlier breast cancer activism (1982). By dedicating herself to the care and nurturing of her unwell body, she enacted the feminist and Marxist ideals that had long informed her work. This embrace of care as a central practice not only defied capitalist expectations but also articulated a politics of care that is deeply personal. As Audre Lorde wrote in *A Burst of Light* (1988): "Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare".

The emergence of the X-ray image

As well as overlaying images to reimagine her identity within *The Final Project,* Spence uses a variety of substitute selves to represent herself. One of the most recurring is the skeleton. Through the use of the skeleton, Spence can be seen to reflect X-ray aesthetics, demonstrating how this imagery is not simply about death and decay; rather, it is a strategy for reclaiming control over her medically imaged body. By layering representations of skin, bone, and blood, Spence challenges the clinical gaze that traditionally renders patients passive and anonymous. As she explains in an interview with Ros Coward, medical imaging often felt depersonalizing, reducing her body to an object for medical observation:

> As a patient you enter the sphere of high technology at that point, and you are given various dockets to go round the hospital to be photographed. You also get your scars photographed sometimes, the injury to you photographed, or the lack of what you had before, as well as your blood, bones and liver being photographed, but nobody ever tells you why it is being done. (Spence in Holland, Spence, and Watney 1987)

This detachment from her own body – being photographed, documented, and studied without understanding the purpose – exemplifies the way medical imaging can strip away a sense of autonomy. By reclaiming these images through her art, I argue that Spence resists this erasure, transforming clinical representations into personal self-portraits.

As noted, Spence frequently incorporated skeletal imagery into her compositions. On Spence's use of the skeleton, Boyer has written:

> Skeletons are iconographic euphemisms. They aren't like corpses: they don't rot or smell. Unlike corpses, skeletons are not – at least as they appear in the symbolic vernacular – differentiated by the historical and social details of cause of death or manner of burial. Unlike a living body that is sometimes mutilated by disease or work or wear, a skeleton often retains the integrity, too, of being fully limbed, intact and seemingly mobile, with a jointed pliability that makes it appear ready at any moment to reanimate. Skeletons are easy and anonymous, at least compared to people in all their wounded particulars.

For Boyer, the skeleton represented something separate from the body, a way of Spence exploring herself without considering the "wounded particulars" of her flesh. Perhaps this is true

for several of Spence's works from *The Final Project* where the artist photographed toy skeletons in different staged settings. However, where Spence used photofantasy to layer photographs of herself with that of the skeleton, often aspects of her flesh, or as Boyer puts it her "wounded particulars", remain in the frame of the image. Where this is the case, I believe that the skeleton comes to represent more than just an "easy and anonymous" substitute self. Instead, these works can be seen to evoke something quite different, suggesting a more complex interplay between the skeleton and Spence's embodied self.

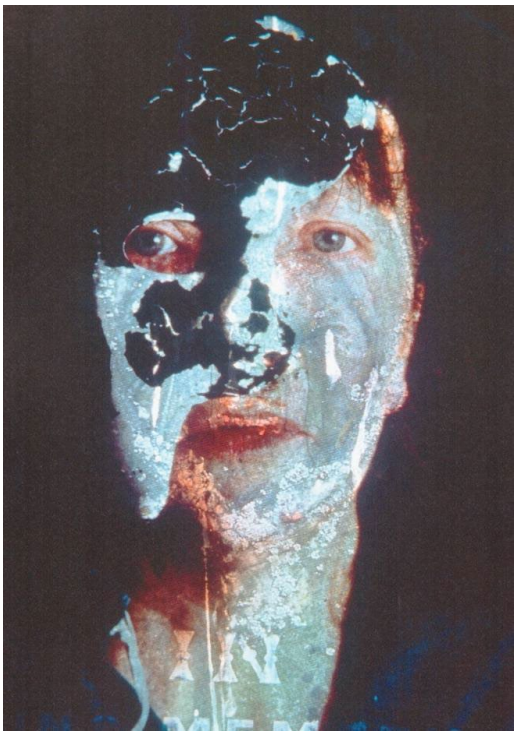


Figure 2.7, Jo Spence, *The Final Project*, 1991-1992.

In Figure 2.7, for example, Spence's inclusion of bone-like imagery can be seen to represent several different things. Boyer, along with Amy Tobin and Clarissa Jacob have interpreted several images from *The Final Project*, that incorporate overlayed skeletons, as conveying themes of decay. Boyer describes these images as "suggestive of decay" (2016), while Tobin and Jacob view them as portraying Spence's body as "decaying, dying, or deteriorating, and overtly staging a moment of return to nature" (in Lee 2013, 34). Tobin and Jacob further suggest that Spence captures decay through "the integration of body and ground by layering slides". In Figure 2.7, a similar technique of layering has taken place: a photograph of Spence's face is overlayed with an image, likely of a gravestone, that is covered in lichens and bears the inscription "in memory". As the lichens cover Spence's face, she appears weathered or decaying, like the gravestone. Additional elements in this image merit attention too, particularly the white mask covering half of Spence's face. This mask is reminiscent of several things: Spence's exposed skull, an elaborate masquerade mask, even the costume worn by the Phantom of the Opera which conceals the character's disfigurement in Andrew Lloyd Webber's well-known musical. The sense that Spence was hiding something potentially disfigured, by masking her face from view, supports the account by Dennett of the new difficulties facing Spence, given her rapidly changing appearance. However, it also hints at the skeleton being more than a representation of decay, for in this instance it becomes somewhat of a shield.

Furthermore, certain visual effects in Figure 2.7 can be seen to evoke the aesthetics of medical imaging technologies, like the X-ray. Predominantly this is apparent where Spence's face appears posterized[11] with extreme contrast, creating bold blocks of colour. Through this effect, bright white patches highlight her cheek, jawbone, and the centre of her neck. These luminous areas, set against a dark background, give the impression of a backlit image and bear a striking resemblance to several of my own X-rays taken during treatment. By viewing Spence's works as engaging with the aesthetics of X-ray imagery, the artist can be seen to explore her relationship with her internal body as well as the ways that someone with cancer might perceive their body through the lens of the imaging machines that render it visible.

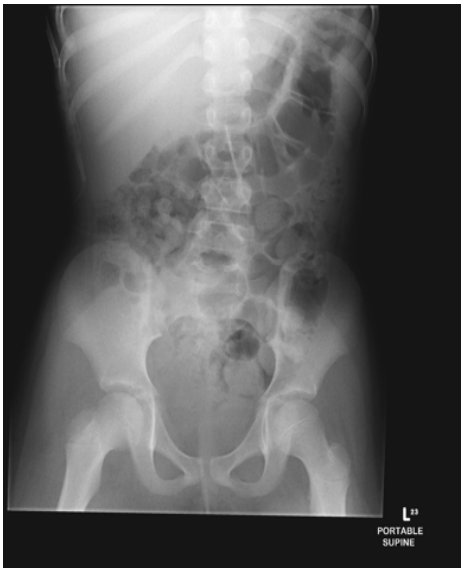


Figure 2.8. Personal X-ray

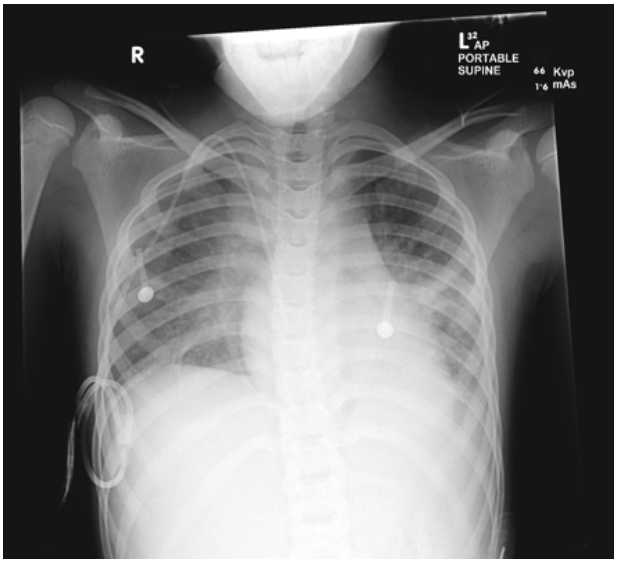


Figure 2.9. Personal X-ray

Through the layering of an X-ray-like image with the body, Figure 2.7 can be seen to explore the reintegration of medical imagery with the self. Jenny Slatman observes that "instead of affirming the image of the body as its own body, internal body images show the foreign and absent body" (2004). This resonates with my experience of viewing my X-rays for the first time. For 16 years after my treatment, I had no idea what my X-rays looked like. When I finally accessed them, I was struck by their unfamiliarity. They seemed completely anonymous, prompting me to search for markers of identity to confirm they were mine. I recognised myself in the slight scoliosis of my spine and the placement of my Hickman line. By locating these familiar aspects, I began to reimagine this alien image as a representation of my own body, bridging the gap between the medical image and my sense of self. In Chapter 5, I will go on to explore how I expressed the anonymity of my X-rays in relation to one of my own artworks, focussing on the impact that

[11] Displaying an image with few, block tones.

medical images can have on one's sense of identity. However, with regard to Figure 2.7, it is important to note the presence of these feelings of strangeness around the internal body to consider why one might choose to represent oneself in this way in light of such imagery. In creating a work that reflects both an X-ray and a self-portrait, Spence can be seen to explore a kind of reclamation of the internal body. By splitting the face in two and picturing the bone that lies beneath her skin, Spence creates an image that shows both what is inside and out, uniting the two as one.

In 'Intimate Visions: Representations of the Imperfect Body in the Age of Digital Medicine' (2020), Catherine Monahon and Elizabeth Jameson address how the transformation and re-invention of medical images has allowed patients and artists to "reclaim their identit[ies]". They give the example of Laura Ferguson, an artist who investigates her scoliosis through detailed medical drawings of her condition. Ferguson is described as seeking "to take anatomy out of the realm of the medical and return it to the personal" (in Monahon and Jameson 2020). By translating her medical images into creative, anatomical sketches that include markers of identity like her skin and her hair, Ferguson reclaims her anatomy and its image. Reflecting on this process, Ferguson writes:

> Over a lifetime of x-rays, I had always been intrigued by these shadowy, mysterious pictures of my own inner body – but they seemed to belong more to the doctors than to me. Putting my x-rays up on my own lightbox, and converting their flattened, black-and-white shapes back into three-dimensionality, I began to feel whole again. (2022)

The co-opting of these methods of imaging, often reserved for medical professionals, affords Ferguson a newfound sense of agency and control. This desire to reclaim ownership over a medically supervised body is similarly evident in Spence's earlier works (1982–1986), created in response to her breast cancer diagnosis. It is thus interesting to consider the ways in which her practice from 1991-1992 has remained on a continuum with her earlier interests in autonomy within the medical encounter. In light of Ferguson's artistic reasoning, Spence can be seen to enact a similar reclamation of her internal body, by turning her self-portrait into an image reminiscent of an X-ray but retaining identity markers like her skin and eyes.

Boyer describes Spence's use of the skeleton in her images as serving a dual purpose, for it functions as both a traditional symbol of death and as a reminder of the conceptual erasure of a specific identity (2016). Boyer explains the idea of the skeleton representing identity's diminishment by suggesting that a skeleton is "a human-like form that has shed the imposed visual markers of race, gender and class" (Boyer 2016). However, in Figure 2.7, Spence appears to retain these identifying features, even though they are partially obscured. While the inclusion of part of Spence's skull could be interpreted as symbolising the diminishment of her identity, it can equally be read as an assertion of it. For me, a key element pointing to this assertion of identity is Spence's gaze. Her milky, glazed pupils, a recurring feature in her earlier portraiture, confront the viewer directly in Figure 2.7. Here, the colours highlight the blue of Spence's eyes, drawing attention to her confronting stare. Instead of being struck by the exposed bone breaking through her skin, the viewer's attention is drawn to the presence of Spence's eyes and face, which remain vivid against the X-ray-like depiction of her skeleton. Rosemarie Garland-Thomson writes that, "our faces and their features are implements of communication, emblems of identity, and interpretive occasions" (Garland-Thomson 2006). Through the muscle, cartilage and skin on our faces we can be recognised, identified and continue to communicate. Thus, Spence's method of collaging, where the skeleton breaks through her skin, is not solely a statement about her bodily decay. Instead, it can be understood as expressing a longing familiar to many cancer patients – a profound desire to retain identity and self within medical processes.

This use of the skeleton alongside Spence's body can also be seen in Figure 2.10, where Spence overlays a skull in place of her face. This work is the cover image of the book *Jo Spence: The Final Project* (Lee 2013). In the image, Spence appears in a black dress, with a large pendant around her neck, carrying a woven bag. She stands with an arm raised, holding the top of her head in her hand. Where her face would be, a skull is superimposed, its mouth slightly agape. While the skull functions somewhat like a mask, obscuring Spence's face, it does not render her anonymous in the

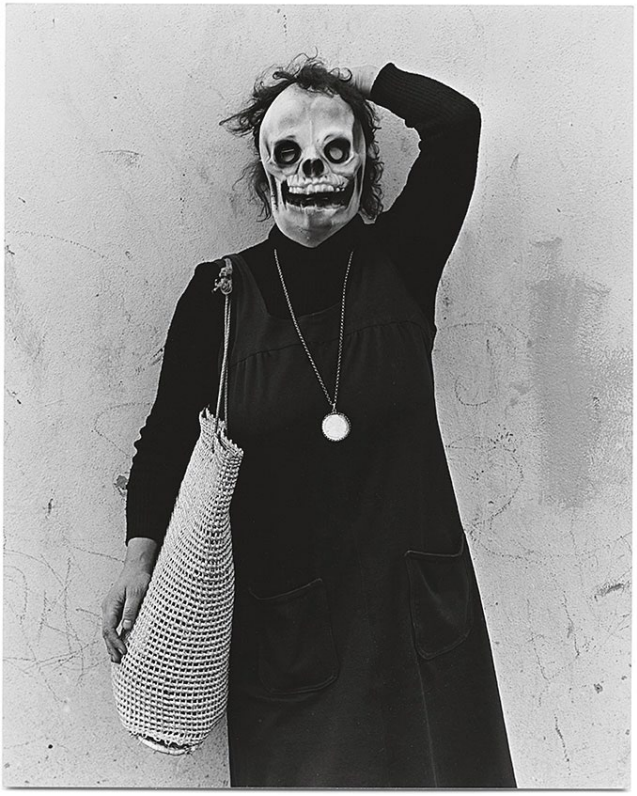


Figure 2.10. Jo Spence, *The Final Project,* 1991-1992.

way Boyer describes the skeleton. Much like with Figure 2.7, Spence's presence is unmistakable behind the skull: her eyes peer through its hollow sockets, her hair flows around it and her hands remain clearly visible.

This practice of incorporating skeletal imagery with the recognisable body can also be seen in the work of John Heartfield. His photomontage, *Adolf the Superman* (1932) is actually visually very similar to Spence's work (Figure 2.10) highlighting his influence over her approach. Figure 2.11 pictures Adolf Hitler with a transparent torso. In this image, Hitler's rib cage is visible and coins have been used to replace his spine. At the base of his torso a pool of coins collects. Heartfield's photomontage was a pointed critique, intended to show how Hitler "swallowed gold and spouts junk". By employing imagery of the X-ray, Heartfield appears to uncover the hidden truth beneath the surface of the person he depicts. This speaks to the early 20th century belief that X-rays could "purportedly expose a person's naked character and uncover his or her deepest passions" (Dijick 2005). Through the inclusion of parts of the skeleton alongside the human body, as well as the use of high contrast shadows, it is clear how Spence's work recreates aspects of Heartfield's. His influence on her work is even acknowledged in the text *Photography, Ideology and Education* (1976), co-written by Spence and Dennett and housed in the Goldsmiths Women's Art Library. It is therefore highly likely that Spence was intentionally redeploying elements of Heartfield's practice in her own work.

Figure 2.11. John Heartfield, *Adolf the Superman, Swallows Gold and Spouts Junk,* 1932.

When Spence draws on Heartfield's photomontage techniques in *The Final Project*, she adapts their intended meanings. There is a history of using medical images in the practice of photomontage that can be seen in the works of both Heartfield and Hannah Höch. Höch, another pioneer of the practice, was well known for her works critiquing gender roles and societal norms. In *Naked to the Bone: Medical Imaging in the Twentieth Century* (1998), Bettyann H. Kevles explains that Höch, "traces the roots of photomontage to postcards, war photography and radiography". According to Kevles, both Höch and Heartfield "used the

technique [of photomontage] to express their political outrage and developed it into an art form that exposed hypocrisy by showing the evil within as *if* in x-ray images" (137). Although Spence appears to have taken visual inspiration from Heartfield's work, the idea that Heartfield and Höch used X-rays to expose "the evil within" appears quite removed from Spence's self-portraits. Rather than using X-rays as a tool of political critique, Spence appears to employ them to explore and interrogate the truth of her internal condition. Through this approach, she repurposes elements from these early photomontage artists, shifting the X-ray's function from one of social interrogation to a tool for self-exploration and reclamation.

Figure 2.12. Jo Spence, *The Final Project,* 1991-1992.

Part of this self-exploration appears to involve the mapping of Spence's internal bodily matter. In Figure 2.12, she overlays a skull onto her face, yet more subtly than in Figures 2.7 and 2.10 as the skin on her face remains far more visible. This allows Spence's features to emerge through, rather than being entirely replaced. Instead of the skull sitting statically on the surface of the image, it appears to press against Spence's skin or even break through in places. This is particularly noticeable in the white highlights of the skeletal teeth that mark Spence's face. Through the blurring of bone and flesh, Spence can appear to engage in an act of excavation, whereby she peels back bodily layers to reveal the structures beneath, much like medical imaging technologies that make the internal body visible. In addition to Spence's visible skeleton, red flecks are scattered across the image, resembling blood. This layered depiction – progressing from blood to skin to bone – suggests a process of visual penetration, as though Spence is reconstructing her body from the inside out. Medical imaging technologies such as X-rays, CT scans and MRIs function similarly, rendering the body transparent by breaking it down into layers, and reconfiguring it into diagnostic data. However, while these technologies are typically used to objectify and classify the body from an external perspective, Spence reclaims this process for herself, transforming her own image into a site of self-exploration. Through photofantasy, she invites her viewer to enact the same process that medical imaging performs, to move beneath

the skin, to visualise the body as something both familiar and unfamiliar and to witness her process of self-discovery in action.

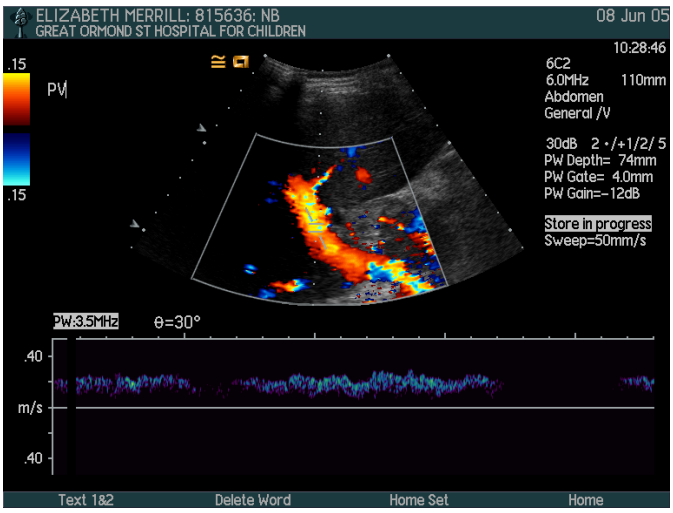


Figure 2.13. Personal abdominal scan

This notion of mapping the internal body is reinforced through Spence's use of colour in Figure 2.12, which appears similar to the palette of one of my own doppler ultrasounds (see Figure 2.13). This medical scan uses sound waves to create an image depicting blood flow through red, blue and yellow patches. In my own experience undergoing a doppler ultrasound, I was struck by how the screen translated my body's internal movements into shifting patches of colour, flickering in response to my heartbeat. The sonographer played the sound of my blood pulsing through my veins out loud at points during the scan, turning the image into something both seen and heard, mechanical yet alive. Thus, Spence's use of similar colours in Figure 2.12 evokes this same sense of movement for me. The red that is cast across her face reminds me of gushing blood, bringing with it the mechanical whir of the ultrasound. While the bright white patches mirror the illuminated tissue I saw in my own scans that would gently pulse. The colour choice of Figure 2.12 thus makes the image feel dynamic rather than static and even somewhat alive. The body and its depiction of the skeleton is thus not simply depicted as a decaying form by Spence, but an active, living entity, with its presence animated by the very blood that courses through it.

Spence's engagement with skeletal imagery and medical aesthetics can thus be seen to extend beyond an exploration of death and decay. By capturing the shifting colours of the ultrasound, she presents a map of her living body as well as its internal movements. Further to this, Spence can be seen to use this internal body imagery as an act of reclamation. By layering skeletal imagery with colours evocative of medical scans, Spence reimagines her internal body, mapping it in a way that recreates the clinically objectified scans produced by medical imaging software, and asserting agency over these. In doing so, *The Final Project* moves beyond conventional interpretations of mortality, instead offering a more nuanced reflection on illness, embodiment, and transformation.

Conclusion

Spence once asked, "how do you make leukaemia visible? Well, how do you? It's an impossibility" (Spence 1995, 215). In this chapter, I have begun to outline several ways in which *The Final Project* brings the often-hidden experiences of leukaemia into focus. By viewing Spence's works as dynamic traces of the artist's lived experience with disease – artifacts that reflect the evolving realities of her illness – I have introduced a new approach to understanding her final project. This perspective has allowed me to move beyond the prevailing narratives that frame *The Final Project* as being primarily concerned with death and decay. Instead, I have introduced several alternative interpretations that reconsider Spence's engagement with the body, exploring how experiences of illness manifest through the practice of photofantasy.

I began by addressing how critical writing and curatorial framing have historically cast *the Final Project* as "Spence's last innovative work on her approaching death" (Dennett in Lee 2013, 9). In examining how existing readings have overlooked the complexity of Spence's engagement with illness, I have introduced several counter narratives. By examining the repetition of images within several of Spence's works from *The Final Project*, in which the artist appears floating over various landscapes, I have demonstrated how multiple ideas and meanings emerge. For example, while a work depicting Spence's body fading over a field has been interpreted as illustrating her "returning to nature" (Wellcome 2019–20), I have challenged the notion that this is the sole interpretation. By analysing additional works in which Spence's body fades over different backdrops, I have expanded the discussion to consider a broader range of meanings emerging from her imagery.

One of the most focal aspects of *The Final Project,* that I argue illustrates Spence's exploration of leukaemia, is her engagement with a slide of leukaemic cells, taken under a microscope. In several works, Spence overlays this slide onto photographs of her face or body, creating compositions that visually integrate her body with the transformations occurring within it. By closely examining two of these works, I have argued that Spence introduces the zombie as a metaphor for her experience of illness. Traditionally, the zombie has functioned as a Marxist symbol, representing capitalist exploitation, the dehumanisation of labour and the loss of autonomy within oppressive systems. However, Spence reinterprets this figure in a radically different way, using it to express the lived realities of her illness. Through this transformation, the zombie in *The Final Project* no longer signifies the mindless subjugation of the working class but instead becomes a symbol of resilience, survival and a politics of care – one that acknowledges the struggles of maintaining an unwell body while resisting the erasure of identity

and agency. By reframing the zombie as a figure that represents the endurance of the unwell body rather than a symbol of bodily deterioration, Spence can be seen to consider her condition within broader discussions of illness as an ongoing, lived experience. Simultaneously, she can appear to highlight how her political engagements changed in the face of critical illness, to refocus on a politics of care. This in turn challenges the notion that her later works marked a retreat from activism.

Spence's work also critically interrogates medical language and imagery. In 1990, Spence posed the question "What are we able to say if we turn to the medical language of tumours, drugs and surgical procedures: a language which is crucial to medical professionals in helping to diagnose and treat cancer, but which can only speak of people as mechanical objects?" (Spence et al 1990). Here, Spence highlights both the limitations of medical language and its tendency to depersonalise patients, reducing them to mere objects of clinical observation. This concern forms a central thread in her later work, particularly in her exploration of skulls and skeletons. Where these symbols have often been interpreted as "iconographic euphemisms" for death (Boyer 2016), I have instead examined how they can be understood as representations of medical imagery – specifically, the ways in which scans and X-rays penetrate beyond the skin to reveal the internal body. By reframing how these works are perceived, I argue that Spence actively engages with the reclamation of her body from the medical gaze in several pieces from *The Final Project*. Through a comparative analysis with photomontage techniques, particularly the work of Heartfield, I have repositioned *The Final Project* within the broader history of medical imaging and artistic autonomy. This perspective not only connects Spence's final works to her earlier projects but also demonstrates continuity in her resistance of institutional authority, shifting the discussion from a preoccupation with death to one of agency and self-determination.

Through this chapter, I have challenged the prevailing understanding of *The Final Project* as a meditation on mortality. Instead, I have demonstrated how it reflects Spence's ongoing commitment to self-representation and political engagement, even as her body and artistic practice are adapted to the constraints of her illness. By exploring the tensions between medical authority, personal agency and visual representation, this analysis not only reframes *The Final Project* but also expands broader discussions of how cancer is visualised in contemporary art. Spence's work urges us to reconsider how artistic practice can function as both a personal coping mechanism and a radical act. Thus, in the following chapter, I will explore how the practice of photofantasy has enabled my participants to navigate their

experiences of cancer. Specifically, I will examine how the physical act of cutting, central to this practice, can reframe our sense of autonomy as well as providing a means for exploring agency in the face of illness.

Chapter 3: Cutting, slicing and pruning

> *"Once we feel it is safe to proceed we can share our 'new' stories with allies, and we can begin to re-imag(in)e who we are, both visually and verbally" (Spence 1986, 214).*

Maria Werner described Jo Spence's pre-1991 practice by noting that "in Spence's hands, the camera, this charmed tool of metamorphosis, also intervened like a surgical instrument – a scalpel with which to excise hypocrisy and falsehood" (cited in Hatherley 2020, 5). While Werner's metaphor intended to emphasise how Spence's camera functioned as a tool of critical interrogation, this interpretation of Spence's artistic tools as surgical instruments becomes particularly striking in the context of *The Final Project*, where the metaphor takes on a literal dimension. In this later body of work, Spence effectively replaced the camera with a scissors and a scalpel, shifting her artistic practice toward a direct engagement with the physical act of cutting and excising. Unlike her earlier photographic work, which involved capturing and framing reality, photofantasy required Spence to physically cut apart and collage pre-existing images to create something new. In this context, the act of cutting moved beyond Werner's metaphor; the excision of "hypocrisy and falsehood" instead became a far more literal process.

This direct engagement with cutting has also served as a recurring theme explored in the collages of my workshop participants. Behind the physical cuts enacted through the collage-based practice lies a range of different metaphorical meanings. Artist Serrah Russel has drawn a powerful connection between the cutting of paper and the emotional and political cuts experienced in life: " As I responded to the physical cuts and tears I made, I was also internally processing the cuts and tears happening politically." (cited in Elizegi 2019,192). This metaphorical dimension of cutting recurs throughout the photofantasy works. As the workshop participants used different visual symbols to represent themselves, from plants to bodies, the act of cutting images took on new significance, transforming into the pruning of stalks or the slicing of flesh. In these instances, the collage-maker became both the surgeon and the gardener, wielding the scalpel as a means to reexamine and reclaim the metaphorical wounds inflicted upon their bodies. Several of these works engaged directly with experiences of surgical cuts and procedures, exploring them as representations of the violence inflicted upon patients' bodies and the power dynamics at play within the medical encounter. This chapter will thus closely examine how cutting operates within both Spence's work and the workshop artworks,

exploring it as a means to highlight surgical violence and as a strategy for rethinking the balance of power between patient and medical authority.

Throughout this chapter, I return to the idea of "power". I am approaching "power" in terms of the ability to exercise agency. In *The Politics of Women's Health: Exploring Agency and Autonomy* (1998), Susan Sherwin clearly distinguishes between agency and autonomy, and I will use her framework in this discussion. Sherwin argues that "women often demonstrate agency by making choices regarding their healthcare." However, she differentiates this decision-making freedom from "autonomy." According to Sherwin, autonomy is based on "a more comprehensive notion of freedom, where not only is the immediate choice uncoerced, but the circumstances shaping that choice are also free from the coercive influence of oppression" (12). She further explains that "many patients who are either ill or at risk of becoming ill are easily frightened into overriding their own preferences and following expert advice, rather than risk abandonment by caregivers by rejecting that advice" (19). In such cases, patients may be exercising agency, but not autonomy, because their choices are influenced by external factors. In several of my participants' circumstances, autonomy was not present, for agency in decision-making around treatment and diagnosis had to be fought for. Before being able to consider whether decisions are autonomous, they must first be made available. Thus, I will be using the term "agency" when considering the power that participants wrested back by exploring their experiences artistically.

In the first section, "Collage Maker as Surgeon", I explore how the cuts Spence made in one of her photofantasy works acted as an assertion of power against her physicians. I then consider how the collage-maker can adopt the role of a surgeon through the practice of photofantasy, as well as the implications this has for asserting agency. Leading on from this, I examine how the act of cutting engages with the tension between care and violence in surgical interventions, challenging the assumption that surgical processes are inherently healing. In "A Return to Power", I explore how the practice of cutting extends beyond Spence's work into the participatory workshops, becoming a means for participants to reclaim control over their medical experiences and symbolically challenge medical authority. In the final section, "Patient as Plant", I consider how this metaphor reflects a loss of agency and the passivity often expected of patients within the medical encounter. I then examine how photofantasy enabled participants to confront these dynamics within their artworks.

Collage Maker as Surgeon

The surgical encounter is often familiar to many people who are diagnosed with cancer. For this reason, it was a recurring topic of conversation within the participatory artmaking workshops and has arisen repeatedly throughout Spence's work. Where Spence focussed heavily on the surgery to remove part of her breast within her breast cancer works from 1982-1989, she also depicted imagery related to surgery within *The Final Project*. One of the primary focusses of Spence's works that depict the surgical encounter was the power differentials at play between medical professional and patient. Medical educator John Launer outlines how a sense of power and powerlessness is constructed between the patient and the physician:

> As any patient will tell you, the power differential is not just about doctors being well and patients being ill, or even about doctors being in the hospital voluntarily while patients are there on the whole without much choice. It is about the enormous range of privileges that any doctor—even the most junior—possesses by comparison with a person lying in a hospital bed. These include the privileges of standing up while the patient lies down, and of being dressed in normal clothes while the patient is in pyjamas. They include the rights of deciding if and when to come and talk to the patient, how much time to spend in doing so, and what to tell or not to tell. Each one of the unthinking everyday rituals of ward life carries with it a set of choices that are available to the doctor, while the patient can influence them little or not at all. (Launer 2009)

In this excerpt, Launer highlights the many everyday decisions and privileges afforded to doctors which remain inaccessible to patients. These examples represent only a fraction of the broader structures that contribute to a patient's sense of powerlessness in relation to their own care. I will thus consider how, through the practice of photofantasy, Spence explores and actively disrupts this dynamic.

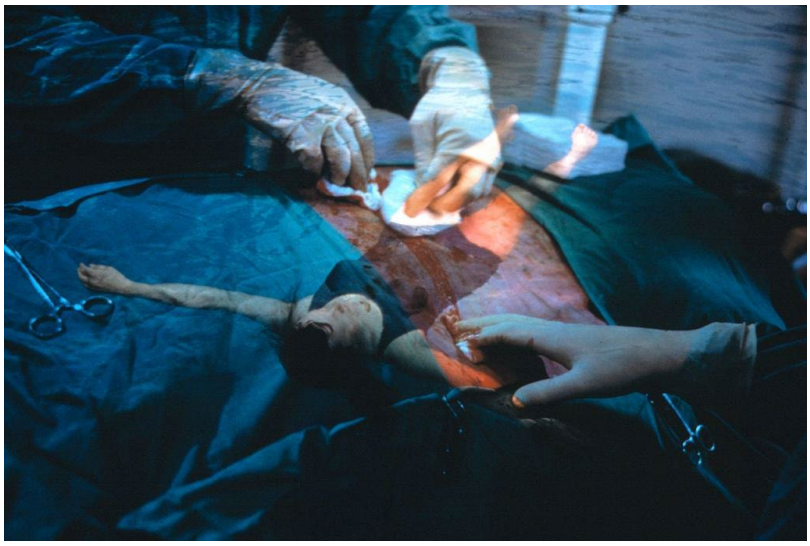


Figure 3.1, Jo Spence *The Final Project*, 1991-1992

In Figure 3.1, an image from Spence's *The Final Project,* the artist engages directly with the image of a surgical cut. Within the piece, there are two photographs that have been collaged

together. The first captures a surgical scene, in which two surgeons with gloved hands blot the open wound on a patient's body that is partially obscured behind a surgical drape. The second photograph features Spence herself, as she floats in a body of water – an image that I highlighted in the previous chapter. Through the overlap of these images, the gaping wound is visually imposed onto Spence's body and the surgeons' hands appear to be tending to her. This composition is immediately situated in the medical theatre, where the surgeons' oversized hands, in comparison to Spence's miniature body, create a sense of the surgeons' authority in contrast to Spence's lack. This is emphasised further by Spence's passive positioning. She is reclined with her eyes shut and her arms outstretched. Through this positioning it is almost as though her body is offered up or made available for surgical intervention.

However, this initial impression does not appear to reveal the whole story. Where one reading could insist that the piece captures the power of the surgeon over the patient within surgical encounters, a closer examination complicates this. Despite Spence's seemingly passive role, there is one aspect that mystifies the scene. Two pairs of operating scissors within the image lie just next to each of Spence's outstretched hands. Spence's proximity to the surgical scissors in this image is strikingly unusual, calling into question whether they have been used by the artist to inflict the wound that reaches across her middle. Where initially Spence appeared to be the patient, of whom the surgical cut was being enacted on, it is now apparent that her role might be more. The wound at the centre of the frame may instead not be the result of an external procedure but in fact a deliberate act by Spence herself. If self-inflicted, this action alters the interpretation of her presence within the image significantly, positioning Spence as an active agent rather than the subject of intervention.

Examining how power operates within the medical encounter has been a central theme within Spence's work. In both *Putting Myself in the Picture* (1986) and *Cultural Sniping* (1995), Spence discusses the power relations between patient and medical profession that she navigated following her breast cancer diagnosis, as well as how she explored this within her works, from 1982-1989. She recalled finding it hard to express how she was situated within various hospital interactions "as a powerless patient" as well as how she felt "subjugate[ed]" to the medical profession due to a lack of knowledge about her own body (1995, 107). The camera, however, was determined as Spence's tool to break free of this passivity, for by photographing her experiences she "determined to document for myself what was happening to me. Not to be merely the object of their medical discourse but the subject of my own investigation" (1985, 153). During the period of 1982-1989, Spence's resistance to medical authority took the form of

documenting her hospital interactions and restaging several of these before her camera to reinterpret the power relations at play. In Figure 3.1, a similar interest in restaging power relations can be seen to appear, however, with a clear escalation of the artist's defiance. Where her life could have been perceived as being in the surgeons' hands in Figure 3.1, Spence resituates it as firmly within her own. By causing herself harm in the image she directly defies the objectives of surgery and the surgical encounter. Thus, by engaging with the act of cutting, Spence does not simply challenge the authority of the medical profession, she seizes and redirects its power. Rather than being the passive subject upon whom surgery is performed, she takes control of the surgeon's scissors.

Interestingly, however, the power that Spence claims within the image can be seen to extend beyond the surgical wound which is depicted in Figure 3.1. There are, in effect, two versions of Spence at play within this piece, the one visible within the image, who appears to have cut herself with the scissors and the one outside the frame, who physically created the work using that very same instrument. This piece collapses the boundary between these two versions, asserting that Spence both in and out of the image has reclaimed these medical tools. No longer solely an object of medical intervention, she transforms the scissors from a tool of surgical authority into one which exercises her personal, artistic agency. By wielding them both in the frame to assert control over her own body and outside the frame to shape the image itself, Spence repositions the scissors as an instrument of creative power rather than medical dominance.

This exploration of the collage-maker's tools both within and outside of the frame of the image can be seen further in a photomontage by John Heartfield. When discussing her experiences of powerlessness within the medical encounter in *Cultural Sniping*, Spence drew attention to Heartfield, noting that he made "visible what is not being talked about by those in power" (1995, 107). Heartfield, who I have already drawn upon in the previous chapter as one of Spence's artistic influences and a pioneer of photomontage, once again offers a striking point of comparison to her practice of photofantasy. Like Spence, Heartfield has drawn attention to the tools used by the collage maker in one of his works, emphasising their dual function as instruments of both creation and power. Heartfield's collage (Figure 3.2), titled "Self-portrait

with the Police Commissioner Zörgiebel" (1929), pictures the artist holding the head of Karl Friedrich Zörgiebel (a German, social democratic politician who served as Chief of Police) with his left hand and severing him at the neck using a pair of scissors, with his right. Even though this image represents a violent execution, there are aspects of the encounter that are similar to Spence's surgical one. For instance, Zörgiebel's physical positioning suggests the trust and resignation of the surgical patient – his eyes are shut and his body tilted as though partially reclined. The expression on his face is relaxed as though anaesthetised and Heartfield's hand holds him still so that the cut can be made with precision. The image makes clear that power resides with Heartfield, yet this dominance is not solely established through bodily positioning. Rather, it is the tool he wields – the sharp blade poised to sever flesh – that most directly signals his control. These scissors, like those in Spence's work, become a symbol of authority, embodying both the capacity to harm and the potential to reshape. Crucially, both Spence and Heartfield direct their interventions at figures of authority. Just as Spence subverts medical dominance by taking control of her own surgery, Heartfield stages the execution of a political authority figure. In both cases, these acts of cutting become radical gestures of defiance, disrupting the structures of power that seek to render them powerless.

Figure 3.2, John Heartfield, *Self-portrait with the Police Commissioner Zörgiebel* (1929)

Beyond just reclaiming power in his photomontages, Heartfield's collage-based practice has been likened to a kind of surgery. In her book *Revolutionary beauty: the radical photomontages of John Heartfield* (2014), Kriebel describes Heartfield's "incisions that penetrate [a man's] photographic flesh" are "a solicitation that turns the artist into a surgeon or a magician" (14). The characterisation of Heartfield as a "magician" arises from the sheer impossibility of his action – cutting a man's head off with scissors is likely near impossible, as is the reality of the image that Heartfield creates. Thus, where he turns fantasy into photographic reality, we see Heartfield become a kind of "magician". However, his comparison to a "surgeon" is far more provocative, as it generates a parallel that can be seen to cast new light on how we interpret

surgical intervention. The violence seen in Heartfield's photomontage is not normally a violence that would be associated with surgery, especially because his cutting appears to be causing harm rather than healing or doing good. However, for Kriebel this power that Heartfield has to "conjure a new body" or entirely reshape the one before him with scissors is where his similarity with the surgeon lies. Beyond the act of cutting, Kriebel further highlights the surgical parallel within Heartfield's practice of photomontage through what she terms "suture". She argues that Heartfield deliberately conceals the "rupture[s]" in his work, made by piecing snipped images together, and in doing this achieves "a virtually seamless bonding of separate pieces", referred to as a "suture" (Kriebel 2014, 11). A suture, by definition, is typically related to surgery and the practice of mending flesh and piecing together (i.e. suturing, collaging). This definition is stretched in Kriebel's example to extend to the mending of photographic flesh and pictured realities. Heartfield can be seen to mend the violent cuts he inflicts on photographic bodies within his collages, by sticking them seamlessly back together, often as hybrids. The collage maker's glue thus becomes synonymous with the surgeon's healed stitches.

This notion of the collage maker as a kind of surgeon can be seen further in a photograph of Spence at work in her studio. This photograph, from the Jo Spence Memorial Library archive, shows Spence pictured at a white desk, with 35mm film clippings illuminated on the shelves in front of her (see Figure 3.3). The artist is holding an image to the light in her right hand and holding part of another in her left. On the desk are several photographs of Spence, negatives as well as prints, books, and a pot of stationery, with a large pair of scissors protruding. I found this photograph as a negative, amongst other negatives that Spence used to create *The Final Project*. It appears to be documentation of her process of making that has otherwise gone unseen. Although obviously different, the set-up of Spence's home studio can be likened to the operating theatre. The illuminated negatives are visually similar to X-rays; for before their digitisation, X-rays were printed on the same film as photographs and viewed over a lightbox.

Figure 3.3, Jo Spence in her studio n.d.

Spence's illuminated negatives are pinned to the wall in a similar fashion to X-rays also, for ease of viewing. There is a large light that hangs over the desk which is positioned above two portraits of Spence. This light mirrors both the surgeon's and the dentist's harsh moveable light that hangs over the patient, allowing them to see clearly and act with precision. In this instance, Spence's portraits take the patient's place, facing the scrutiny of the harsh light alongside the artist. The tools just within reaching distance, with scissors at the forefront, are reminiscent of the tools on a nearby trolley in the operating theatre and the large desk appears surgical in its cleanliness as well as its pristine whiteness. This portrait of Spence as surgeon, similarly to Kriebel's comparison of Heartfield to the surgeon, highlights the power the practice of photofantasy affords to Spence. As she drew the blade of the scissors across her own photographic body, she actively reshaped her reality, just as her surgeons once did.

However, where their artistic practices can be seen to compare to surgical encounters, both Spence and Heartfield can appear to make explicit the violence inherent in the collage maker's tools. The scissors and scalpel are no longer merely implied as instruments of the collage's construction; in both Spence's untitled work and "Self-portrait with the Police Commissioner Zörgiebel", their violent impact on the photographic subject is made explicit. In Figure 3.1, the visible cut across Spence's body is suggestive of a violent act that appears to have occurred before the moment captured in the image. The staging suggests that Spence, somewhat awkwardly, sat up on the operating table, leant forward with the scissors in hand and deliberately dragged their blade across her stomach with force before collapsing back onto the table. Similarly, in Figure 3.2, Sabine T. Kriebel highlights the violence of Heartfield's cutting action, writing: "the blade separating the police chief's head from his body was not the solitary edge of a guillotine, executing the condemned with a single merciful thwack, but the twin edges of long-handled shears, slowly decapitating the victim with a repetitive joining and separating, each gesture widening the gap between head and body, helped along by Heartfield's tugging fingers" (Kriebel 2014, 19). In each of the works, the violence of cutting is exaggerated through the way that the images are staged. In Spence's case, this is apparent in the aftermath – the image captures her collapsed form, the body bearing the mark of the incision. For Heartfield, as Kriebel suggests, the brutality is implied in the anticipation of the violent act about to take place – the slow, painful execution of the police chief.

By drawing attention to the violence of her chosen medium as well as its association with surgery, Spence's work can be seen to comment upon the violence inherent in the surgical encounter. Where she creates a sense of ambiguity as to whether the wound on her body in

Figure 3.1 is self-inflicted, Spence can appear to show how the perception of violence alters depending on who is inflicting the wound. If it is perceived as self-inflicted, the cut can be viewed as an unnecessarily violent action created to do harm to the body. However, if the cut is perceived to have been made by the surgeons, the sense of violence in the image is significantly diminished. This is because surgical violence is often overlooked as violence at all; instead, it is framed as a necessary act of care. Rachel Prentice, in her book *Bodies in Formation: An Ethnography of Anatomy and Surgery Education* (2013), articulates how surgeons distinguish between the violent actions they produce and the caring outcomes they intend: "A surgeon I know describes what she does as 'controlled violence'. These two words define surgery as the use of physical force to promote healing or improve function. The phrase also tersely captures the ethical stakes of surgery… The difference between violence and harm is 'ethically vast, but practically narrow' and often rests upon the surgeon's first word, 'control'" (137). This idea of "controlled violence" becomes a way to articulate violence that is done to promote care. However, Prentice goes further than this to suggest that where surgeons may do "violence", they will never do "harm": "The notion of harm begins with 'evil', suggesting malicious intentions or a malicious deed. 'Violence', on the other hand, can entail injury, with connotations of moral wrong, but 'damage' does not always have decisive moral significance" (Prentice 2013, 60). In this sense, the violence of surgery is not perceived as morally objectionable because it is performed with intent to heal and under controlled conditions. Nevertheless, regardless of this distinction, the effects of surgical violence are still deeply felt. Patients must endure the pain, scarring and prolonged recovery caused by surgical interventions in the same way they would if their injuries had been inflicted through morally objectionable means. Figure 3.1 can be seen to expose this contradiction, forcing a confrontation with the reality that surgical interventions, while justified, still leave lasting wounds, both physical and psychological. In doing so, Spence challenges the assumption that violence can be easily excused when enacted in the name of healing.

Historically, the violence of surgery has not always been so clearly distinguished. In an account from the British Medical Journal, published in 1913, it is revealed that the role of the surgeon was not always one of healing but often one of discipline and punishment. The account recalls how, in certain countries, the public executioner historically practiced surgery, highlighting the unsettling overlap between the skills of execution and the skills of healing:

> in former days there were certain countries in which the public executioner practiced surgery. It is not strange that the mediaeval executioner found the transition to surgery

> easy and alluring, for his practical knowledge of anatomy must have been considerable. To sever the head rapidly and neatly from the trunk of his kneeling victim needed skill as well as strength… To lop off finger by finger, to amputate the hand and foot, to cut strips of skin off a prisoner's back, to stretch on the rack, to draw and quarter, all required some practical skill, which was turned to good account when the sentence had been executed, and the mutilations inflicted called for surgical aid. (The Executioner Surgeon 1913, 1177- 1178)

This account underscores how the technical expertise of the medieval executioner – the precision and anatomical knowledge required to cleanly decapitate, amputate, or mutilate – directly intersected with the skills expected of a surgeon. The executioner's knowledge of anatomy made the transition to surgery a natural one. What Spence's work draws out is the disturbing continuity between these roles: that the violence of the cut remains the same, but our perception of it is transformed when it is framed as an act of healing rather than harm. This alignment suggests that what separates the surgeon from the executioner is not the nature of the cut itself, but the intention behind it – an intention that is socially constructed and historically contingent.

It can therefore appear that through Figure 3.1, Spence uses the act of cutting to explore the complexities of the surgical encounter, highlighting both the power dynamics at play and the contradiction in how surgical violence is perceived. By adopting the surgeon's tools as her own, she appears to reclaim agency over her body, subverting medical authority and repositioning herself as an active participant rather than a passive recipient of care. Where the image resists a straightforward reading through the ambiguous placement of the surgical scissors, Spence can be seen to challenge the framing of surgical interventions, which although often physically invasive and traumatic, are framed as acts of healing rather than violence. In doing so, she forces a reconsideration of the ethical complexities of medical intervention, asking where the line truly lies between harm and healing.

A return to power

Just as Spence can be seen as a kind of surgeon in her work by cutting and reassembling photographic bodies, this practice of symbolically stepping into the role of the medical professional was also seen in the participatory workshops with both Opal and me. In our work, we each engaged with the cuts/incisions that had been made, or had been threatened to be made, to our bodies. In two of my works, I envisioned the potential outcome of a surgical procedure that was once considered for me but never actually took place. For Opal, she attempted to visually recreate two of the therapies she had received as treatment for her cancer. While my collages served as a way to grapple with the psychological weight of a surgery that never happened, Opal's work functioned as a form of communication. In each instance, through the participatory workshops, the incisions that were to be made to our bodies were reimagined on our own terms.

Figure 3.4, Researcher's Workshop Artwork

I created two images around the removal of a mass on my eyeball in the participatory workshops. The first, Figure 3.4, shows an ophthalmic photograph of my eye. From this image I have cut out a lesion that was of great concern to my doctors. Next to this, I have added the words "we're worried" in collaged typography. The second piece I created around this same experience was Figure 3.5. In this work, I have put the cut-out lesion in the centre of a page. In an attempt to make the image look like a medical scan, I added a series of wavy purple lines at the bottom of the image, some blocks of red and blue around the lesion to represent blood flow and some unintelligible writing to the right of the image to represent the measurements being recorded. I was trying to mimic one of my echocardiograms

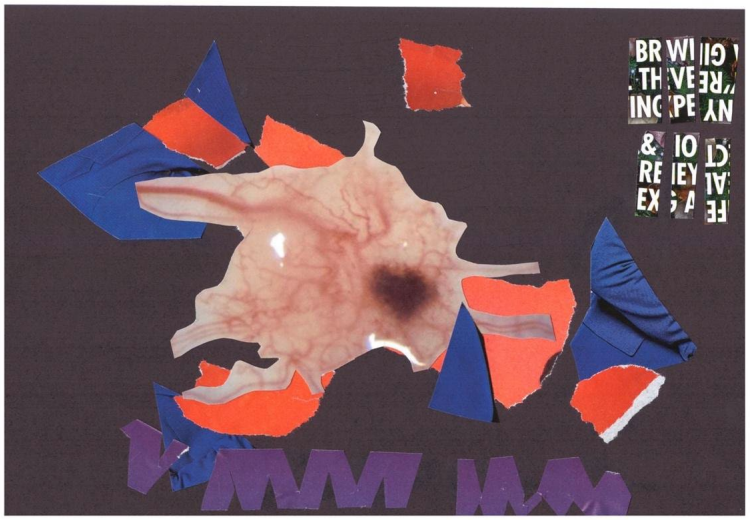


Figure 3.5, Researcher's Workshop Artwork

and thought that the lesion which represented the “potential danger” that these scans are checking for was the ideal centre point.

When exploring the cutting of my own eyeball in Figure 3.4, I was thinking about the back and forth that occurred around the potential of surgery. The growth on my eye had initially been discovered after my treatment for leukaemia, in one of my many follow-up appointments. After this moment of discovery, there were numerous scans, second opinions, referrals and photographs taken. The people I saw at the ophthalmology clinic were almost certain the lesion was benign, but confirming this would require monitoring it for growth. A more immediate solution was to treat the lesion as though it was malignant and remove it. For both my clinicians’ and my parents’ sake, this would fix any sense of worry that had arisen from it. For several months it was weighed up, between my parents and my doctors, whether the lesion warranted immediate action. Ultimately, the decision was made to leave it alone, yet the process leading to that conclusion was anything but straightforward. There was a long period of indecision about its fate, where I felt the heavy weight of my doctors’ and parents’ hypervigilance towards my body. As someone newly in remission, there was an increased risk of my cancer reoccurring, so every small medical concern was treated as though otherwise. My body was a minefield of potential risks and recurrences that everyone worked hard to minimise and keep at bay.

Figures 3.4 and 3.5 spoke to the reluctance I felt, as a child who had already experienced my fair share of surgery and inpatient stays, towards having further medical interventions. Where I cut the lesion out of my eye in Figure 3.4, I wanted to draw attention to the blank space it left. To do this I backed the image onto a black piece of paper. The large black space in the centre of the piece creates a real sense of the absence that removing part of my eye would have created. By putting the words “we’re worried” next to this large, hollow space I had carved, I wanted to show how the surgery to remove the lesion might quiet my parents’ and doctors’ fears, but it would also involve taking away a part of me. Often, I was reminded by my parents throughout this process that removing the lesion would be easy, as it would be a minor operation and so recovery would be simple. In Figure 3.4, I feel like I was rebelling against this and reminding those around me that although “simple”, my feelings towards the surgery were complex, especially if there was a potential that it was not necessary. Similarly, in Figure 3.5, I continued to explore my experience of intense medical scrutiny following remission. By putting the cut-out section of my eyeball within a composition that I modelled after a medical scan, I aimed to reflect on how the clinical gaze was so harshly focussed on certain parts of my body. The piece

spoke to how I was often seen, not as a whole person, but instead as a collection of body parts, symptoms and abnormalities to be scrutinised and managed by medicine.

The inspiration behind these two works felt almost childlike, as though I had reverted to being ten years old again, challenging my caregivers with a defiance that said: “fine, if you want it gone, take it”. Cutting the lesion out of the photographs was something I did impulsively and it represented the frustration and lack of control I had felt during that period of medical uncertainty. However, while making cuts in the photographic image, I was surprised to find the practice deeply satisfying. As I traced the shape of the lesion, pinpointing its boundaries, I excised once and for all this growth that had become a question mark looming over my health. I did not feel the same fear of losing part of my body nor the potential absence that removing this part of my eyeball would cause. Instead, I felt what I imagine my parents and my doctors might have felt about surgery to remove this lesion – the relief that came with making it disappear.

By positioning myself as the surgeon and my photographs as representative of the patient’s body, I created distance from the physical experiences of surgery. I didn’t have to deal with the hurt, the associated recovery or any of the typical discomfort. This allowed me to play out the actions that would have taken place from a position of power and safety. George Hajian writes that, “Similar to a corporeal existence withering away, paper – homologous to human skin, absorbs, folds, fades, wrinkles, is cut, abraded, and has memory. Once torn, cut, creased, or punched, is scarred forever – a stigmata of trauma, displacement, misplacement, and overuse” (Hajian 2022, 102). In this discussion of the corporeality of paper, it is clear to see why the method of working with a body made of photographic paper is so effective. Where the paper can mirror the “folds, fades, wrinkles… cut[s], abrai[sions]” of human skin, it is also able to do so without mirroring the same mental affect that such physical damage might cause a person. I was empowered to cut, without facing the repercussions of these wounds, in the same way that the surgeon is. This process, which came about organically and with little conscious thought, allowed me to re-enact my fears and concerns within safer parameters.

In my case, a sense of safety emerged when I created a stand-in for my corporeal self. By transforming physical flesh into a photographic representation, the need to endure or resist the effects of surgery was no longer necessary. The photographic flesh before me was able to do what I was not – to bear all the marks of the surgery with none of the emotional implications. As a result of this, I felt an unexpected relief. I could reenact and imagine the mass being cut away, experiencing the reassurance this would offer to those who cared for me, without enduring any of the aftermath myself. What began as an act of protest against what I felt was the unnecessary

cutting of my body, evolved into a chance for me to explore agency over surgical interventions. In this way, photofantasy not only allowed for the cutting of photographic bodies as if they were real, but it also provided a crucial layer of protection, a distance from the pain associated with surgical cuts.

As I took on the role of surgeon in altering my photographic images, Opal explored two of her treatments in a similar way. Figure 3.6 was created in the participatory workshop I held with Opal. As this workshop was held in her home, she wanted to print off a photograph of one of the treatments she had, for use in the session. This treatment was called brachytherapy and involved the placement of several radioactive seeds near a tumour in Opal's anus. These seeds were inserted into the body using needles. All of this is pictured in Figure 3.6, the photograph Opal printed from the internet. The only thing she changed in this image was the placement of the needles in relation to the body on show, using a coloured pen to bring them closer to where the anus would be. The connection between Opal's work and mine became evident when she edited the image. While looking for an image to print, Opal remarked that she could only find diagrams that showed brachytherapy to the prostate, rather than for her specific experience. To address this discrepancy, Opal coloured in part of the image to reposition the needles closer to the figure's anus, ensuring that they accurately reflected her own treatment. This act of spatially adjusting the needles was like a kind of surgical reenactment. Although Opal did not create the original image, she exerted control over the placement of the radium needles, much like her physicians had done in reality. Through this act, Opal, like me, restaged one of her procedures on the paper in front of her.

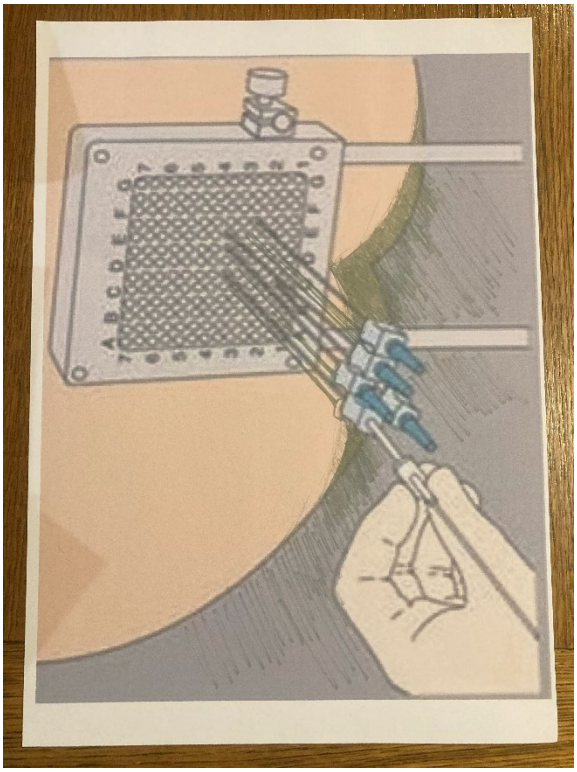


Figure 3.6, Opal's Workshop Artwork

However, Opal's work introduced an additional layer to the restaging of surgical cuts and incisions. Figure 3.6 was only one part of Opal's exploration of this experience within the participatory workshop. A large portion of her experience was conveyed to me verbally, with Figure 3.6 acting as a prop to aid these explanations. By reconstructing her treatment in such detail, using both visual and spoken elements, Opal seemed to assert her presence within the

medical encounter, to avoid being cut from the narrative. In a sense, by retelling her story in medical terms, Opal engaged with a very typical mode of storytelling one shaped by cultural and medical expectations. As Frank explains: "The shape of the telling is moulded by all the rhetorical expectations that the storyteller has been internalizing ever since he first heard some relatives describe an illness, or she saw her first television commercial for a non-prescription remedy, or he was instructed to 'tell the doctor what hurts' and had to figure out what counted as the story that the doctor wanted to hear" (Frank 2013, 3). Opal's retelling was structured, factual and logical, closely mirroring the nature of clinical explanation. She described her brachytherapy treatment with precise details, explaining that she had ten radium needles inserted around her anus, with "little seeds at the end [of each]". She also noted that the needles had silk threads, because "silk is pure so it wouldn't cause any infection". However, while her explanations reflected medical language, they also demonstrate what Frank terms the "postmodern experience of illness", in which "ill people recognize that more is involved in their experiences than the medical story can tell" (Frank 2013, 6). For, throughout the explanations of treatment she gave in the workshops, there was an intense recollection of pain, physical sensation more broadly, memory and humour that would be missing within the "medical story" alone. For example, when explaining how she was finally able to have a bowel movement after her brachytherapy, Opal recalled: "eventually they gave me a castor oil enema which involved tilting the bed upwards, so my bottom end was raised. But after all that, I came out of the toilet and Mary, this lady, said to me, 'How did you get on?' I said, 'It was a success,' and she said, 'Oh, jolly hockey sticks!'" These instances, where Opal recalls the humorous interjections of people around her while she was being treated, demonstrate how her experience of illness could not be fully captured by medical descriptions alone. The clinical procedures she endured were inseparable from the environments within which she received them and the people who inhabited these spaces alongside her. For Opal, during the workshop, she gave equal importance to both the act of artmaking and the discussion surrounding the images. Figure 3.6, alongside the conversations it generated, can thus appear to reinforce the idea that important personal details should not be cut from the "medical story".

The act of cutting can therefore be understood to manifest in two ways within Opal's images – first, through the restaging of the surgical cuts and incisions inflicted upon her body, and second, as a symbolic act of asserting her presence within the medical narrative, resisting the possibility of being cut from it. This can be seen further in another of Opal's works, Figure 3.7, which was created in response to a specific treatment she underwent. Following her initial diagnosis, Opal experienced several cancer recurrences, ultimately leading to metastasis in her pelvic bone, which resulted in a fracture. To treat this metastasis, she received external beam radiation followed by chemotherapy. Much like her process in Figure 3.6, the creation of Figure 3.7 began with Opal looking for a specific image – the image of a pelvis. I happened to have one of my own X-rays on hand, which I gave to Opal for her to use in this piece. She changed the scan by adding a large red cross to mark where she received the radiotherapy treatment as well as two small black marks that were created during her treatment to align the radiotherapy machine. At the bottom of the work, Opal added some of her medical notes from the time. This addition came later in the workshop when we were discussing the piece and Opal mentioned that it related to some notes she had. When reading from these, I remarked that "that bit would go with this picture", to which Opal replied "yes it would, yes it would! We can cut it out and add it."

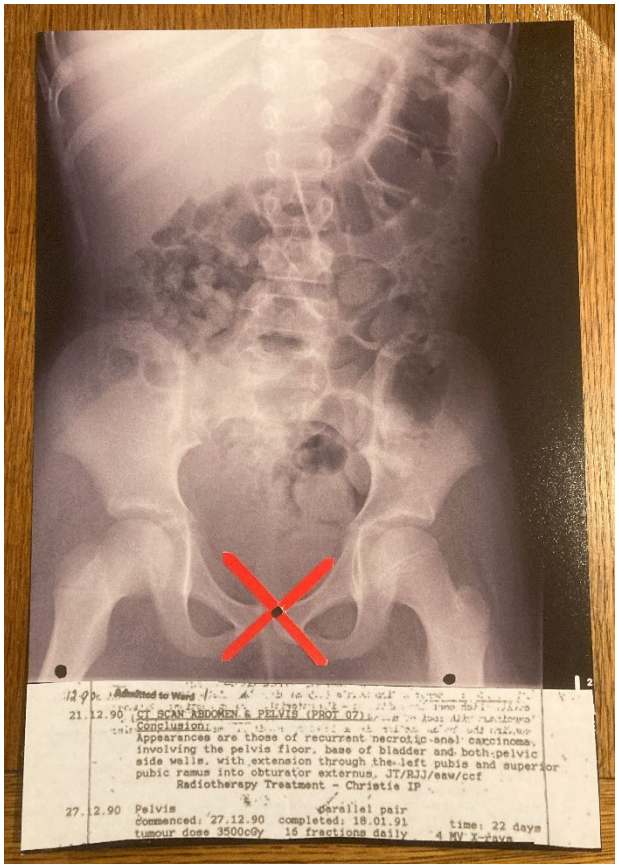


Figure 3.7, Opal's Workshop Artwork

It can be seen that, in Figure 3.7, Opal once again adopted the role of the medical professional by marking the photographic body before her. She mirrored her radiotherapy tattoos, pinpointing the exact site where the radiation was targeted. Although there are no surgical cuts to the photographic body in this example, the tattoos Opal received involved creating small, controlled cuts in the skin with needles to deposit ink, creating wounds that would leave a permanent mark. Thus, when Opal recreated these tattoos on the X-ray in front of her, she enacted a similar process to recreating surgical cuts. Unlike with Figure 3.6, however, the intent behind this piece was somewhat different. When verbally articulating her experience around the time of her

cancer's metastasis, Opal recalled how her symptoms were initially ignored by physicians, even though she felt that something was very wrong. She had to push to have her symptoms taken seriously even though at one point, during a doctor's visit, Opal recalled finding it impossible to raise her leg onto the doctor's bench without support – she only managed to do so by using both of her hands. Of this experience she said, "listen to the patient and what she's saying. Why am I having to lift a leg onto the bench… like hello? You have to fight, and you shouldn't have to fight". In this context, Figure 3.7 goes beyond merely reconstructing the treatment she received. It serves as an assertion that Opal knew her body better than anyone else, as well as an insistence that the discomfort she felt and the symptoms she recognised at the time of her metastasis were real and valid, even when dismissed by the medical profession. By marking the X-ray with the symbols of her very necessary treatment, Opal can be seen to emphasise that her body had been right all along, even when the medical system failed to listen.

Where Opal recreates these medical tattoos on her own terms, she is positioned as the radiologist/tattooist, but with difference. Unlike the medical professionals, who rely on scans and tests to diagnose illness, Opal's embodied experience alerted her to the recurrence of her cancer. Her trust in what she felt ultimately led to her subsequent diagnosis and treatment. This work, therefore, extends beyond the metaphor of collage maker as surgeon and instead it repositions the collage maker/patient as an expert in embodied medical knowledge – an expertise that remains inaccessible to the physician. This closely aligns with a sentiment shared by Spence that "power resides in knowledge" and being excluded from medical knowledge "results not only in ignorance but in a belief that there is only 'one truth' about the ways in which the mind and body function" (1986, 158). Essentially, Spence believed that restricting medical knowledge to professionals not only disempowers patients but also reinforces a rigid, singular narrative of health and illness, one that disregards the lived, bodily experience of the patient. Thus, by recreating two of her treatments and repurposing medical notes, Opal asserts a form of patient power that challenges the authority of medical professionals. Her work foregrounds the idea that medical knowledge is not solely based on institutional expertise but is also deeply tied to the patient's own bodily experience, an insight that, in her case, was crucial to receiving the care she needed.

Ultimately, both Opal's and my work illustrates how reenacting medical interventions, which often involve cutting the body in some way, can serve as a means of negotiating agency within the medical experience. For me, I found comfort and safety when exploring the surgical cuts that my body might have received through the medium of photofantasy. For Opal, revisiting

these medical interventions afforded the opportunity to assert the importance of lived experience and embodied knowledge within the medical encounter. In restaging our experiences through visual means, we each explored the limitations of a purely medicalised approach to the body, as well as the importance of being allowed to actively control and participate in one's own medical experience.

Patient as plant

Beyond the surgeon's cuts or the artmaker's refusal to be cut from the narrative of their illness, a third kind of cut emerges within the artworks. There is a repeated motif of pruning, where plants, vegetable, trees and stems of varied kinds are pictured as being trimmed. In these instances, the plant or stem is often acting as a stand-in for the artmaker/patient. The leaves and greenery that are being pruned are a metaphor for the cancerous body parts that the surgeon cuts away. This can be seen in Figure 3.8, one of Sasha's artworks. I draw on this piece further in the next chapter, so will only focus on one aspect of the work here: where Sasha has depicted secateurs cutting branches. On the right side of the work, several images of hands cutting plants are visible. Just below this, a flower blooms in the sunshine, positioned next to the image of a person relaxing on a sunbed. This imagery can be seen to suggest that the pruning taking place within the work allowed for the plant pictured to eventually bloom. This acts as a representation of Sasha's perception of surgery. When initially diagnosed with stage four bowel cancer, Sasha was told her cancer was terminal. However, following a second opinion, she was given the option of treatment. Sasha explained her piece in greater depth:

Figure 3.8, Sasha's Workshop Artwork

> So these are black clouds because my prognosis was going to go onto palliative treatment and then it would be end of life, but I asked for a second opinion and from that came some hope in the shape of two surgeons – and these secateurs are them cutting

> things out – who agreed that they would do an operation and cut the tumour out, along with several of my other body parts. But that was the only option, and they said it was my best chance. So, the cat is a kind of, its snarling at basically my oncologist who basically was saying no that's it you can't have this removed because it's attached to your duodenum, and you can't live without a duodenum. But you can, cause I haven't got one and here I am. So that's a snarl to that kind of initial diagnosis. And this symbolises, for me, cutting out the dead wood, the cancer, and the bits attached to it or that it had become attached to.

In light of this, Sasha can be seen to have explored pruning as a metaphor for the surgery that saved her life. It represents care, hope and remission. For Sasha, this work was in part about showing her first oncologist that they were wrong, that her body could be operated on, and she could achieve remission. In drawing this parallel, Sasha compares the metaphor of the gardener pruning a plant to her surgeons cutting away parts of her body to save her life. Just as certain plants require pruning to prevent disease from spreading and to encourage new growth, Sasha's surgeons removed parts of her diseased body to allow her the best chance at life. For Sasha, the figure of the gardener, therefore, appears to symbolise both care and the potential to live a healthy life, free of disease.

In this respect, pruning was explored quite differently by me, most likely because I did not feel the danger or risks of a malignant growth as powerfully as Sasha. In Figure 3.9, I picture myself as a plant being pruned by my mother. As she crouches above me, the face I have added to represent hers looks repulsed and uncomfortable with what it sees. Although her hands remain on the sprouting plant, her gaze is turned to face its roots. Within these, I have added the same cut-out image of a mass (that was feared to be malignant) within my eye, as discussed above. Its blood vessels mingle with the plant's roots, symbolising the way that this mass was so closely embedded within my body. Although my mother would never have been the one to physically cut the mass from my eye, her will and desire for me to be healthy pushed for this to take place. Therefore, the image represents my parents'/doctors' hypervigilance towards my

body and their willingness to cut parts of it away. This experience was especially profound for me because I felt little to no control over the decisions being made. As Spence was pictured at the mercy of the surgeon's hands, I was now at the mercy of my mother's. Where pruning in Sasha's work represented the necessity of surgical cuts, within my work it explored the potentially excessive nature of cuts made under the guise of precautionary measures. Removing the mass from my eye was not a medical necessity, it was not even confirmed as necessary. This mass, which turned out to be completely benign, serves as an example of the harm that can be inflicted upon the body in the name of monitoring and prevention.

Figure 3.9, Researcher's Workshop Artwork

When discussing Figure 3.9 in the participatory workshop, I said that I was trying to express: "this idea that you're being kind of watched and watched and watched" once you leave the hospital. Even though I was closely supervised while inside the hospital, this almost intensified when I moved from the hospital back home, with my parents taking over the role my doctors once held. They remained incredibly vigilant to any small changes in my body, appetite, and behaviour. Following my remission, my parents were made aware that there was a 20% risk of cancer recurrence in the first five years following my treatment. This marked the beginning of five years in which I was free from the hospital but subjected to my parents' monitoring. If I was too bruised, my body bled too much at small cuts or any other potential symptoms arose, these were noticed immediately. In Figure 3.9, I have imagined this experience as if those around me after my remission were standing by with pruning shears, ready to trim away or correct any part of me that appeared to be malfunctioning. In reality, this manifested through frequent doctor's visits, my parents keeping my consultant on speed dial, and an inevitable barrage of questions any time my body bled or bruised. For me, pruning shears have come to represent the spectre of corrective measures - the threat of imminent surgical intervention that comes with constant bodily supervision. Every time my body presented with something potentially abnormal, there was an immediate discussion regarding how to assess, manage or remove it.

Representing the dynamic between the gardener and the plant became my way of representing the powerlessness I felt around decision-making to do with my health. The plant symbolised the passive state that seemed to be expected of me when being subjected to surgical procedures. In *Plants as Persons: A Philosophical Botany* (2011), Matthew Hall outlines why plants have historically been viewed as passive. He argues that "key figures in the history of botany", particularly Plato and Aristotle, "have contributed to entrenching the view of plants as passive, mute, and morally inconsiderable" (37). These philosophers conceived that "plants were designed expressly for the use of animals and humans" (41), which in Hall's words "enslaved" them for the use of others (42). While I do not equate my own body with Hall's notion of enslavement, the terms "passive" and "mute" resonate deeply with my experience. Hall further observes that, "because it is depicted as devoid of the attributes which require human attention – such as mentality, agency and volition – nature is left out of the sphere of human moral consideration" (Hall 2011, 1). In suggesting that nature is "devoid of the attributes" of "mentality, agency and volition", Hall highlights a perception that can be seen to mirror the patient's experience. The patient as plant comparison is not to suggest that people who are ill lack these qualities, but rather that the agency and volition of the unwell person can often be overlooked or undermined in instances of medical care and treatment. When faced with being cut or pruned, the plant is the idealised passive patient, who does not challenge, resist nor contradict the medical practitioner.

This feeling of a loss of agency within the medical encounter was also explored by Helena in relation to the metaphor of the patient as plant. In Figure 3.10, Helena collaged an image of Prince William with his family[12] alongside the two tag lines "plants with purpose" and "hello good news". When discussing the meaning behind this collage, Helena explained that while the central image represents "the

Figure 3.10, Helena's Workshop Artwork

[12] Helena's piece was made in 2022, before Kate Middleton was diagnosed with cancer, so all discussions took place prior to this news.

kind of perfect family," it also serves to highlight how the medical profession often views women through a narrow lens – in terms of their capacity to be mothers. This idea led Helena to explore the concept of "plants with purpose", drawing a parallel between the way plants are cultivated for specific functions and the way women's roles can be similarly predetermined within medical and social frameworks. On the process of making Helena said:

> I had already seen [the plants with purpose phrase] before and it reminded me of, well, I suppose during my illness I had to deal with a lot of expectations around gender. And I was told a few times that in a way my purpose, I'm not sure if they used the word purpose, but the message was that it was to bear children. And I remember they did say that a woman's health, it overlaps with a woman's ability to bear children, which I did not agree with. So again, plants with purpose because many times I felt treated like a plant with a purpose. And yeah, the purpose was to have the very happy perfect family, which has never been a dream of mine, meaning children and all that. [13]

Helena continued to explain to me that her doctors' concern for her capacity to bear children was related to the kind of cancer she had, ovarian cancer. The doctors repeatedly expressed their reluctance to completely remove Helena's ovaries and there was a back and forth when Helena asserted her desire to be cancer free (with a lowered risk of recurrence) and her doctors pushed back because of their concern for her to remain fertile. In Helena's case, little attention was paid to her as an individual (particularly as an individual who placed little weight on her own capacity to reproduce). Instead, Helena's doctors imposed their own normative sexist beliefs in the function of women's bodies/lives.

It is from Western medicine's emphasis on preserving reproductive capacities that the plant emerges as a metaphor for patient experience. Russel Hitchings explores the dynamic between the gardener and the garden, writing that "the garden was something like a docile landscape

---

[13] Unfortunately, Helena's experience is all too common, for there are numerous accounts in news outlets of women being denied hysterectomies, that would stand to benefit their well-being, because they are considered 'too young' to opt out of potential childbearing and face menopause. In an article from the BBC, 22-year-old Megan Archibald, who was seeking a hysterectomy for unbearable period pain, said, "a woman's worth appears to [be] based around her ability to have a child, not whether she can enjoy life free of debilitating pain and invasive examinations" (BBC 2019).

upon which the creative stories of gardeners were written"(2003, 104). Similarly, the patient's body can be perceived as a passive canvas upon which surgeons can project their own medical ideologies and assumptions. Just as a gardener prunes and grows a plant to fit a predetermined purpose, the medical system can often treat patients – particularly women – as subjects to be moulded according to societal and institutional expectations, rather than as autonomous individuals. Hitchings also addresses a key tension in gardening: while gardeners can seek to impose order and uniformity, the plants themselves have diverse and conflicting needs. He observes that, "whilst the humans of the garden wanted, then, to have things ordered and organized into attractive docile landscapes, the plants which lived there had some other concerns… they wanted to survive in the garden and different sorts of plants had different ideas about how to do this and to manage the things around them to achieve these ends" (2003, 104-105). When this perspective is extended to the hospital setting, the metaphor shows a critical failure to appreciate the uniqueness of patient desires and opinions. Just as different varieties of plant require different conditions to live, patients enter the hospital with unique needs and desires that are sometimes disregarded in favour of a rigid one-size-fits-all approach. This metaphor of patients as plants, therefore, can be seen to highlight the inadequacy of a medical system that too often treats people as interchangeable, rather than recognising their distinct perspectives and requirements.

Beyond just being a metaphor for the act of pruning as a kind of surgical encounter, the metaphor of patient as plant can thus be seen to have developed in several further ways within the photofantasy workshops. For Sasha, being pruned, as though a plant, represented having her "dead parts" removed and having the surgery that enabled her cancer remission. For me, being a plant represented existing in a state of passivity, where my body and my growth was constantly monitored by those around me. For Helena, picturing herself as a plant reflected an instance where she was not afforded agency in the medical encounter and instead treated like "a plant with a purpose" rather than a person with individual desires and needs. Each of these instances serve to reveal how medical authority can impose different forms of control over the patient's body, whether through the necessary removal of diseased parts, the excessive vigilance of post-treatment monitoring, or the imposition of societal expectations about reproductive purpose. By engaging with the patient as plant metaphor, it appears that participants were able to address instances where they had faced surgical cuts and represent the power structures at play, expressing and exploring their feelings of passivity and lack of control.

Conclusion

Kriebel writes of Heartfield's practice of photomontage that "as a form of representation, photomontage offered a way of disassembling and reassembling the world order, deconstructing conventional representations in order to construct a new world or an ideological critique" (2014, 7). A similar process of "deconstruction and reassembling" has been seen to take place within the practice photofantasy, where both Spence and my workshop participants have critically engaged with their experience of medical encounters. Through the act of cutting and reassembling images, photofantasy has allowed us to intervene in photographic realities. For instance, where I explored how discussions about removing a mass on my eyeball made me feel powerless, I reasserted agency over this encounter by taking matters into my own hands. Similarly, Sasha recreated images symbolic of a surgery she had to remove her duodenum as a statement towards her original doctors who said the surgery was impossible. Although we each explored the empowered role of the collage maker, the outcomes were unique, reflecting our individual relationships with medical intervention and agency.

Just as photomontage enabled Heartfield to adopt the role of surgeon within his images through the practice of cutting and slicing, I have shown how photofantasy has enabled a similar transformation. By viewing Spence's work in light of Heartfield's, it becomes apparent how the slicing of photographic flesh can mirror the cutting of the physical body within both practices. This has had several different outcomes for the photofantasy works. For Spence, becoming the collage maker-turned-surgeon was an act of defiance. By slashing a hole in her stomach, she rejected the passivity expected of patients, reclaiming agency over her body. For me, by reflecting my discomfort onto the piece of paper in front of me, I was able to explore the surgical encounter from a position of safety and detachment, without having to make my own body vulnerable. Opal was able to assert the importance of her lived experience within the medical encounter, reinforcing the authority of patient knowledge. Meanwhile, Sasha was able to express her fury towards surgeons who did not give her desired treatment a chance. In each case, photofantasy provided a means to not just reflect on past medical experiences but to actively reshape them, whether through defiance, detachment, assertion or protest. The act of cutting became more than just an artistic technique, it was a tool for reclaiming power, reinterpreting trauma and resisting the limitations imposed by medical authority.

One of the focal aspects that photofantasy can be seen to enable is a reconsideration of violence. The action of cutting – whether with a scalpel, scissors, or secateurs – is inherently violent, yet in medical settings, this violence is often obscured by its intended purpose of healing. I have explored how surgical procedures, despite their necessity, are rarely acknowledged as acts of violence because of their propensity to do good. However, photofantasy provided participants with a means to express and confront the presence of this violence, whether they were happy for it to take place or not. Thus, one of the aspects that makes photofantasy particularly powerful is its ability to create a safe distance from any violence inflicted upon the body during treatment. By imagining other things in place of their body, participants were able to engage with their experiences without having to shoulder the immediate emotional or physical burden. The violence of the knives, scissors and secateurs that participants pictured could instead be explored in relation to other things, when recreating memories or expressing specific instances. This process not only enabled participants to more safely address the violence of being cut open, but it also allowed them to reclaim agency over these experiences.

Photofantasy not only invited us to reimagine moments of powerlessness and a lack of agency but also gave rise to the recurring metaphor of the patient as a plant. This metaphor became a powerful visual tool for expressing the passivity expected of patients undergoing surgical interventions. Similarly to how plants are pruned, trimmed and shaped by gardeners without agency over the process, patients can find themselves subjected to medical decisions made on their behalf, their bodies monitored and altered according to external judgements of care. For me, the patient as plant metaphor was a means to express the intense medical supervision I had experienced, particularly in the years following my remission. My body, much like plant, had its growth monitored, so that it could be "pruned" to fit expectations of health and normalcy, often without my input. In a similar way, Helena used the same metaphor to illustrate how she was treated as an object to be fixed, in an instance when she was explicitly denied agency over her own treatment. Her doctors, who prioritised what they perceived to be best for her body, resisted her choice. In both cases, the metaphor of patient as plant can be seen to have been used to highlight the imbalance of power in medical encounters, emphasising how the agency of the patient is closely tied to their treatment as a person rather than a body to be fixed. By engaging with this imagery through photofantasy, we were able to critically examine and visually articulate these experiences, making the invisible structures of medical control more tangible.

Through its method of cutting, reassembling and reimagining, photofantasy has provided participants with multiple tools to explore and reconsider their experiences of cancer. As well as serving as a medium for fantasy and creative reinterpretation, collage-based methods can also be seen to act as “a form of time travel” (Elizegi 2019, 192). Where images are excised from their original contexts and placed into new scenes, past and present are collapsed into a single visual space. It is, however, not only the practical aspects of photofantasy that have enabled a reconsideration of how time is experienced within the artworks. Thus, in the next chapter, I will explore how photofantasy interacts with time, not just as a tool for reordering memory but as a way of navigating the altered temporalities that come with illness.

Chapter 4: Strange Temporalities and Cancer Time

> *"In one swift motion, the cancer prognosis detonates time, which scatters like so many glass shards. Having harbored cancer in one's body all that time before diagnosis, when one thought one was quite well, thank you, mystifies both past and future."* (Jain 2013, 28)

Kathy Charmaz writes that "living with serious illness and disability can catapult people into a separate reality - with its own rules, rhythm, and tempo. Time changes - drastically" (1991, 4). This was echoed in the photofantasy workshops run as part of this study, where several participants reflected on how their illnesses had altered their perception of time. The theme of time emerged in discussions, as well as through the visual symbols and metaphors employed by my participants in the making of their collages. As Charmaz suggests, it appears that "being ill gives rise to ways – often new ways – of experiencing time" (Charmaz 1991, 4). The altered perception of time when experiencing disability and chronic/critical illness has been referred to as "crip time" (26). This notion emerges from "crip theory", coined by Robert McRuer in 2006, through a resignification of the slur "cripple" to represent a cross-over between critical disability studies and queer theory. The notion of crip time has been built upon significantly by Alison Kafer in her book *Feminist, Queer, Crip* (2013). Kafer writes that "operating on crip time" can be "about a slower speed of movement" as well as the "ableist barriers over which one has little to no control"; ultimately it "involves an awareness that disabled people might need more time to accomplish something or to arrive somewhere" (2013, 26). Kafer explores disability in broad terms throughout her book, considering both critical illness, remission, pre-diagnosis and various instances of health insecurity as processes that shape people's experience of "crip time". Beyond considering the ways that physical disability may require additional time in the day that is often unaccounted for, Kafer suggests that crip time is also the "strange temporalities" (35) that disabled people face which alter their experience of time. Cancer experience has been described as generating "a radical rupture in the flow of time, changing our sense of temporality beyond recognition" (Cardona and Iohe 2023, 9). As a concept, therefore, crip time can be understood to apply to cancer experience also.

Ellen Samuels has further explored the meaning of "crip time", outlining a variety of different experiences that fall within this umbrella. Samuels suggests that crip time is "time travel… grief time… broken time… sick time… writing time" (2017). It is being extracted from linear time, spending hours grieving for a different body or way of being, painstakingly breaking oneself in to fit to different schedules or simply living through illness, perhaps even writing about it. Although

critical accounts of cancer experience, such as those by Lochlann Jain (2013) and Carmel Cardona and Taey Iohe (2023), have touched on some aspects of Cancer Time, there is not a unified account of the various facets of cancer experience in relation to time and temporalities. Thus, in this chapter I will begin to intertwine several accounts of how the experience of cancer patienthood specifically alters our perception of time and temporality to contribute towards a more detailed understanding of Cancer Time. I am understanding 'time' as the way we measure a sequence of events and the space between them, whereas I am considering temporality to be the subjective experience or perception of time.

Cancer Time attests to time spent waiting, enduring, healing, dying, but mainly *living* with cancer. It is the strange temporalities that cancer patienthood uncovers and the feelings that this generates. In exposing some of the ways that Cancer Time was experienced and artistically conveyed by both Spence and my participants, I will consider how time can affect our perceptions of the self, as well as our embodied realities. Although Cancer Time can be used as a universal term, it is by no means one sole universal experience. In starting to bring together some of the many facets of Cancer Time, I want to emphasise the uniqueness of experiences to generate future and further conversations around how time is experienced when critically unwell. Kafer explores the question "how might disability affect one's orientation to time?" (2013, 26) reflecting that "part of the problem I'm tracing in these pages is the assumption that there is only one side to the question of disability and that we're all already on it" (2013, 19). To push back against the notion of a sole generalisable experience of cancer, I will consider the multiplicity of ways that Spence and my participants experienced and represented time and how their visual expressions create new ways of understanding it. It is for this reason that I view this chapter not as a definitive analysis but as a starting point for thinking about Cancer Time, as well as an invitation to further dialogue and reflection.

The practice of photofantasy confuses time and temporalities. As images are excised from their original contexts to create new scenes, past, present and future are irrevocably altered. Through this relation, photofantasy affords the opportunity to reimagine temporalities. This practice has thus opened up new ways to conceptualise the experience of time for people who have cancer – from generating new metaphors to visual symbols and structures for understanding how people with cancer can experience time. The first section, "Liquid Time", explores how water and liquid metaphors, such as droplets and clouds, capture the altered experience of time during cancer. These metaphors convey the feelings of being suspended, slowed down, or stuck in moments of uncertainty and waiting, with the imagery of viscous, sticky substances like honey symbolizing

how Cancer Time can feel sluggish, heavy, and difficult to move through. This idea of suspension in time, as explored through liquids, leads into the section "Ghostliness and Liminal Temporality". Here, cancer is likened to a state of in-betweenness, where one may feel caught between life and death. The concept of ghostliness symbolises this liminal space, reflecting how one may feel neither fully present in life nor absent, a feature of cancer experience that Spence also highlights in *The Final Project*. Cancer Time, in this instance, means finding ways to exist within liminal temporalities. The final section, "Mushroom Time", continues to explore liminal temporalities, shifting the metaphor from ghostliness to mycelial decay and regeneration. Rather than simply signalling decline, Mushroom Time highlights how periods of illness and stillness can also foster unprecedented growth and transformation. It offers a way to approach, process and understand the strangeness of Cancer Time by embracing the unknown potential of liminal temporalities.

Liquid Time[14]

Water and liquid often punctuate temporal metaphors. Sayings like "treading water", "turning tides" or "riding the wave" all use aquatic imagery to attest to different experiences of time, whether to convey endurance, change or stagnation over time. Both the feeling of being in water and the properties of different kinds of liquids became metaphors for the altered experience of Cancer Time in my primary data. Through repurposing existing metaphors and generating them anew, my participants and Spence speak to the surrealness of their experience of time through the language of liquids.

Sasha's work represents what Cardona and Iohe describe as a "rupture in the flow of time" (Cardona and Iohe 2023, 9) through further liquid metaphors. In Figure 4.1, Sasha imagines the moment she was diagnosed in the form of a large liquid droplet. The work tells the story, from top to bottom, of Sasha's diagnosis of bowel cancer. The clutched stomach, abdominal pain and bloating represent the symptoms that she was experiencing that led her to seek medical

[14] Zygmunt Bauman has a book titled *Liquid Times* (2007) which explores global economic uncertainty. Although this section is of the same name, my conception of liquid time is applied quite differently.

advice. The explosion positioned below these initial images represents the point of diagnosis, alongside the words “gone to pot”, and the large honey droplet that appears to leak from the explosion represents how “it felt like my life and my joy and vigour was kind of slowly dropping down out of me”. It is through the organisation of images that an impression of time starts to emerge. To begin, the images in her collage are close and overlapping, creating a sense of chaos in the way they are bunched together. The explosion, both representative of Sasha’s internal pain and the moment of diagnosis “detonat[ing] time” (Jain 2013, 28), marks the culmination of this chaos. Instead of chaos, below the explosion, there is now uncertainty, pictured in the form of a long viscose droplet.

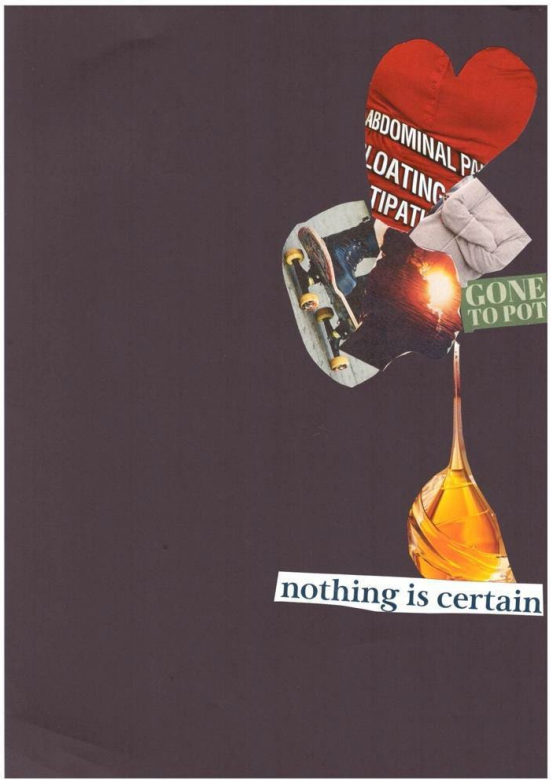


Figure 4.1, Sasha’s Workshop Artwork

This droplet marks a change in Sasha’s experience of time - the moment where time begins to slow. Petra Kuppers discusses how crip time can often mean a life led in slow motion, drawing on Australian author and activist Anne McDonald’s experience of cerebral palsy (2014). McDonald writes: “I live life in slow motion. The world I live in is one where my thoughts are as quick as anyone’s, my movements are weak and erratic, and my talk is slower than a snail in quicksand” (McDonald *in* Kuppers 2014). There is a physical slowing associated with crip time, where the disabled or critically unwell body cannot keep pace with the ableist expectations of day-to-day living. For Sasha, slowing is more metaphysical, as there is a sense of her life becoming suspended. Both health uncertainty and periods of waiting have caused time to suspend like a slow viscous droplet waiting to fall.[15] The liquid that Sasha pictures generates a sense of stickiness in both its colour and its viscosity. It appears to resemble honey or syrup –

[15] Interestingly, the droplet as an image has also recently been used by Hedva in the poster for their show *Genital Discomfort* 2024, as posted on their Instagram account (Hedva 2024). This exhibition coincides with the publishing of their book *How to Tell When We Will Die: On Pain, Disability and Doom* (2024). Regarding the image used in the exhibition poster, Hedva described it as “a time piece made of mouth-blown glass”, this glass “slowly excretes black goo that destroys the carpet beneath your feet, edging toward the end”. In this context, the droplet similarly evokes the slow passage of time, involving a viscose substance that is both sticky and destructive, symbolising how one can become trapped or suspended within it.

both thick, slow-moving substances that leave a sticky residue behind. This stickiness can express the experience of time for someone recently diagnosed with cancer, whereby that diagnosis may feel difficult to move beyond. Cardona and Iohe describe the onset of cancer as entering "suspended time" (2023, 12). Just as syrup clings and resists flow, one can feel emotionally or psychologically stuck, unable to advance from the present moment. With experiences of critical illness there is often reference to life being "on hold" (Charmaz 1991, 14, 33). Within the metaphor of a viscous liquid, one's life is not put on hold so much as it is caught in a slow dragging flow —where progress is still possible but feels painfully delayed or weighed down by uncertainty. The expression "wading through treacle" is very much drawn upon through Sasha's inclusion of a viscous liquid, highlighting the slowness and difficulty of progression when diagnosed with cancer.

The visualisation of a large liquid droplet speaks to both uncertainty, inevitability and a constantly growing pressure. As volume builds at the base of the drop, we know gravitationally that there is only one outcome. Often, though, when waiting for a drop to fall, time can extend before us and what we thought was inevitable, we can begin to question. Charmaz describes this feeling of time suspending while uncertain or awaiting information: "when pangs of uncertainty lead to fear and dread, people want to know, to be sure. They wait for information. They wait for change. They wait for telling symptoms to develop. And they wait for them to subside. Between signs and clues, time stretches into a long, empty duration" (1991, 32). The droplet therefore captures this sense of suspense and slowness. When imagining time in liquid form, for Sasha, it becomes viscous and unpredictable.

As Charmaz outlines, the experience of time as slow can be based on the many ways that people who have cancer are forced to wait. We "wait for information", yet no information is ever quite enough. Even when offered something that appears concrete, like a diagnosis or prognosis, there is still precarity and a lack of certainty around the future. Lochlann Jain imagines "prognosis time" as a way to theorise how information (in the form of a prognosis) often does not end periods of waiting and can even lead to greater precarity.

> a prognosis seems like a fact, if only a scrap of flotsom frenziedly bobbing in the rapids of cancer treatment. But its stunning specificity ("34.7%") shields the bloodlessly vague platitude: in five years, you, yourself, will be either dead or alive. The prognosis purees the I-alive-you-dead person with the fundamental unknownness of cancer. (2013, 29)

The suggestion is that, although often irritatingly specific, prognosis casts you into a place of uncertainty rather than one of knowing. Irrespective of whether you receive a potentially positive survival rate, it is impossible to know on which side of the statistics you will fall. Despite offering information about one's illness and the potentials of the future, prognosis really generates little other than what Jain describes as "the unknownness of cancer".

Figure 4.2, Sasha's Workshop Artwork

A further metaphor for this uncertainty can be seen in another collage made by Sasha (Figure 4.2), where black clouds appear at the forefront of the work. The original intention behind these clouds was to represent the bleakness of her initial diagnosis, which was a terminal one: "these are black clouds because my prognosis was going to go onto palliative treatment and then it would be end of life, but I asked for a second opinion and from that came some hope". However, the temporary nature of clouds, as well as the eventual remission that Sasha achieved, give the collage dual meaning. Clouds interfere with our ability to see outwards; like the idiom of "cloudy judgement", they suggest an altered or restricted view of the world. Where Helena says, "I was waiting for a second surgery, but it was almost like a liminal space", clouds can create a sense of the liminal. They draw on a similar tension to the liquid droplet, of wondering when, if ever, they will spill. The image of clouds when considering temporality thus expresses both a barrier to futurity and a disorientation around the experience of time.

Dark clouds possess an "oppressive quality" (Bielby and Puw Davies 2024, 2) but they do not solely represent bleakness. As precursors to rain, storm clouds sustain life – and in the case of Sasha's work, can appear to sustain "hope". From the pictured clouds, water flows onto the word "hope", positioned over the image of a flower in bloom. The flower for Sasha meant "a small kind of blossoming of new life and sunshine and better things". It is interesting, therefore, that the flower can appear to be nurtured by the very clouds that cast a shadow over it. This juxtaposition can be seen to reflect how the difficult, challenging experiences of cancer can,

once endured, nourish one's future happiness. However, until the clouds spill, they can remain imposing, threatening and disrupt our view outwards.

While the clouds loom in Sasha's work, there's a sense of nature taunting her. In the same way that Figure 4.1 pictures a long viscose drop waiting to fall, in this piece there's a similar tension of waiting for the clouds to spill and eventually clear. The inclusion of a person's hand extending from the clouds and holding the hose that directs the flowing water can be understood to represent a physical intervention forcing water to fall. The hand can be seen to represent how Sasha intervened in her cancer care to reorient and grow her future. As discussed in the previous chapter, this piece was partly inspired by Sasha's rejection of an initial medical prognosis, which recommended she move to palliative care. Instead, she sought a second opinion that led to the removal of her duodenum and ultimately her remission. The introduction of a hand bearing a hose, peeking out from within the clouds, indicates a similar reclamation of control that Sasha explores through the snarling cat. If the clouds won't water her hopes and help her bloom, she'll intervene and manage it herself.

Where clouds can be seen to highlight a personal reclamation of power for Sasha, they can also underscore the difficulty of escaping the "fog" of Cancer Time. In Charmaz's research, Sara Shaw (an interviewee) reports experiences of "'monochromatic time,' a time that flowed without dimension, change or color; 'it was the same shade of gray.'" Shaw goes on to add that "[Time] was like a fog, you know, like having a fog around me" (Charmaz 1991, 89). It is not only Jain's sense of uncertainty that speaks to a metaphor of clouds, but also the repetition of events, routines and schedules. When in treatment, "everything can blend into each other, the moments – because it's the same thing… it can all become one [duration of time] very easily" (Charmaz 1991, 89). This metaphor of clouds/fog is thus two-fold, for it represents being unable to see out and also the seemingly endless repetition of routines. The positioning of Sasha's clouds speaks to how difficult it can often feel to move away from the 'fog' of Cancer Time. In the collage, black clouds sit above various experiences that Sasha symbolises through images: surgery, treatment, healing and remission. Although remission is visualised by a woman reclined in the sun, the presence of these clouds on the page suggests that they remain in proximity. This speaks to how the uncertainty of prognosis time can persist throughout and beyond the experience of cancer; whether being told what kind of cancer you have or even being told that you are potentially cancer free, there are no guarantees or promises of a life free from disease. As Cardona and Iohe write, "Oncologists refrain from declaring someone 'cancer free',

as they can never quite be one hundred percent certain that cancer is not present (Adamson). Instead, they use the phrase 'NED: No Evidence of Disease'" (2023, 10).

Following my own treatment and remission, at each of my follow-up appointments we would track how many weeks or months I had spent without disease. Each leap in time signified a slightly better prognosis five years down the line, and every appointment eased our sense of worry. But there was no one moment where this worry entirely subsided. Even now, the sight of new bruises in large groups revives a fear that I may again be diseased. Once you've been on the precipice of cancer, it is hard to come away entirely. Instead, we can continue to live in a state of "unknownness" for years beyond remission. That is not to say that our uncertainty does not ease, but rather that it might not ease in a linear way. Clouds, therefore, are one way to imagine the changing density of our degrees of uncertainty. Some days our uncertainty is thick, the clouds are more tightly packed, and we can see the future less clearly, but other days there is only a translucent covering of cloud, allowing the light to reach us.

Cardona articulates how the future might feel unavailable on days more densely packed with uncertainty:

> before my diagnosis I felt young, excited about the future, and I was always making plans. My sense of self was formed from a combination of my past, present and future. But while I was on the treatment treadmill, I felt as though time was truncated. My sense of future consisted only of the days until my next medical appointment. I stopped talking about the future; stopped making plans; stopped articulating dreams. Instead, I entered a period of stasis: time was suspended. (Cardona and Iohe 2023,10)

The notion of a shrinking future can often align with experiencing time as static. This idea of stasis or suspension is captured in one of Spence's works from *The Final Project* (as discussed in both the introductory chapter and Chapter 2) where the artist appears suspended in a body of water, still other than the gentle ebb of waves. With the reflection of light on water, cast over her face, it looks like Spence is floating underwater. Like a sensory deprivation tank, Spence's hearing and vision are blurred. When underwater, it is easy to lose a sense of time altogether. Thus, the water becomes a metaphor for Spence's experience of cancer, its boundaries enveloping Spence's body and altering her perception of reality. This work can also be imagined as an articulation of the feelings that Cardona discusses of a future arrested and a period of stasis.

Figure 4.3, Jo Spence *The Final Project*, 1991-1992.

In the inclusion of a body underwater, Spence imagines a liminal space. When submerged in water, sound and light are muffled. What we experience sensorily can be quite surreal. There is a feeling of being suspended again, unable to fully see or hear beyond the water. These properties of water create a liminal space because they disrupt our usual sensory cues, creating a detachment from reality. However, unlike the expressions of liminality in Figures 4.1 and 4.2, Spence does not appear to resist her invitation into this liminal space. The positioning of her body makes her appear as though embracing the waters and giving herself over to the waves. Thus, when Charmaz discusses the idea of "becoming lost in time as well as in illness" (1991, 87), it can seem that Spence has given herself over to this new reality, to one of unknownness, being lost and existing in a surreal kind of time.

This surrender to the present shares some parallels with Jack Halberstam's analysis of queer time during the AIDS epidemic, where the loss of a predictable future created a focus on the present moment. Halberstam notes that "horizons of possibility have been severely diminished by the AIDS epidemic… creat[ing] a new emphasis on the here, the present, the now, and while the threat of no future hovers overhead like a storm cloud, the urgency of being also expands the potential of the moment" (2005). The "no future" he speaks of is not just one that applied to people who were diagnosed with AIDS but also one that applied to communities perceived as being at greater risk of contracting or transmitting the disease. There were barriers to travel, treatment and other freedoms that generated what Halberstam describes as "an emphasis on the here, the present, the now". Alison Kafer discusses Halberstam's analysis of the "strange temporalities" that AIDS presented in terms of "crip time". She notes that:

> by Halberstam's reading, it was living, and dying, with AIDS that pushed (some) gay men out of a normative life course and into queer ruminations on urgency and emergence.

> Given that Halberstam's iteration of queer temporality stresses illness as much as sex, one could certainly make the argument that the time of the epidemic is both queer and crip time. (2013, 36)

Kafer suggests that "living and dying with AIDS" fostered a heightened sense of "urgency and emergence". This was driven by the way that stigma around the disease began to diminish the freedoms of those diagnosed or perceived as at risk, as well as the often terminal outcome of an AIDS diagnosis in the 1980s/90s.

The cross-over with Spence's work arises from the way that a terminal diagnosis, like AIDS *was* or cancer *is*, can truncate time, making the future feel unavailable. Cardona and Iohe's research considers this. When reflecting on her cancer diagnosis Cardona describes how it led her to "rethink her relationship with futurity" as "the normative linearity of life had been ruptured and she could no longer rely on the future to unfold predictably". Instead she describes having "found solace in queer temporalities" which "resist the dominant temporal order". She explains rather than "privileging the future" she began to prioritise the present. Managing her cancer treatment became a process of adjusting to a future that had "shifted from a great expanse of possibility to smaller increments of time, focussed on treatment and survival" (2023, 12-13). For Cardona, the link between queer temporalities and crip time, or more specifically Cancer Time, is a resistance to the temporal order that privileges the future. The future can feel like it's disappeared in cancer time as it does with queer time because future possibilities have been (albeit perhaps temporarily) diminished.

Willig and Wirth's research supports this further, for they determine that terminal illnesses can impact a person's "anticipated life trajectory" or their "relationship with the future" (2018, 12). Thus, just as Halberstam writes that AIDS "created a new emphasis on the here, the present, the now", terminal cancer forced Spence to focus more closely on the present moment. This is visualised when the artist embraces the waters in Figure 4.3, for she can metaphorically be seen to embrace the surreal, truncated experience of cancer time. It is also expressed in the way that Spence, while creating *The Final Project,* begins to focus on caring for herself and her body, in the present moment, above what Boyer terms "a politics of futurity" (2016).

Part of giving oneself over to illness, in Spence's case, has relied on embracing a life of care. When speaking of her routine with leukaemia, Spence said: "I've taken up tapestry and gardening because that's the only way I know how to have any peace in my life… it feels at this point as if I will never do anything again except look after myself. The task of looking after myself

with leukaemia is like having a newborn baby to look after; the amount of things daily that I have to do to nurture myself" (1995, 217). It is not only the many acts of care that Spence engages with each day but how this has affected how she visualises herself. This comparison of the artist to a "newborn baby" alters the image of Spence floating in water; it transforms the water into a womb-like space, emphasising care, regeneration, and the intimate focus on the present moment.

This self-centred focus challenges traditional ideas about time and futurity and draws further similarities between queer and crip time. Kafer points to Lee Edelman, who writes that we cannot "conceive of a future without the figure of the Child" (Edelman 2004, 11). This is based on the idea that the future of our children is what causes us all to act, politically, socially or otherwise. Using gay marriage as an example Kafer, suggests that "depending on one's stance, gay marriage either destroys children's well-being or enhances it, but both sides agree that the future of children is what is at stake in the debate and therefore what should guide our decisions" (2013, 28). Spence can be seen to playfully toy with this notion of the Child, in the way that she compares herself with leukaemia to a "newborn baby". Spence alters Edelman's metaphor; instead of picturing a future focused on the needs of a metaphorical Child, she positions herself as the "Child" that guides decision making. Spence reframes the future around herself, prioritising her own care and immediate needs. This act of turning inward shifts the narrative away from societal expectations and reorients her future in terms of personal well-being, breaking away from conventional notions of future-oriented productivity.

This act of focusing inward is seen as an alternate kind of temporality and time predominantly because of its distinction from capitalist systems. Taraneh Fazeli asserts that, "one thing that unites disabled people with those in other fluctuating states of debility is that their bodies are simply not as valuable to capitalism" (2016). This is in part because the sick or disabled body is often not as able to work but also because "the most anti-capitalist protest is to care for another and to care for yourself. To take on the historically feminized and therefore invisible practice of nursing, nurturing, caring" (Hedva 2022). Time spent sick, caring for the body or healing can be perceived as a kind of slowing because it defies productivity. By prioritising her health and her care, Spence steps outside the relentless drive for productivity, instead embracing an alternate temporality defined by care and personal healing. In doing this, she is reborn, not only in the sense that her body is like a "newborn baby", but also in that her focus has changed, turned away from the demand for productivity. This can be seen to reflect a deeper transformation – one where survival, healing, and introspection take precedence over

external demands. In this rebirth, Spence reclaims her time and body, not as a site of productivity, but as a space for personal renewal.

It can thus appear that each of these metaphors for Cancer Time – the droplet, the cloud and the pool – point to (and ultimately seek to challenge) experiences borne out of capitalist expectations. When the body turns the focus from work to care and the future becomes secondary to the present, we perceive a kind of stagnation taking place. This is ingrained socially, by a world that values productivity and work above all else. What has been articulated through the language of liquid is how surreal these experiences of slowing, resting and caring, have become in a world that leaves no time for them to take place. The droplet articulates feelings of uncertainty and slowness, with its viscosity speaking further to a sense of difficulty or obstruction. The cloud or fog speaks to a blurred vision and an inability to imagine the future: it is both an obstacle and a liminal space. The pool becomes many things at once, a sensory deprivation tank, an embrace of the present, a womb. But each metaphor ultimately underscores the challenges of Cancer Time – especially the struggle of existing in liminal or in-between states and spaces where conventional notions of time and productivity no longer apply.

Ghostliness and Liminal Temporality

Although liminality emerges in cancer experience through periods of waiting, uncertainty and health insecurity, arguably one of the most liminal aspects of the disease can be the experience of feeling as though you're between life and death. Even though this is perhaps no truer than it was prior to diagnosis, there can be a renewed feeling of one's proximity to death and a reminder of one's mortality when diagnosed with cancer. Learning to exist within this new state of uncertainty and in-betweenness is reflected in how Spence and my participants express liminal ways of being in their artworks.

Ghostliness is the primary example of this. Finding a representative outlet for existing within liminal temporalities is where the ghost first begins to emerge. Boyer describes herself as "existing in a way that [I] feel [I] don't exist" (Boyer 2019, 144) while experiencing cancer. This state of surreal non-being leads directly to the figure of the ghost. The idea of a ghost can take on many meanings and appearances: the soul once left the body, a shadowy trace, a haunting presence, a memory. However, one of the formative likenesses between ghostliness and cancer experience seems to be a feeling that one can relate neither fully to the living nor the dead.

Cancer for many can mean being suspended in a state that is experienced as between life and death. The ghost, therefore, represents this liminality. The ghost is defined as inhabiting a "liminal position between visibility and invisibility, life and death, materiality and immateriality" (Blanco and Peeren 2013, 2-3). By adopting the guise of the ghost, one can appear to be responding to the difficulties of existing in a state of uncertainty or betweenness. The ghost represents learning to exist within a kind of purgatory.

Spence engages directly with ghostliness in *The Final Project,* where she pictures herself fading into various landscapes. Our present visual impression of ghostliness is based heavily on the Victorian practice of Spirit Photography, which sought to capture photographic impressions of ghosts. These spirits appear "as phantoms-bodies rendered optically strange, semitransparent or out of focus, dissolving into shrouds of gauze or simply incongruously "floating" in the space of the photograph" (Gunning 2007, 99). Much like the ghost, in *The Final Project,* Spence appears repeatedly as "semitransparent", "dissolving" and "floating" amongst the various landscapes she encounters or superimposes her image within.

This action of fading into landscapes has been read critically as Spence "teaching herself a dialectical mode of dying" (Boyer 2016). Boyer asserts that Spence's fading represents a kind of "decaying" or "return to nature". This perspective has not been challenged thus far in the writing on *The Final Project*, perhaps because of a socially ingrained belief that people with terminal illnesses are directly focused on dying. However, Boyer's approach risks reducing Spence's work to a limited interpretation. Willing and Wirth, in their study with people who have terminal cancer, identify "holding on to life" as one of the key focuses of their participant group. They suggest that it "is an effortful activity that describes the hard work required of patients to find a way of living meaningfully with terminal cancer" (2018, 234). In this idea, Willig and Wirth touch on something that is often left out of discussions of *The Final Project*: even though she was dying, Spence was very much alive. Spence's ghostly impression thus explores this superimposition of contradictory states of existence.

As Clarissa Jacob and Amy Tobin reflect, *The Final Project* "present[s] the particular in-between state of the subject of terminal illness: living but marked by death, a presence structured by absence" (in Lee 2013, 34). However, through the figure of the ghost, Spence's presence in these works can be understood as far more assertive and indicative of a desire to remain in the frame of her images. Where Nasra Mumin describes the ghost as "the 'no-thing' that ruptures temporality" (2019, 12), Maria del Pilar Blanco and Esther Peeren suggest that the ghost instead "is first and foremost something visible. It is of the visible, but of the invisible visible, it is the

visibility of a body which is not present in flesh and blood" (Blanco and Peeren 2013, 38). The ghost can thus be understood as a marker of presence, a refusal of invisibility and a desire to be seen. As the body begins to vanish, which in Spence's case can be related to her weight-loss, reduced mental capacity and exhaustion (Dennett in Spence 1995, 222), the ghost represents the spirit that endures. Spence's works can therefore be seen as a refusal to exit the scene or to "go quietly". In another image from Lee's book on *The Final Project,* Figure 4.4, Spence appears reclined on a hospital gurney, covered by a sheet, with her feet sticking out. Above her head is a sheet of paper that reads "**WRITE** OR BE **WRITTEN** OFF". This sentiment echoes throughout *The Final* Project. Spence expresses her presence by littering her body across a variety of scenes, exploring her visibility as much as her forthcoming invisibility. This desire not to be "written off" persists even in works where the artist's mortality is explored. The liminality of the ghost is thus an indicator as well as a cry to be remembered as present in the face of impending absence.

Figure 4.4, Jo Spence, *The Final Project*, 1991-1992.

Spence's works are uniquely positioned to explore notions of ghostliness, for the artist was terminally ill during their production. Carla Willig and Luisa Wirth describe the liminal experience of terminal illness as being "an experiential space that is in between what was and what will be, a kind of twilight zone on the threshold of death… There is a bell-jar quality to this experiential space" (2018, 233). As well as this idea of being on the "threshold of death", which perhaps abruptly positions the terminally unwell person on a precipice that they might in actuality be quite far from, Willig and Wirth position terminal experience as "other" or "external" to both the experiences of the living and the dead. This is where the ghost can become an enticing symbol for terminal experience. The ghost is both alive and dead, unable to identify fully with either category.

For me, the ghost emerged within periods of treatment, recovery and waiting. In one of my works, Figure 4.5, I picture several distinct elements: an injection, a hospital corridor/room, a woman surrounded by affirmations, a slide of bacteria and a smiling doctor at their desk. In the centre of these images is the outline of a head and shoulders, cut out of newspaper. The effect of the outline is inherently ghostly: there's an immediate sense of the missing body. When creating this work, however, I wasn't thinking about myself or my representation. I was thinking about how, when you're in the regular, repetitive routines of treatment, various experiences fill and frame your day, and we often just float through them unthinkingly. I was thinking about the unmoving, unwell body, fixed in its bed, how the world and the hospital appears to flurry around us and how we sometimes feel peripheral to it. I became an avid spectator when I had cancer and in that I became a kind of spectre as well.

Figure 4.5, Researcher's Workshop Artwork

The etymology of spectator and spectre are very similar. Both contain the root "spect", meaning to look at or see. This idea of the convergence between spectators and spectres is hinted at in Boyer's *The Undying,* when she recalls a moment post-mastectomy where she was required to "give a three-hour lecture on Walt Whitman's poem 'The Sleepers' – 'wandering and confused, lost to myself, ill-assorted, contradictory' with surgical drainage bags stitched to my tightly compressed chest" (2019, 157). Boyer uses Whitman's poem to describe this moment of teaching, likening herself immediately to Whitman's spectral narrator who visits the homes of various sleeping people, "go[ing] from bedside to bedside", looking upon them. The narrator is distinguished from the sleepers at the start of the poem, caught in a relation that is much like observer and observed. Boyer, although without the invisibility of Whitman's narrator, experiences a similar distance between herself and her students, writing "my students have no idea what has been done to me or how much I hurt" (2019, 157). The idea of a spectating spectre for Boyer comes from the surreal nature of her forced return to teaching and how this has rendered her physically unprepared, perhaps even dissociative.

This idea of the spectating spectre manifested slightly differently for me. From my hospital bed I saw what was going on around me, visitors that had come from other places, friends that were doing things I couldn't at that time imagine myself doing. Even in the hospital school there were things I couldn't be part of because of how immunocompromised I had become. Instead of being an active participant in the stories of my friends or the goings on outside my room, I instead became a spectator. What went on inside my room, the games, the TV, the crafts, did not feel like real life. They felt like activities that punctuated time until I could return to real life, to school, to my house, to being a part of the stories of my visitors. Ghostliness in this instance appears derived from the constrictions of patienthood and treatment, and how they turned my hospital room into a liminal space, where I waited for the life I had before to resume. Charmaz writes that "the events ill people experience seem surreal – unreal… They wait to get through the present so that 'real life' can go on in the future just around the corner" (1991, 31). Part of being a spectre for me came from feeling out of action as a participant, at the mercy of my body and its treatment.

This feeling of passivity and anticipation, where one feels as though "real life" is on hold, creates a temporality that seems to exist outside of conventional time. During such periods of waiting, it can feel almost as if the actions you are engaged in don't contribute to the broader trajectory of your life. Carobeth Laird, a seventy-nine-year-old woman who was confined to a nursing home after gallbladder surgery, described this experience in her memoir, *Limbo*: "because of the timeless monotony of institutional life, I have forgotten how long I was in The Ward"; for her "time dragged on in its peculiarly timeless way, which can certainly be understood only by those who have been confined in nursing homes or prisons" (1979, 53, 131). In *Limbo,* Laird imagines the nursing home as a purgatorial space, where life can feel "timeless" due to its monotony. It is both this sense of monotony and the feeling I described of becoming a passive spectator to the goings on around you that turns the institution into somewhere timeless.

The concept of ghostliness therefore resonates profoundly with Cancer Time – reflecting the deeply liminal experiences of cancer, embodying the tension between presence and absence, participant and spectator, life and death. As we can find ourselves drifting through a surreal reality, disconnected from the rhythms of everyday life, and existing in a constant state of flux, the ghost emerges as a symbol. Beyond highlighting a renewed awareness of our proximity to death, ghostliness can be about navigating the ambiguous space where one is simultaneously living and fading, visible and unseen, close ("right here") and distant (somewhat elsewhere, removed, floating above or in-between). This haunting duality reflects the strange temporality of

Cancer Time, where the boundaries of past, present, and future blur, and the familiar markers of time, space/self-locatedness and identity are destabilised.

Mushroom Time

Cardona attests to experiencing cancer patienthood as a "liminal time" but also a "gestational time," suggesting that these periods of suspension and uncertainty are not merely passive but hold the potential for transformation (Cardona and Iohe 2023, 9). A further way that the transformative potential of this time is imagined is through metaphors of decay and growth. This can be seen in an image accessed from Richard Saltoun's private Spence archive (Figure 4.6*)*. This was one of several of Spence's works from *The Final Project* that I had never before seen or had available to me but were furnished upon request from the gallery. In Figure 4.6*,* Spence links terminal illness with decay through an image from *The Final Project* where she overlays her body with an image of mould. Spence's body appears reclined, arms outstretched, surrounded by different shapes and colour spores. The deep green flecks with lighter patches look like germs under a microscope but are taken from an image of lichens on weathered stone. They have a round appearance with varied rings of colour running throughout, making them appear like both germs and fungus. In the act of fading, there is a suggestion of becoming, of one body merging with another. As Spence fades into the spore-like image, she becomes a decaying body, a weathered body and a fungal body all at once.

Figure 4.6, Jo Spence, *The Final Project,* 1991-1992.

This notion of Spence as a decaying body is not new. Jacob and Tobin suggest that the images of Spence fading within *The Final Project* present "the healthy body in tension with nature, foreshadowing its collapse in future: the integration of body and ground by layering slides which symbolically tint images of her body as decaying, dying or deteriorating, and overtly staging a moment of return to nature" (in Lee 2013, 34). They explore Spence through a retrospective lens and with a focus on how the

artist was approaching death at the time of the work's creation. Similarly to Boyer, Jacob and Tobin posit Spence's visual decay as the artist "teaching herself a dialectical mode of dying" (2016). However, artist Abi Palmer's writing on mushrooms can offer an alternative way to theorise this work. Palmer draws parallels between her experience as a chronically unwell person and the nature of mushrooms:

> I have developed such an affinity with the fungal kingdom and its fruiting bodies. To be chronically ill, to be one of the sick ones - a postscript in the wake of a global pandemic - is to live like fungus. No matter how dignified you appear, or how majestic, there is something of a stench of death about you. There's an association with breakdown and decay. (2022)

Palmer draws a similarity between mushrooms and the chronically unwell person based on their "association with breakdown and decay". As unwell bodies deviate from normal function, failing to perform as they once did or were expected to, this comparison emerges. Although all living bodies are decaying ones, Palmer speaks to the perception of critically or chronically ill bodies as behaving in ways that align more with death than with life, perhaps due to failing functions or long periods of stillness, introducing "the stench of death" to theorise this. Decay by Palmer's conception is a part of life with chronic/critical illness, rather than a process that signifies the end. This in turn can alter the perspective on Spence's late work, allowing it to be read as representative of her lived experience of critical/terminal illness, rather than merely as an anticipation of the artist's death.

When looking at Figure 4.6, in terms of the experience of critical illness, it can be understood to speak to the liminality of the sickbed. Culturally, the bed-bound body has been closely tied to the rotting one. Palmer writes: "recently I have been very tired. I fall asleep late at night and wake early unrefreshed… I feel yeasty, fermented" (2022). There is an association with time spent in sleep, rest or stillness as allowing oneself to stagnate or ferment. This link has more recently been explored in the TikTok trend of "bed rotting"[16], which involves relaxing in bed for prolonged periods of the day and engaging in passive activities. Whether unwell or resting as a

[16] This is a modern trend, associated with the idea of mental health breaks and rest for those feeling burnt out, stressed or emotionally drained. In the wake of the pandemic, this is a particularly timely trend, for there has been a heightened awareness of mental health issues like stress and anxiety. Additionally, with more people working from home, the lines between work and one's personal life have been blurred. Both the self-care movement and social media influence have helped to promote and normalise ideas of taking time for oneself as an essential form of well-being and "bed rotting" has emerged as an indulgent form of this.

form of care, being reclined in bed can be understood as a slow process of decay while living. These periods of time spent in the sickbed have been expressly experienced as liminal in some of the examples I have explored. Artist and curator Elizabeth Price affirms this in her writing on the Hayward Touring show, *In a Dream You Saw a Way to Survive and You Were Full of Joy* (2016). This exhibition, curated by Price, includes one of the images of Spence's fading body from *The Final Project* and explores the reclined body in a variety of states, categorised as: sleeping, working, mourning and dancing. In the exhibition catalogue, Price suggests that "the horizontal state, whether literally or figuratively expressed, proposes an interval", going on to suggest that "the affective power of the horizontal state or composition lies in its strange dream of immanent liveliness" (Price 2016). For Spence, this is not necessarily entirely true; the reclined state is certainly imagined as "an interval", however there is not necessarily a "dream" or focus on any kind "of immanent liveliness". Spence appears to embrace the reclined state, its stillness and these ideas of decay, leading to the idea of Mushroom Time.

Palmer first conceived of Mushroom Time through conversations with friends, writing: "the conversations operate on Mushroom Time – refusing to manifest for long, unspecified periods, and then bursting in many directions all at once, and as if from nowhere, like pearlescent oysters after a bout of rain" (2022). Mushroom Time for Palmer represents moments of liveliness in decay, taken from the way that mycelia begin to fruit, sporadically and without visible warning. Further to this, however, Mushroom Time can be conceived of as the experience of living and decaying simultaneously, to highlight that periods of rest, decay, stillness and fermentation are simultaneously lively. As fungi both decay and live, Mushroom Time acknowledges the critical/chronic/terminal experiences of rest that are often referred to merely as intervals, as substantive and fruitful experiences of life.


Figure 4.7, Jo Spence, The Final Project, 1991-1992.

Unlike the metaphors of ghostliness that present cancer experience as peripheral and inactive, Mushroom Time reflects the fertile potential of these liminal states of being. It reimagines cancer not as a static suspension but as an ongoing process of transformation, where moments of stillness, decay, and waiting can give rise to new ways of being. This is further visualised in an image by Spence where leaves are overlaid with a skull. The vibrant leaves

form the recognisable shape of a skeletal face, with carved out eye/nose sockets, indented cheeks and a detached lower jaw. There is a suggestion of contrast and convergence, in this image: the leaves appear alive, still growing, while the skull is an iconographic euphemism for death and decay. The leaf skull is representative of being both alive and dead, existing in an in-between. It is like the mushroom in this sense, representative of both dimensions. Unlike Spence's works where the artist pictures herself as merely decaying, in this image she becomes a "fruiting body" (Palmer 2022) too.

Boyer discusses Spence's use of skeletons in *The Final Project,* writing that "skeletons are iconographic euphemisms [for death]. They aren't like corpses: they don't rot or smell" (2016, 5). This is arguably true; the skeleton is not a part of processes of decay but instead what is left behind when decay has taken place. However, this piece is not solely representative of the skeleton. Through the addition of leaves, Spence imagines the re-forming of flesh and skin. Where the leaves re-cover the skull and the bone becomes hidden once more, an action oppositional to decay appears to take place: regeneration. Palmer likens ideas of productivity or the body producing to the fungal notion of a "fruiting body", which causes spores and mushrooms to form. In this piece, both decay and a kind of regeneration are taking place, with one leading to the next. Through such a reading, the skeleton does not merely signify something already dead and decayed, as Boyer suggests, but instead represents a vivid living present, challenging the idea the idea that Spence's use of the skeleton serves to reflect or represent her impending death.

The cancerous body cannot escape being linked to decay for it produces abnormal cells that lead to the breakdown of the body. However, this decay is rarely linear. Bad days are interspersed with good, or vice versa, and the body can appear to grow often as much as it may appear to break down. In treatment this process is amplified, where the body is forced to deplete and then regenerate cells over and over again. Thus, when long periods of time are spent in the liminal space of rest, the notion of "Mushroom Time" appears increasingly relevant. The mushroom or fungi highlights the active, cyclical nature of existing in a body that is both breaking down and regenerating. It challenges the social perception of critically/terminally unwell bodies and their deterioration as paving the way for death, instead suggesting that periods of rest and stillness allow for various kinds of growth. In addition to this, the mushroom or fungus suggests that death is not an absolute end, but part of a continuous cycle. In *The Final Project*, this symbol disrupts the sense of finality, highlighting how life and growth persist even in the face of death.

Similarly to Spence, my participant Fairy explores this regeneration in more direct terms. In Figure 4.8, Fairy pictures a series of images that progress into one another. From top to bottom there are: bacteria, weeds, bulbs, roots, snowdrops, roses and a woman smiling, reclined with her legs raised. Of the piece, Fairy said: “I’ve worked it from then to now. So, I've visualised weeds and cancer cells to then regrowth, to roots, to spring, to summer, to me”. Fairy’s intention was to engage with “phoenix like imagery” to represent her experience of cancer. Through this image she captures both the degeneration the body undergoes because of its disease and the invasiveness of cancer treatment, as well as the body’s subsequent regeneration. Similarly, bulbs – like mushrooms – symbolise the generative potential of stillness and rest. Though they may remain dormant during winter, storing energy, bulbs burst into life when the conditions are right. This can mirror the body’s experience during cancer, where periods of decay, stillness or inactivity become necessary parts of a broader cycle that eventually leads to recovery or transformation. For many people with cancer, especially during treatment, time can become intertwined with the idea of dormancy and renewal.

Figure 4.8, Fairy's Workshop Artwork

My own chemotherapy cycles followed this pattern. Over five months, I had four rounds of chemotherapy. After each round, my blood cell counts would be wiped out and I would watch, through the statistics that returned from my daily blood tests, my cell counts creeping back up - my body regenerating what it had lost. Once my cell counts were back to a healthy level, I would have a few days out of the hospital, spent at home with friends and family, before coming back in for the next round. Once again, chemotherapy would obliterate all the cells that my body had worked so hard to produce and the process would repeat. It was like pressing factory reset. The

bulb, for the way that it springs anew each year, before withering once more, only to come back with even greater vigour, mirrors closely what happens to the cancerous body during treatment.

Fairy's depiction of roots in her collage echoes this theme of resilience and regeneration. When talking to Fairy about her work in our session, I remarked that "the roots - these look kind of dead. But I know that often plants can look dead, and you plant them and they kind of come back. You can cut off an absurd amount of them and they literally just come back." In this instance, roots become a metaphor for the resilience of the body. Despite damage, plants can regenerate from their roots, much as the body can from both cancer and its treatments. In Fairy's work, the roots are barren, lacking flowers, leaves or any greenery; they appear almost entirely dead. However, they are very much alive – capable of sprouting blooms once more under the right circumstances. Beneath the surface, there is an invisible growth that takes place with roots, even if the part of the plant above the earth appears withered or dying. The growth of roots, especially with seasonal plants, relies on faith in a process that isn't immediately visible, much like treatments for cancer. Roots can remind us that healing can happen out of sight, in periods of stillness, rest or decay. Like fruiting mushrooms, which emerge unexpectedly from decaying matter, this unseen regeneration can appear when we least expect and from the most surprising circumstances.

Conclusion

In *Feminist, Queer, Crip* (2013), Kafer asks: "Is someone who had cancer years ago but is now in remission disabled?" (11). This question doesn't have a clear-cut "yes" or "no" answer; instead the answer is often "sometimes". Sometimes, people who have had cancer find themselves disabled following treatment. Sometimes, people with cancer are disabled during the course of their illness but no longer identify as such after remission. Sometimes, people who have cancer experience mild to no symptoms and carry on living unencumbered by their bodies. Kafer's question may not be intended to have a definitive answer but rather to draw attention to a broader issue: whether people who have had cancer share mutual experiences with people who are disabled. The answer again is "sometimes". Thus, when Kafer goes on to talk about crip time and how disability creates strange/new temporalities, some of this is directly applicable to cancer experience. However, as outlined earlier, Kafer acknowledges that there is not one sole perspective on disability that aligns with everyone's experience. As there are nuances between different people with disabilities, there are also nuances based on what condition one has, what

age one was when one became impaired, one's gender and so on. What this chapter has started to do is to unite discussions of Crip Time, with several expressions of how time was experienced and expressed by a group of people who've had cancer, myself, my participants and Jo Spence, considering the moments of overlap and those of difference. From this I have outlined a new subset of the Crip Time experience: Cancer Time.

When exploring how my participants expressed their experiences of time, Sasha's work revealed that Cancer Time can involve intense periods of waiting. Whether waiting for information, waiting for an operation or waiting to see whether treatments are successful, one's time with cancer is often defined by periods spent in wait. Both Sasha and Spence's work captured these periods of waiting through various liquid metaphors. By evoking the viscosity of honey-like droplets, the heaviness of storm clouds and the experience of being immersed in water, they showed how surreal the experience of waiting can be for someone experiencing cancer. This analysis offers a new interpretation of one of Spence's most well-known works from *The Final Project,* as well as identifying visual metaphors through which the experience of waiting during cancer patienthood can be better understood. By drawing connections between Sasha's work and Spence's, I have been able to highlight how these experiences of waiting, suspension, and stagnation are rooted in broader capitalist expectations. Thus, in part, Cancer Time, much like Crip Time, emerges from moments where people are no longer able to adhere to conventional notions of timebound productivity.

What emerged from these moments where conventional notions of time and productivity were disrupted by periods of waiting was the ghost. Not only did the ghost attest to Spence's feelings of being caught between life and death but also my own feelings of being trapped in the liminal experience of cancer. Through my own work, I explored how identifying as a ghost, or even a "spectre", represented my minimised engagement with the world. It also represented the role I assumed within the hospital: that of spectator rather than an active participant in life. In each of these examples, the ghost became a clear representation of the liminal temporalities experienced by people who have cancer. It became a symbol of the periods of waiting that are so common, as well as a way to imagine existing within these periods of waiting. Thus, Cancer Time can be seen to give rise to the symbol of the ghost as a way to navigate the experience of an altered reality.

The ghost, however, was not the sole approach to living within this strange temporality. By examining a work from Richard Saltoun's private archive, I have introduced a new visual theme within *The Final Project:* that of fungus and spores. Where Spence's work has already been

associated with themes of breakdown and decay, the introduction of the fungus suggests the generative potential of the declining body. In addition to this, by drawing on Palmer's writing on mushrooms, fungi can be seen as symbols of fertility and transformation within the liminal states of being associated with chronic illnesses, like cancer. This perspective not only expands the interpretation of Spence's project but also invites a reconsideration of her use of skeletal imagery. Rather than seeing the skeleton merely as a symbol of death in Spence's work, it can instead be viewed as a fruiting body rich with possibility. Through Fairy's work, this metaphor evolves even further, whereby the bulb emerges as a parallel symbol, representing the body's capacity for dormancy, regeneration and renewal. Cancer Time, in this instance, comes to represent the hidden potential for growth and transformation within periods where time has felt suspended or liminal.

Cancer Time thus serves as both an acknowledgment of the temporal disruptions that cancer experience brings, as well as a recognition that these liminal periods are not merely passive intervals of waiting or decline but can also be sites for transformation. Within this framework, I have demonstrated how Spence's *The Final Project* can no longer be considered simply a meditation on death but rather a living project, that actively engages with the unwell or dying body as a site of huge generative potential. By exploring the varied expressions of time within my participants' artworks, I have sought to develop a more comprehensive understanding of this specific facet of Crip Time, which I have termed Cancer Time. The practice of photofantasy has facilitated the incorporation of new metaphors to articulate these experiences of time, while also generating new ways of understanding them. The surreal nature of these altered experiences of time can often lend itself to surreal forms of expression. In this context, photofantasy, through its emphasis on emotional resonance with images and its resistance to linear narrative, has provided a space for spontaneous and unexpected reflections to emerge. Like Kafer's exploration of Crip Time, Cancer Time is not meant to define a singular experience but rather to embrace the multiplicity of experiences it encompasses. The diverse ways in which my participants have represented the passage of time in their artworks highlights the fluid and entirely subjective nature of Cancer Time, reinforcing that no singular framework or expression can fully capture its complexities. With this in mind, my study serves as a starting point for further explorations and expressions of the experience of time when living with or after cancer, inviting continued dialogue and new perspectives on these strange temporalities.

In this chapter, I have touched on how the experience of time led both Spence and me to reimagine our bodies through the figure of the ghost, illustrating how illness can reshape one's

perception of the self. This can be seen to reflect a broader tendency to reinterpret one's identity in response to the experience of disease. Just as Cancer Time disrupts conventional notions of embodiment, cancer itself can alter the way individuals inhabit and perceive their bodies. This shifting relationship between the self and the body raises questions about agency, identity and bodily autonomy. By drawing further on the artistic expressions of Spence and my workshop participants, the following chapter will consider how cancer challenges fixed understandings of the self, revealing our embodiment as fluid, fragmented and often unpredictable. Through this lens, I will consider how bodies affected by cancer can exist in states of transition much like the temporal disruptions explored within Cancer Time.

Chapter 5: Hybridity and a Fusion of Parts

Jay Baglia writes that "in my cancer experience, the word fusion surfaced again and again. At one point, I received a blood transfusion – in the infusion room – and my chemotherapy was infused for the six months of my treatment. The etymological root for fusion is the Latin fundere, the process of being blended" (2012, 149). For Baglia, seeing his body fused with medicine, catheters and machines was a focal aspect of his treatment.

As Baglia attests, when diagnosed with cancer, the body can experience many alterations: the addition of ports and catheters, the removal/repair of parts, the use of technologies that reimagine the cancerous body and the infusion of various medicines. These changes can alter one's embodied sense of self. Mary H. Wilde writes that "existence is known through the body", defining embodiment as "how we live in and experience the world through our bodies, especially though perception, emotion, language, movement in space, time and sexuality" (1999). When cancer and its treatments alter the body, these fundamental ways of experiencing the world can shift dramatically. This chapter will explore how cancer and its treatments can influence one's embodied sense of self.

When considering the body in the aftermath of medical treatments, the metaphor of patchwork arose within the workshops. Patchwork attested to the reunification of a body that had been fragmented through treatment and disease. Ingrid Bauchmann, in her chapter 'Bodies in Need of Repair' from the book *Entangled Bodies* (El Sheikh 2020), considers how medical efforts to restore bodies that have been cut open or fragmented in some way often try to hide their repair efforts, erasing the trauma that these bodies have gone through. What arose within my workshops, however, was contrary to this. Participants appeared to draw attention to the ways their bodies had been fragmented and repaired. In doing this, participants highlighted the cuts and wounds that their bodies had experienced, turning the metaphor of the patchwork body into an acknowledgement of the trauma still present in bodies that have been 'repaired' by surgery or treatment.

A further way that the body was conceived of in the workshops was as a hybrid. This involved imagining the fusion of two or more disparate parts, whether it was the joining of a patient with an infusion line or the removal of a tumour and the resealing of flesh. This even extended to the various ways that bodies can be tracked, mapped and understood in healthcare. Medical imaging, statistics/data and physical sensations are all used to inform one's understanding of one's condition and these can often create conflicting accounts. An outcome of this conflict is

experiencing the body as a hybrid of these methods of processing. Moreover, as the body is transformed and redefined through the experience of cancer and its treatment, the workshop artworks have illustrated the impact of living within this state of instability. Chemotherapy and surgeries disrupt the body's integrity, causing "the boundaries of our bodies [to] break. Everything we were supposed to keep inside of us now seems to fall out" (Boyer 2019, 49). This upheaval is marked by hair loss, sickness, cognitive changes and physical pain, all of which underscore the fragility of bodily boundaries. Across several pieces, participants have examined this loss of boundaries, delving into themes such as violence, humour and monstrosity to articulate their experiences.

When exploring both the metaphors of patchwork and hybridity through the practice of photofantasy, the art-making method has resonated strongly. Photofantasy involves collaging images to explore thoughts/ideas and to generate meaning. In this sense, it mirrors the creation of patchwork, through the combining of multiple elements. In the same way that patchwork is a hybrid of several parts, photofantasy is a hybrid practice that relies on bringing together previously distinct visuals to form something new. Thus, when exploring cancerous bodies and identities, photofantasy allowed for (and even encouraged) participants to explore themselves as a construction of individual parts which could be perpetually reconstituted and reimagined, adhering to no single, fixed narrative or form of the self or the cancer experience. When including themselves or their bodies in the collages, participants rarely settled on one singular image from the collage materials. Rather, they combined various images, generating a body that was a hybrid or a composite of multiple parts.

Beyond the method of artmaking, the way that the sessions were organised allowed for ideas to be developed across the workshops. As I met with each participant one-on-one, I introduced them to the ideas and outcomes of previous sessions as we discussed our own artworks. Although there was no conscious discussion about continuing one another's ideas in any of the sessions, there were various themes and visuals that proceeded to be built upon as sessions progressed. Through both the collages I made and the conversations that were had around the artmaking, participants became aware of one another's ideas and further contemplated these in their own works. In this way, photofantasy became a dynamic and supportive framework for exploring hybridity and hybrid identities.

When combining visuals to construct a body within the photofantasy works, the notion of a cyborg body began to emerge. Crip theory has closely engaged with the numerous ways that disabled and unwell bodies are made hybrid through the figure of the cyborg (Fox 2021, Lupton

2015, Sulik 2011, Klugman 2001). Donna Haraway's *Cyborg Manifesto* (1985) was a focal text in the conception of cyborg theory, defining the cyborg as a "cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction" (2016, 5). However, Haraway's manifesto has been rejected by some crip theorists for its lacking engagement with disabled people's realities. Even though "at the time Haraway published her Cyborg Manifesto in 1985, many people were already living with technologically augmented bodies for medical therapy" (Haddow, King, Kunkler and McLaren 2015), this was largely left out of Haraway's manifesto. Jillian Weise suggests that for Haraway, "the cyborg is a matter of fiction" and that the "manifesto coopts cyborg identity while eliminating reference to disabled people on which the notion of the cyborg is premised. Disabled people who use tech to live are cyborgs. Our lives are not metaphors" (2024). This is reiterated in Episode 66 (2019) of the *Disability Visibility* podcast with Ashley Shew, Gillian Weise and Alice Wong, all of whom explore their own crip/cyborg identities, when they deem Haraway a "tryborg": someone who "is a faker, a wannabe, a poser", someone who, unlike a "cripborg", doesn't require technology to live. The approach of Shew, Weise and Wong has informed my analysis of the cyborgian aspects of the artworks. Although I refer to Haraway for some definitions of the cyborg as a concept, I have focused closely on the lived experiences of people with cancer who self-identify as a cyborg within my study.

A focal perspective on this is Baglia, who addresses the role of technology in the construction of patient identity through the lens of his own experience of treatment for late stage Non-Hodgkins Lymphoma. Baglia draws on the cyborg, through Haraway's definition, for his experience of being supported by catheters, medicines, machines and technology. He explores the various "cyborg appendages" that supported his treatment, as well as how their addition affected and troubled his sense of identity. By referring to Baglia and his writing, I consider the cyborg as a way to visually unify disparate parts and also to capture the disjointed and partial experiences of my participants. Baglia's reflections illustrate how technological interventions can blur the boundaries of the body, transforming both identity and embodiment. This dynamic of fragmentation and reconstruction is not unique to his experience; it resonates with the broader ways in which cancer treatments alter the body and sense of self.

Thus, this chapter will examine the ways in which cancer and its treatments can profoundly alter participants' embodied senses of self. By engaging with metaphors of patchwork and hybridity, I will consider how the medical processes of fragmentation and reconstruction not only reshape the physical body but also mirror the intricate, and sometimes contradictory,

experiences of identity transformation. Building on this, I will examine how these disruptions to bodily boundaries – whether through medical interventions, illness progression, or healing processes - prompted my participants to renegotiate their senses of self, often navigating between feelings of loss, adaptation and reclamation.

Patchwork, regeneration and replacement

As Sasha explored the ways that her body was altered by both cancer and medicine, the idea of the body as patchwork began to arise. Patchwork, which is defined as a fabric composite of different cloths sewn together, is a hybrid object. It is formed through the combination of various parts, united to create a whole. Patchwork can be used to craft unique patterns, make use of scrap fabric or repair garments that have broken. Participants linked the patching up of worn fabric to the patching up of the body, and this idea of repairing or replacing broken/cancerous parts.

The association between the cancerous body and patchwork was drawn by Sasha in one of her collages. In Figure 5.1, a cuckoo is the focal element of the work, chosen by Sasha to represent her cancer as "it's something that is somewhere where it shouldn't be", because the cuckoo takes up other birds' nests. Behind the cuckoo are images of roots, chosen to represent "the tendrils of the cancer going into the lymph nodes and possibly round the rest of the body". Above this is an image of water pouring from a watering can, used to express how Sasha's doctors were "trickling chemotherapy in and drugs and fluids into the body to try to get rid of [her cancer]". To the left of this, Sasha explores the outcome of the discovery of her cancer and its subsequent chemotherapy treatment. She pictures dry plant husks and dirt, chosen to represent how the treatments made her feel. She sought to capture in these images how dead chemotherapy made her body feel and also how it was ultimately unsuccessful, with nothing good growing

Figure 5.1, Sasha's Workshop Artwork

from what was left. Alongside the husks are three images: multicoloured candles spelling out "Joyeux Anniversaire", the words "stark truths" and a patchwork quilt. Of this Sasha said:

> in the midst of [my diagnosis and treatment], I had my 60th birthday, which was supposed to be this great occasion when you reach 60 and you have a big party. I did have a party but it was so diminished for me because of the chemotherapy and the treatment that I was going through and I had to be told stark truths that the chemotherapy wasn't working and a lot of the time I felt like a patchwork quilt - that there were different segments of me but also you know having injections and I had a picc line and I now have a port-a-cath and I had a stoma as well, so I did feel a bit like a patchwork quilt, that bits of me were being cut up and yeah, chucked around.

Where physicians inserted injections, a picc line, a port-a-cath and a stoma in order to repair Sasha's functions and provide access points for her treatment, it resulted in Sasha experiencing her body as a collection of individual parts, stitched together in an attempt to heal her. This is where the metaphor of the patchwork quilt can be seen to attest to the various surgical alterations Sasha has undergone. Patchwork, in this sense, does not only represent the addition of new parts, but also how the repair and reunification of the existing body can come with feelings of fragmentation and grief.

Through the idea of repair, Sasha's experience resonates with how Arthur W. Frank conceives of navigating illness experience. In *The Wounded Storyteller*, Frank introduces the concept of being "shipwrecked by the storm of disease", losing your "map and destination" (2013, 54). This metaphor attests to how illness can disrupt one's anticipated life's course, throwing the future off track and making parts of one's life appear redundant. Frank draws the conclusion that where a life is disrupted by disease, one is left to gather the fragments of one's life that remain after the shipwreck, while filling in for the parts that were lost in the storm (54). In Sasha's case, this metaphor becomes quite literal—her body, much like a wrecked vessel, is pieced together with the remnants of her former self, while medical interventions fill in for the parts that have been 'lost.' Through surgeries, chemotherapy, and the installation of devices like the picc line and stoma, Sasha's body transforms into a patchwork quilt, reflecting both the damage caused by cancer and the ongoing process of repair. Each medical insertion is like a stitch in the quilt, representing both the fragmentation and resilience of the body in the face of illness. Frank's metaphor invites us to see this process as not merely about loss, but also about adaptation—where rebuilding the body is intertwined with rebuilding the self. Ultimately, Sasha's patchwork body stands as a testament to the profound ways that illness reshapes identity, offering a visual

narrative that parallels Frank's idea of repair after the shipwreck, where the working parts of the body are preserved and adapted to new circumstances.

Although the metaphor of the body as a patchwork quilt can convey resilience, Sasha and I discussed how it also reflects discomfort and vulnerability. I shared with Sasha that when I first saw her work, her quilt brought to mind the one I had kept on my bed throughout my own treatment, which had been a source of warmth and comfort, rather than a reflection of my physical state. I remarked: "you're not supposed to feel like [a patchwork quilt]; you're supposed to be comforted by it," and Sasha agreed. In this way, the metaphor of the cancerous body as a patchwork quilt becomes a paradox: on one hand, it symbolises resilience and the body's ability to endure and mend, but on the other, it shows the emotional and physical strain of living within a body that feels fragmented and vulnerable.

The experience of the cancerous body as simultaneously resilient and vulnerable is also imagined in Rose's work where, using tape, Rose depicts the cancerous body as having been patched back together. Figure 5.2 captures several quite distinct elements. At the top right of the page is an image taken of a forest canopy. Of this image, Rose said: "I also really like the perspective of this, someone's obviously lying on the floor and looking up and whilst it may be really bleak at the bottom it looks really hopeful and positive at the top and I liked the bird sort of soaring, like that's where you could be, you could get to that". Running down the side of the page are various images of cheese, the veins of which symbolised the source of leukaemia. At the bottom of the piece is an image of leaves surrounded by gardening implements; the intention here was to represent how leukaemia is "brutal and they throw everything at it". This notion is reiterated in the central image of this work, which is a natural landscape that has been taped over. Of this, Rose said: "I deliberately used the tape as this was kind of a perfect picture. If you delved into it, there would

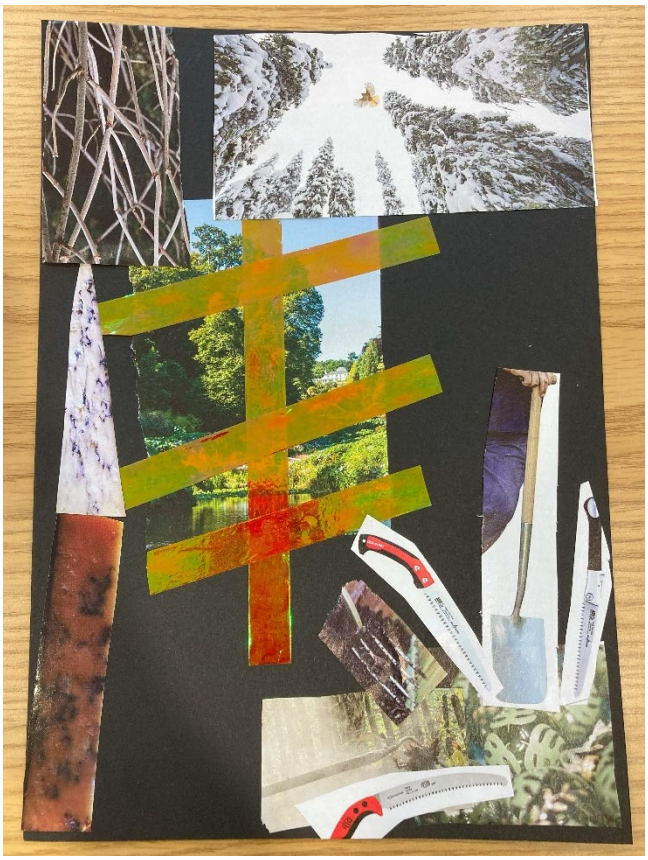


Figure 5.2, Rose's workshop artwork

probably be some weeds or something, but I found to treat leukaemia you just have to destroy everything". Behind the tape, the perfect image does remain intact, however, the obstructive bright tape suggests both a necessary intervention and an obstructive addition to the image. Rose spoke further about this, suggesting that, "it was a beautiful image and it's being patched up and it's never going to be the way it was before. There'll always be scars". In this sense, the landscape covered in tape represents the irreversible changes that the cancerous body goes through and how it is marked by these, as well as how resilience and fragility go hand in hand within visualisations of the cancerous body.

Rose's attempt to "patch-up" the landscape which represents her body is reminiscent of the Japanese repair method of kintsugi. This "ancestral technique, developed in Japan during the fifteenth century, consists of repairing a broken object by accentuating its cracks with gold—instead of hiding them". Beyond just being a method of repair, kintsugi is a philosophy that "goes much deeper than a simple artistic practice" (Santini 2019). Céline Santini writes that kintsugi "has to do with the symbolism of healing and resilience. First taken care of and then honored, the broken object accepts its past and paradoxically becomes more robust, more beautiful, and more precious than before it was broken" (2019). Although in Rose's work the gold tape obstructs the natural landscape, intending to show how treatment has obstructed and altered her body, like with kintsugi the tape does not piece the scene together in an attempt to hide its imperfections. Rather, Rose has accentuated the piecing back together of her metaphorical body by capturing it in gold. In the same way that patchwork can both mend and accentuate the repair that a fabric has undergone, kintsugi, as a practice and an ideology, invites an acknowledgement of the imperfections that cancer reveals.

Perhaps the focal difference between kintsugi and Rose's collage, however, is the obstructive nature of the tape she has used. Both Rose's use of tape and kintsugi seek to highlight repair efforts. However, where kintsugi seeks to appreciate the imperfections that repair reveals, Rose attempts to highlight the excessive repair required as a result of treatments like chemotherapy which, as she put it, "destroy everything". Where the repair efforts that Rose undergoes, through the use of this bright gold tape, may be considered decorative like kintsugi, the fact that they are so extensive and disruptive of the original image appears to act as a reminder that the treatment Rose underwent was destructive and exhausting. Where the sentiment behind applying kintsugi as an approach to repairing our cancerous bodies is very inviting, Rose's collage instead reiterates that *first* there is an urgent need for more gentle, targeted treatments that do not

obliterate immune systems and create devastating late effects[17] which require such extensive patching up or repair. The patching up that Rose captures appears as a testament to the brokenness of the post-treatment cancerous body, rather than an acknowledgement of the repair it has undergone.

Figure 5.3, Jo Spence, *The Final Project,* 1991-1992

The brokenness of the cancerous body is also captured in Spence's work. Figure 5.3, taken from *The Final Project,* shows Spence's nude breast, with lumpectomy scar, alongside a ribbon rosette with a pair of breasts in the centre. This photograph has been overlayed with a further image of a paved pathway lined with grass. The overlaying of images makes Spence's body appear as though it is cracking and fragmenting. Her body appears a collection of pieces paved together, rather than the smooth, intact surface it once was. Clarissa Jacob and Amy Tobin suggest that throughout *The Final Project,* Spence visually depicts decay through overlayed images such as "peeling walls and falling leaves" (Jacob and Tobin cited in Lee 2013, 33). This observation can be seen to extend to Figure 5.3, wherein the paving stones segment Spence's body, introducing the idea of her skin cracking and coming apart. Like a monument crumbling or old ruins being weathered, Spence's cracked torso can be seen to represent both her body's presence and its implied destruction. As Jacob and Tobin suggest, within her images of decay, Spence "tread[s] a borderline between existence and destruction" (cited in Lee 2013, 34). This is where patchwork once more comes to represent the paradox of resilience and vulnerability. As the paving stones give the impression of a patchwork body, they can be understood to imply the binding together of bodily fragments as well as their breaking apart.

This appears similar to Rose's work, whereby the fragmentation of the body is used to emphasise the devastating effects of cancer and its treatments. Despite the fact that both

[17] Late effects are health problems that occur as a result of a disease or its treatment, months or years after one is diagnosed or their treatment has ended.

Rose's metaphorical body and Spence's body have been patched (or paved) back together, both works seem to draw attention to the brokenness of the body that has required mending in the first place. Like with kintsugi, attention is drawn to the ways that fragments are bound together. Figure 5.3, like much of *The Final Project*, is a merging of two pre-existing images, both from Spence's personal archive. Where the image of Spence's torso was originally part of her breast cancer works (1982-1989), it has been reimagined in light of her leukaemia diagnosis. Initially, the image of Spence's nude torso was an acknowledgement and exploration of her lumpectomy scar, which sits at the bottom of Spence's breast. However, the focus of the image is no longer this large scar. Instead, the statuesque texture of the body and its fragmented, broken parts become the focal point of interest. In *The Final Project,* beyond just her breast, Spence's whole body is now crumbling, coming apart and being put back together within her work. Where the healed scar suggested Spence's body had been surgically repaired, the whole of her body now appears segmented and reattached. Although at the time *The Final Project* was created, repair in a general sense was no longer possible for Spence due to her terminal diagnosis, this imagery of the shattered body reassembled can be seen to speak to both the brokenness of the cancerous body and Spence's effort to acknowledge or even reclaim her fractured identity.

This reclamation is in part what kintsugi promotes and precisely why there is an emphasis on highlighting the irrevocable change present in broken objects. Ingrid Bachmann writes of how, in Western art history, restoration focusses on "return[ing] something to its original condition, ideally with no evidence of its repair or restoration… with no scars, no traces – to erase all evidence of reconstruction". Bachmann relates this approach to Western medical practice and the way that surgeons/physicians seek to return the unwell body to the state it was in prior to illness. Of this Bachmann asks, "what are the consequences of this erasure, of the denial of trauma and pain on individual bodies, as well as cultural bodies? What are the stakes in denying a body's hybrid histories?" (cited in El-Sheikh 2020, 13-14). Bachmann appears to suggest that medical practices which mask or hide the effects they have had on the body risk denying the trauma and pain that those bodies have experienced. Both Spence's, Rose's and Sasha's works directly defy this notion; rather they emphasise both the fractures and the repair that their bodies have undergone. Picturing the patched-up or patchworked body is the primary way that they do this. Where Spence and Rose fragment an image in their works, they re-imagine the various medical interventions and surgical cuts that their bodies have endured. Where they then picture the tape or cement that rejoins these segmented parts, Spence and Rose reclaim their fractured identities by acknowledging that their bodies are not restored to what they once were but instead are something new. The metaphor of patchwork used in photofantasy can thus be

read as an acknowledgement of the trauma that the cancerous body undergoes as well as a reflection of its resilience. By emphasising both fractures and mending, patchwork becomes a powerful metaphor for the interplay of destruction and restoration that treatments for cancer can cause.

Assemblage, the cyborg and medical technologies

A further way that the body was explored in the workshops was as a hybrid. The collage making aspect of photofantasy allowed for bodies to be expressed as a construction of individual parts. Much like the metaphor of patchwork, this allowed participants to explore their bodies as something new. This hybridity was then mirrored in the structure of the workshops, whereby visual symbols and ideas were built upon as each session progressed.

Figure 5.4, Researcher's Workshop Artwork

In a collage that I created (Figure 5.4), I used one of my medical images in my construction of a hybrid body, made up of multiple visual parts. Beginning from a chest X-ray, I worked from the centre of the page outwards to "map" the rest of my body. This process began as an attempt to find characteristics I could identify with within my medical images. On first look, these X-rays appeared somewhat anonymous and devoid of identifying features. As I added images to represent more of my body, I used numerous visual metaphors. The arms and the skeleton are perhaps the only identifiably human body parts that I included. In the workshop discussion, I addressed some of the chosen metaphors: "I got these little Christmas tree lights for sparks of thoughts and ideas and then the Northern Lights are just this wafting curiosity and then a hat cause I was always wearing hats at this time". I also included a fruiting plant to represent my left leg; this is accompanied by a more barren plant in place of my right

leg, as my leukaemia manifested in my right hip, which is where I experienced the pain that first brought me to hospital and led to a subsequent cancer diagnosis.

I chose to explore this pain through the image of a fiery explosion. This imagery was inspired by a collage made by Sasha in the session prior to my making of Figure 5.4. As discussed in Chapter 4, Sasha pictured an explosion in one of her collages to represent her anguish at the moment when she was diagnosed, as well as the internal pain she was experiencing as a result of her cancer. The metaphor of a fiery explosion as representative of physical pain resonated with me and reminded me of the discomfort I felt in my right hip when I was first admitted to hospital. When I found this image of an explosion, I was reminded of Sasha's work and I was also thinking about how skin that is burnt can often feel scorched, tight and inflexible, any movements resulting in a sharp, hot pain. Like an explosion, this pain I experienced prior to diagnosis spread from a central point, igniting all it came into contact with. When remaining still, my hip had a threatening dull ache, prepared to detonate at the smallest jolt. As I picture both the plant and the explosion side by side, I capture how fire, much like the pain I was experiencing, threatens to spread across dry, barren forests - with each movement I made, my right leg was set ablaze.

Further to this, I wanted to avoid representing the leg that is symbolically associated to my cancer's beginning with unnatural imagery. It felt important that I show both legs as representative of some kind of natural matter. For this reason, I chose plants; both my legs were still living, growing entities, even if one had started to misbehave and cause me pain. Neither plant is necessarily dying or unwell either; instead I represented the leg where my cancer manifest as one that was not bearing fruit. Contrastingly, my left leg was pictured as sun drenched and rich with small berries. The hand reaching to grasp these berries reminded me of my physiotherapy sessions during treatment, and how my "good" leg would be used as a benchmark by the physiotherapist for the range of movement and strength for which my "bad" leg should strive. The berries and the fruiting of the left leg are intended to mimic this relation, where the right leg simply wasn't doing what doctors and physiotherapists believed it should be. I introduced the unnatural imagery of the tape on my right leg to represent the medical interventions that sought to repair its function. I had fluid drained and several dense doses of chemotherapy, each of which, although I am grateful for, were the unnatural addition to my body. Being able to combine various images to construct a hybrid body enabled me to consider how expectations placed on my body affected how I saw it, as well as how the "natural" and "unnatural" elements introduced during my treatment shaped my experience. Ultimately, each

visual addition I made to my collaged body helped me to understand how my embodied experience had shifted throughout my treatment.

Furthermore, by uniting several distinct images within my collage, I attempted to generate a singular representation of my cancerous body. This felt important to do as, throughout treatment, I became used to experiencing my body in a number of different ways which disrupted the notion of a singular representative embodiment. During treatment, I was introduced to numerous ways of tracking, mapping and understanding my unwell body. The doctors used medical imaging that I was sometimes allowed to see; statistics and data were a huge part of monitoring my progress and sometimes my physical sensations were used to inform my condition. More often than not, I would spend the day trying to express to my parents how I was feeling through various metaphors and similes. This is where I first became a hybrid body. Throughout my experience of cancer, my body was conceived of in so many different ways that no singular, whole impression stuck. Instead, I became numerous parts, each of which contributed to the overall understanding I had of my being.

I experienced the photofantasy workshop as an opportunity to unify some of the numerous (otherwise distinct) parts that made up the impression I had of my cancerous body. This process of unifying disparate parts is very similar to the practice of artist Catherine Heard, who creates hybrid collaged bodies in her series of works titled *Automata* (2010). Taking inspiration from Dada and surrealist artists like Hannah Höch, Francis Picabia and Marcel Duchamp, Heard creates collaged anatomies that involve both nature and machine (Heard 2010). Heard wrote of her inspiration behind the series that:

Figure 5.5, Catherine Heard, *Automata*, 2010

> Early historical anatomies resonate with our contemporary philosophical understanding of the body as a structure that may be perceived, regulated and mapped using a number of alternative criteria. Like children's drawings early anatomies simplify forms to create symbolic representations of systems or organs. Frequently, medieval anatomical illustrations featured rich schemata of associative imagery correlating

> diagrams of the body and other natural and scientific systems — such as astronomy or botany— imagine the body as a machine. These imagined overlapping systems inspired me to create *Automata* (Heard 2010)

In her own collages, Heard seeks to unify these "symbolic representations" of the body through images of "astronomy" and "botany," echoing the approach of early anatomical drawings. By employing diverse visual symbols, she suggests that no single perspective fully captures the body's complexity. Heard's concept of the body as "a structure that may be perceived, regulated and mapped using a number of alternative criteria" aligns with how a cancer patient's body might be visualised through medical data, imaging, and physical sensation. Like Heard's combination of "natural and scientific systems" in medieval illustrations, I, too, attempted to integrate aspects of daily life to map the changes in my body, aiming to create a unified impression of these "overlapping systems," as shown in Figure 5.4.

Picturing this overlap, however, appears to express the uneasy unification of the artificial with the organic in relation to the body. Through her title *Automata* as well as the construction of her collages - whereby the body is pictured as a collection of mechanical systems – Heard appears to be invoking René Descartes and his influential conception of the body as mechanical as clockwork. Automata is a term that refers to mechanical devices or robots designed to mimic the human form. It is also the focus of writing by Descartes, who argued that no discernible difference would exist between the human body and automata, as the body's functions could be explained in mechanical terms. Descartes drew parallels between the components of the human body and those of artificial mechanisms, such as water-driven machines. He described nerves as akin to tubes in hydraulic systems, while muscles and tendons corresponded to springs and levers. Descartes even likened the flow of "animal spirits" through the body to the driving force of water in a fountain, with the heart serving as the fountainhead and the brain's ventricles functioning as conduits or reservoirs. Natural processes like respiration, he argued, mirrored the continuous motion of a clock or mill driven by the steady flow of water (Descartes 1998, 99-107). Descartes mechanistic view of the body underpinned much of early modern medicine and has contributed to a Cartesian approach to the body[18]. Margrit Shildrick notes that such an approach employs our bodies as "material housing", implying that operations to correct or replace anatomical and physiological functions should be treated as "purely technical… with few consequences for [our] sense of self". As Shildrick notes, however, this

[18] A Cartesian approach to the body would be one that views the mind and body as separate entities, with the body being material and the mind (or soul) being considered immaterial.

often leads to “high degrees of disturbance” on the part of patients “in the face of such incompatible demands” (2015a). When visualising the various fragmented systems that compose the body, both Heard and I contest the Cartesian view by capturing the disjointed union of the artificial and the organic. Rather than visualising the seamless integration of machinery with the body, we showcase the awkwardness and the fragmentation that is at play.

This is where the concept of the body as cyborg emerges as an enticing metaphor which acknowledges the medical changes made to the cancerous body which may lead to further existential changes too. The term “cyborg” initially defined by Manfred E. Clynes and Nathan S. Kline in 1960, describes a self-regulating hybrid of a living organism and machine, enhanced through biochemical, physiological, or electronic modifications (cited in Gray 1995, 29-33). The cyborg has also famously been theorised by Donna Haraway as “a hybrid of machine and organism” (2016, 5) which embraces “partiality” (2016, 9) and “partial identities” (2016, 15). In this sense, the cyborg appears to be a body that is comprised of multiple parts, aware of the changes that have been made to its organic flesh. The cyborg as an idea recurs within many Dada collages and this has been attested to and explored in Matthew Biro’s *The Dada Cyborg* (2009). Biro considers how, through photomontage and assemblage, artists like Hannah Höch and Raoul Hausmann used the cyborg to visually critique and reconstruct identity, emphasising its transformation under the influence of technology and mass media (Biro 2009, 70). Where the Dada cyborg appears to attest to the transformation of the body in light of technology, the cyborg that I constructed can be seen to reflect the many transformations that my body experienced throughout my treatment for cancer.

During treatment, there are several reasons that the body can begin to feel like a cyborg. Both the transmuting of the body’s information into digital data and the addition of ports, catheters and various access points across the body, can lead to feeling like “a hybrid of machine and organism” (Haraway 2016, 5). For me, I felt that my body became a cyborg when it began to exist across both physical and digital realms. Each time doctors medically imaged my body through an X-ray/ultrasound, or took bloodwork, the results of which were then inputted into a computer, these digital impressions became an entirely new body, a digital body, one from which they determined what should happen to my physical body. The notion of the cancer patient as cyborg was experienced somewhat differently for Baglia, who explores the many ways that cancerous bodies can take on cyborgian qualities in “The Ontology of Oncology: Navigating Cyborgs and Assemblages Through Cancer Treatment” (2023). Reflecting on his own “experiences of treatment and recovery from late stage Non-Hodgkin’s lymphoma,” Baglia

explains that “a surgically implanted port (facilitating blood draws and the delivery of chemotherapy) and the patient portal (representing the results of those blood draws as well as a medium for communication) provide a foundation for how cyborgian assemblages both assist and trouble the cancer experience.” The “trouble” that each addition appeared to create for Baglia was that it forced the reimagination of his embodied sense of self. Whether it was the infusion of treatment or the attachment of various “cyborgian appendages” for monitoring and support (especially the “port and pump,” which Baglia saw as the “most material aspects” of his “cyborg identity”), each addition altered the way Baglia experienced his body. For both Baglia and me, the cyborg emerged as a metaphor that accounted for the interplay between our physical bodies and the digital systems that mediated our treatment. Whether through the presence of physical additions to the body or the translation of the body into digital data, the cyborg attested to the new, altered body that presented each time cancer treatment transformed our bodies and thus our embodied experience.

Deborah Lupton notes that the addition of “cyborg assemblage[s]” in healthcare generates an increased awareness of our bodies. Lupton defines “the cyborg assemblage… as a melding of body with technologies that are able to provide cybernetic (feedback) mechanisms”, thus the “digital cyborg assemblage is not the organism with super-human powers that is so beloved of science fiction fantasy” but rather it is “the ordinary person who uses digital technologies to monitor her or his bodily functioning or movements or perform medical self-care tasks" (2015, 572). This can arguably extend to some of the assemblages that Baglia notes, such as the “port and pump” which facilitate drawing blood and turning the analysed sample into data. Focussing on what this does to our embodied experience, Lupton suggests that the “cyborg assemblage” isn’t just about replacing sensation, it’s also about listening to the body through technology: “The digital cyborg assemblage in the context of medicine and health promotion is focused on monitoring the signs and signals of the body, its patterns and its data. These technologies make their users constantly aware of the fleshly nature of their bodies: how high their blood pressure or glucose levels are, how happy they feel, how many steps they have walked that day” (2015, 574). By Lupton’s suggestion, cyborg assemblages, like those used to provide information about the cancerous body, do not distance users from an awareness of physical sensations but rather act as a reminder of the “fleshly nature of their bodies”. This view, however, appears somewhat idealistic, as there is little recognition by Lupton of how disruptive and challenging a constant awareness of the internal working of one’s body might be. Where Lupton suggests that we are reminded of the “fleshly nature of [our] bodies”, it is implied that digital health technologies record both the physiological reality of our bodies as well as our lived experience, aligning these

as one. However, as is often the case, digital health technologies can record information about our bodies that is entirely contradictory to what we may feel.

Gayle Sulik appears to acknowledge the possibility of this contradiction when suggesting that digital health technologies can lead to the creation of a new kind of "illness identity", which she terms the "technoscientific identity" (2011). According to Sulik, illness identity is built upon the "relationship between the body and the self in the face of chronic illness or disability". Thus the "technoscientific identity" similarly, "involves applying biomedical information and characteristics to a person's sense of self in the face of illness" (2011). The outcome of this "technoscientific identity" can, thus, be one of conflict and disruption when the two aspects do not perfectly align. This was something that I experienced as a daily occurrence while undergoing treatment. Each morning, once my bloodwork had come back from the lab, I would check the results with my parents, going over the figures and what they meant was going on inside of me. I attempted to apply the figures I saw to how I physically felt. However, this process was rarely as straightforward as reading the information and altering the perception I had of my body; it was a constant negotiation. I would often argue with my parents over what we saw in my bloodwork, suggesting that I felt well enough to leave the hospital even when my white cell count suggested otherwise. I also recall, after an X-ray, arguing that the pain I was experiencing in my hip was legitimate when the scans had found no reason for its occurrence. The use of digital health technologies resulted in conflict and distrust, where my bodily sensations were regularly called into question. Although these technologies supported physicians in providing me with more accurate care, their failure to fully capture or validate/account for what I was feeling confused my embodied sense of self.

This is where both the practice of photofantasy and the metaphor of the cyborg lend themselves to capturing the disjointedness of my experience. The disconnect between my digital and physical realities is reflected in the collage that I generated. Despite unifying the digital and the physical within Figure 5.4, with the inclusion of an X-ray scan and human arms, the collaged nature of the image allows these aspects to remain distinct, even when placed side-by-side. I have not tried to blend these elements together, but instead they exist in sharp contrast. Much like the nature of collaged images, the cyborg metaphor also suggests a unity between digital and physical impressions of the body, while capturing how this unity is not perfect; it is messy, uncomfortable and often conflicting. Haraway suggests that cyborgs have the capacity to embody "contradictory" and "partial" identities (Haraway 2016, 15), thus perfectly capturing

and representing the dissonance that I experienced between digital health technologies and embodied sensation.

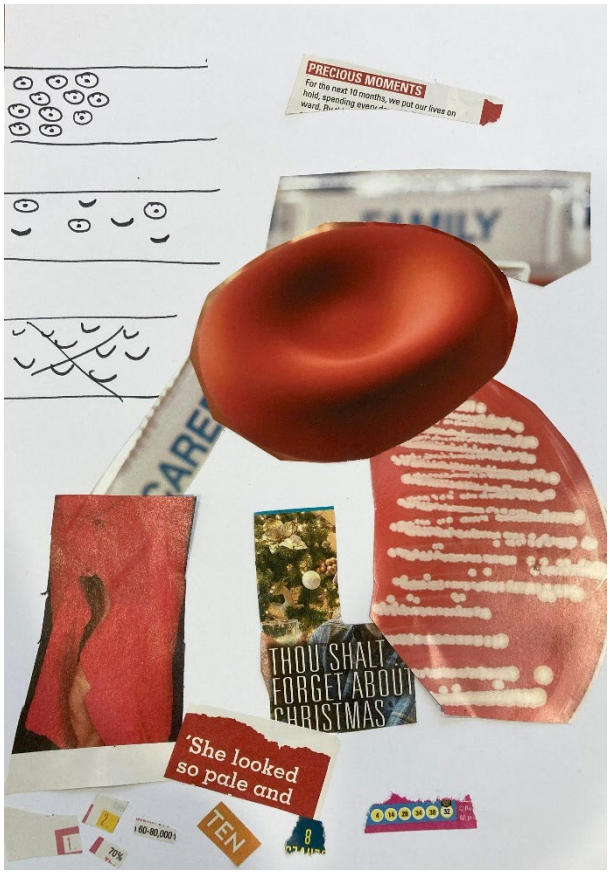


Figure 5.6, Rose's Workshop Artwork

It is not only this dissonance between the physical and the digital that the workshop collages revealed, but also between the physical body and the statistical information that digital health technologies produce. This uncomfortable union is pictured in a collage by Rose (see Figure 5.6), which depicts blood cells, statistics, drawings and test slides. Rose's collage began through a discussion we were having on how cancer is explained to children. From this, Rose drew the diagram for me that she had used to explain what leukaemia was to her young daughters. The drawing in the top left corner of the collage was representative of (from top to bottom) healthy blood cells in a vein, then leukaemic cells entering the vein and finally leukaemic cells taking over the vein. From this drawing, Rose collaged other materials, representing how the blood cell was "dominating over [her] career and anything else" as well as a petri dish to represent her numerous infections. Rose expressed that this collage became an attempt to represent "patient experience and everything I was going through". A focal aspect of this collage, however, is the collection of numbers at the bottom of the page. Of these, Rose said: "it's all about the numbers, I'd almost forgot until you mentioned it, it was the trigger for everything. Every day was what are my numbers… ooh 0.4 it's getting higher… they'd give me print outs of my charts when I went in every day and you know I just, you kind of know 'well this one needs to be between 5 and 4' and 'this one needs to be between 3 and 100' and you know, you just know what the margins are". Numbers and statistics can become a huge point of focus for people with leukaemia, as doctors use bloodwork to ascertain whether cell production within the body is improving or deteriorating. This was no different for Rose, who experienced the presence of numbers and statistics during her treatment profoundly.

In Figure 5.6, there is a clear tension between the organic human body and recorded medical data. Rose captures this tension when she pictures qualitative information about the body being turned into quantitative data. Rose's use of the phrase "she looked so pale and" trails off into a collection of numbers ("ten" , "8", "70%"), making it appear as though a descriptive observation is being substituted for statistics. This transformation echoes Anne Boyer's assertion that "contemporary medicine hyper-responds to the body's unruly event of illness by transmuting it into data. Patients become information" (2019, 52). Further to this, Rose's collage captures this process visually, as the intimate realities of her body are dissected, monitored, and transformed into cold, objective data. This transformation, much like in my work, is not pictured comfortably. The abrupt ending of the phrase and its reduction to meaningless numbers implies that "sensation is the enemy of quantification. There is no machine, yet, to which a nervous system can submit sensation to be transformed into a sufficiently descriptive measurement" (Boyer 2019, 52). What Rose appears to be experiencing is the translation of her physical body into something disjointed and inaccessible. It could even be suggested that where different aspects of Rose's collage are scattered across the page, obstructing, obscuring and interfering with one another that she attempts to emphasise the uncomfortable coexistence of the physical body alongside the digital or statistical impression that healthcare generates. A focal outcome of this composition is the suggestion of confusion and chaos when the physical body is turned into a digital/statistical body.

What both Figures 5.4 and 5.6 appear to reveal, therefore, is how cancer treatment reconfigures identity and can cause our sense of self to feel fragmented when shaped by both physical sensation and digital interpretations. For both Rose and me, during treatment there was a focus on transforming our bodies into quantifiable systems, which we experienced in tension with our own bodily sensations. My own attempts to reconcile personal sensations with medical realities echo in Rose's work, where fragments of natural and clinical imagery meet in collaged compositions, mirroring the fractured, hybrid identity that treatment has imposed. It can thus appear that the nature of photofantasy/collage enables us to imagine the unity of our hybrid (or cyborgian) parts as well as their persisting conflicts.

Baglia reflects that healthcare providers need to work on "the recognition of loss – or at least transformation" that their patients might undergo when they become "everyday cyborgs" (2013). This loss and transformation is in part what the method of photofantasy has begun to acknowledge and represent in expansive and nuanced ways. Through the process of producing my own collage, I explored how my hybrid identity as a cancer patient was shaped by a blend of

personal, medical and symbolic imagery. This method of art-making allowed me to visually reclaim the fragmented aspects of my identity: the lived sensations of my physical body, the clinical data representing my medical condition and the cultural metaphors that resonate with my experience of illness. This led me to draw on cyborg theory, positioning my cancerous body as a hybrid entity – part organic, part digital – that navigates complex, often conflicting realms of self-perception and medical interpretation. Where the cyborg metaphor aptly captures the partial and sometimes uncomfortable unity of the different aspects of illness identity, photofantasy has become a medium for acknowledging this and expressing these disparate parts in a cohesive visual narrative.

Instability and going beyond bodily boundaries

The nature of treatments for cancer can be inherently destructive and traumatic, as Sasha, Rose, Spence and I all explored in our photofantasy collages. Treatment can result in the destruction and fragmentation of the body, as well as the repair and reunification of its parts. Where both patchwork and the cyborg have become metaphors for exploring these processes, they have also visualised how drastically treatment can alter the body. Living through such regular changes can create a sense of bodily instability, profoundly impacting one's sense of self.

Figure 5.7, Fairy's Workshop Artwork

In one of the participant workshops, Fairy captured how her body had been altered by treatment - picturing herself as a slab of meat on a skewer. In Figure 5.7, Fairy reimagines various aspects of her experience of cancer patienthood. When explaining her work, she said that first she chose the image of the person next to a bath full of water, "mainly because I don't know how hot that water is... I don't know, I have no idea what I'm getting myself into." She then noted that the clocks were representative of the time that she felt

was taken away from her following her diagnosis and the snowdrops represented the spring of her youth that was lost. The secateurs were chosen because of the parts of her that were cut away and the vein with blood cells represented the internal body that Fairy felt unable to control. However, the focal image of a large slab of meat was chosen because Fairy described feeling “very much like an experiment” throughout her treatment for Hodgkins Lymphoma. Fairy’s depiction of a slab of meat as a representation of her altered body demonstrates the drastic physical changes she experienced as a result of her treatment. Where the meat is stripped of skin and form it can appear to be rendered anonymous. This hints at ideas of depersonalisation and the loss of bodily identity. The use of this imagery thus redefines the boundaries of Fairy’s body, making it appear malleable and formless, almost like clay that is ready to be reshaped. In this depiction, the meat can be seen to reflect the notion of a passive body, something to be manipulated by medical intervention or a blank canvas for experimentation. However, this experimentation presented profound horror and uncertainty, as Fairy recalled her disorientation at the time, stating she “didn’t know what they were doing with [her]”. The representation of her body as a piece of meat also conveys a sense of violence and trauma. The spikes protruding from the meat suggest the invasive procedures inflicted upon her body, while its raw redness hints at physical injury. The instability of Fairy’s body, subject to continual reshaping and reforming, is therefore experienced and represented as a deeply violent and traumatic process.

Figure 5.7 can also be seen to evoke a sense of horror around the destruction of bodily boundaries. Sara Damiani highlights how the disruption of bodily boundaries draws on the nineteenth century culture of Gothic body horror, whereby the body is “constantly threatened by the terror of being infested by unknown and dangerous elements capable of invalidating its structural equilibrium" and that this is "even more so" apparent "when it is manipulated, fragmented, and reassembled by scientific activities which, though aimed at preserving the body, end up undermining its supposed unity" (Damiani in Leonzio et al. 2015, 256). She gives examples of "embryonic experimentation, genetic mutation research, animal cell cultivations, artificial prosthesis engineering” (Damiani in Leonzio et al. 2015, 256). However, this can equally be applied to treatments for cancer. The nature of chemotherapy results in the destruction and regrowth of misbehaving cells as well as, in my case, blood transfusions and bone marrow harvests. Where one might not experience themselves as fragmented and reassembled in the sense of gaining an organ to replace a failing one, like Damiani goes on to explore, they do instead repeatedly experience the destruction and re-growth of entire networks of cells. Fairy’s collage thus appears to reveal the culmination of several fears around

procedures which “invalidate” the “structural equilibrium” of the body. This is captured in the symbol that Fairy chose for herself, the slab of meat, which acknowledges both the destruction of bodily boundaries and the dehumanisation or dissolution of self that fairy has experienced, through both its shape and its anonymity.

Figure 5.8, Opal’s Workshop Artwork

The instability of the cancerous body has not only been explored for its violence and horror, as can be seen in a collage made by Opal. The creation of Figure 5.8 began with Opal showing me a bag of hair that she had kept after losing it as a side effect of chemotherapy. Before our session had begun, Opal had already envisaged attaching this hair to a bald head. So, once she had introduced me to the hair, she proceeded to print a photograph of a woman wearing a headscarf and affixed the hair to it. The loss of hair, as well as sometimes nails, during chemotherapy are two of the tangible ways that the body can be seen to become unstable or lose its visible boundaries. By reattaching her hair in the collage, Opal symbolically restructured these boundaries, reclaiming what had been lost. Not only has Opal reattached her own hair, but she has given purpose to having lost it in the first place by reattaching it to someone without. In the workshop, Opal shared with me another instance of finding meaning in her hair loss: when in treatment, she gifted a pigtail made from her hair to a hospital porter who admired the “beautiful pigtail” of a younger colleague. It appears that by finding humour and connection in the loss of her hair, Opal was able to reclaim the loss of bodily boundaries that she had experienced. Among my participants, Opal had gone the longest without receiving active treatment, so it was perhaps this distance, at least in part, that allowed for such a playful reflection. It is thus interesting to note that the loss of bodily boundaries, which was recollected as deeply negative for Fairy, can also afford an opportunity for the reclamation and reimagination of the self.

Hair loss, however, occupies a unique space in cancer patienthood, where it can operate as both a signifier of distance from one’s ‘healthy’ self as well as an acknowledgement of one’s

new illness identity. Jane E Shultz's article, "(Un)body Double: A Rhapsody on Hairless Identity" (2009), explores her own experience of hair loss during treatment and the implications that this had upon her sense of self. Schultz recalls preparing for her hair loss by having a haircut, an interaction that she refers to as a "surgery". Similarly to Opal, Schultz then recalls repurposing her hair loss, writing that: "within twenty minutes [of the haircut], my sixteen-inch ponytail is in a Zip-Loc bag ready to make its journey to Locks of Love. If I cannot keep this hair, at least somebody else can have it." With her newly short haircut, Schultz then waited for chemotherapy to make the rest of her hair fall out. However, this reality did not happen as quickly as she had been warned it might, rather Schultz is left for days wondering if she had defied the chemotherapy odds and would retain her hair. Although momentarily pleased by the hope that she might keep her hair, Schultz also reflects on the difficulty that this experience caused her, writing: "until I lose my hair, I inhabit a liminal space: without the credentials to claim kinship with other chemo sufferers and with no inclination to pass as healthy". It is interesting to consider that while hair loss is a bodily boundary that is often crossed when one is treated for cancer, it can also be a boundary that, when crossed, signifies the beginning of treatment. Without the acknowledgement of this beginning, for Schultz her "full head of hair" led to feeling "like an impostor". The significance of crossing certain boundaries can therefore appear to construct identity as well as disrupt it.

It is not only treatment that can cause such reflections on bodily integrity. For, unlike Fairy and Opal, Helena explored the disruption of bodily boundaries in relation to the threat her cancer posed, rather than the effects of her treatment. This is evident in one of Helena's works. In Figure 5.9, Helena imagines "a representation of [her] cancer", picturing her torso and the various parts of her cancer that it contained. The small blue flowers are imagined as the non-invasive implants (otherwise known as nonaggressive tumours) that spread from Helena's ovaries. Sprouting from these is a green stem, representing the neck, where the implants ended. Sitting at the base of these flowers are Helena's ovaries, imagined as two

Figure 5.9, Helena's Workshop Artwork

half-full cups, tipped on their side, about to spill out into the rest of her body. They appear full of a sickly-green coloured liquid, reminiscent of slime or bile. One of them also contains an ominous grey/black shadow, signalling the unknown danger of the cancer within. The cups being tipped on their sides, about to spill into the rest of the body, came from something the doctors had said to Helena - "they told me to be careful until the surgery [to remove a tumour], not to go on public transport because if [my tumour] broke then there would have been nothing else to do really". The cups ready to spill signify the precarity that Helena lived with in the lead up to her surgery. The juxtaposition of delicate flowers with the "green… slimy" liquid that Helena described, coupled with the looming threat of spillage and contamination, underscores the fear of one part of her body harming or corrupting another. This leads to ideas of toxicity and contamination around the risk of Helena's cancer spreading which assigns the cancerous parts of Helena's body as dangerous or monstrous.

The monstrosity in Helena's collage appears to derive from one of the same central themes that Margrit Shildrick explores in her book *Embodying the Monster : Encounters with the Vulnerable Self* (2002). Shildrick identifies that "transhistorical horror and fascination with the monstrous" centres partially on the "disruption of the corporeal limits that supposedly mark out the human" (37). For Helena, her "corporeal limits" are disrupted by the cancer that threatens to spill out but also through the "bloating" that she described having had, which had been caused by a tumour the size of an orange in her ovaries. For Helena, at the time of her diagnosis, this bloating was not something of concern. She had initially assumed that it was a result of having eaten a lot of food over Christmas. However, this very specific transgression of bodily boundaries, where the lower belly begins to protrude, draws an interesting connotation with the second central theme that Shildrick identifies in the cultural fascination with monstrosity: that of the origin of monsters, specifically in relation to pregnancy.

Although Helena did not explicitly connect cancer and pregnancy during our workshop, we had an in-depth discussion about the conversations she had engaged in and the decisions she had made concerning her fertility in the context of her treatment. Helena recounted that her doctors had prioritised preserving as much of her ovarian tissue as possible to protect her fertility, even though this posed risks to her health. She explained having had to "fight a bit with the doctors to have the surgery" to remove her ovaries. Despite the significant risk that "any piece of ovary left" could lead to a high chance of the cancer returning, her doctors were strongly motivated by the prospect of preserving her ability to become a mother. This tension over fertility and motherhood was central to the themes Helena explored during our session, particularly her

rejection of the motherhood her doctors had envisioned for her. This theme emerged as early as her first artwork, which depicts a pregnant belly with a question mark above it. The pregnant belly symbolised the impossibility of pregnancy for Helena following her surgeries, while the question mark represented the shape of a scar she has that runs from her bellybutton to her pelvis. In her final collage, Helena portrayed Prince William, Princess Kate[19] and their family to represent the "kind of perfect family" her doctors had imagined for her – a vision of life she did not share or desire.

Figure 5.9 can therefore be interpreted as a reimagination of pregnancy and birth, with monstrous outcomes. Rather than focussing on the future that doctors had pictured for her, Helena made a direct connection between the toxicity and threat posed by her ovaries. Instead of nurturing a human foetus, the ovaries are depicted as the site of a "demonic pregnancy", where one is "pregnant with his own death" (Sontag 1983, 14). This perspective aligns with Helena's description of feeling that "the ovaries became synonymous with cancer" during her diagnosis and treatment. Shildrick highlights the association between the pregnant body and monstrosity, observing that: "the pregnant body is not one vulnerable to external threat, but actively and visibly deformed from within. Women are out of control, uncontained, unpredictable, leaky: they are, in short, monstrous" (2002, 39). It is precisely these qualities that Helena appears to emphasise in her own collage. The unpredictability of her body is captured in the ominous black shadow lurking in one of the cups, while the out of control, leaky aspect rests in the green liquid that threatens to spill forth. The monstrous aspects of pregnancy and birth are thus highlighted in Helena's collage to illustrate the danger and threat that her cancer posed. Where the body was once "closed, smooth and intact", it now looks "as if it may tear apart, open out, reveal its innermost depths" (Creed 1993, 58)[20]. This depiction can be interpreted as a retort to her doctors, who had vehemently advocated for retaining her ovarian tissue, emphasising the potential for future fertility. By visualising how violently cancer threatened to disrupt her bodily boundaries, Helena's artwork serves as a stark warning of the consequences of prioritising theoretical futures over immediate threats to her health. The collage not only challenges traditional notions of the maternal body but also critiques the medical framework that often prioritises fertility over a patient's broader well-being. Through her

[19] This image was made in 2022, before there was any public discussion of Princess Kate receiving preventative cancer treatment or care.
[20] This is a description used by Barbara Creed to highlight the monstrous aspects of the pregnant body.

representation, Helena asserts control over her narrative, embracing her bodily instability and rejecting the idealised motherhood imposed by her doctors.

Where both cancer and its treatments have led to the disruption of bodily boundaries for my participants, they have simultaneously exposed the profound instability of the body and the shifting nature of self-perception. From the violent realities of living in a body subjected to experimental treatments, to the emergence of new identities revealed through hair loss, to the visceral expression of the cancerous body's perceived monstrosity, photofantasy has provided a lens through which people who have experienced cancer can explore and reconcile the altered embodiments caused by a loss of bodily boundaries.

Conclusion

As Shildrick observes, "biomedicine in general, and surgery in particular, rely on the notion that the body can be remoulded either without consequences to the embodied subject, or at least in the case of some aesthetic procedures, with only controlled consequences... Whether that takes the form of drug regimes, radiotherapy, the setting of bones, or cutting the flesh, the clinical care of the body frequently entails what in other circumstances would constitute the legal category of battery, and yet we implicitly contract and explicitly consent to such assault in the provisional and convenient artifice that our corporeality has no bearing on our selves" (2008). This perspective reveals a fundamental tension in the biomedical approach: it separates the body from the self, treating corporeality as a malleable and detached entity subject to intervention. However, as Shildrick highlights, this assumption falters when we recognise that "we do live through our bodies and not just in them". The collages examined in this chapter underscore this inseparability, demonstrating that our embodied experiences are intrinsic to our sense of self and identity, challenging the reductionist tendencies of Western medical paradigms.

Building on this critique of the biomedical notion that "the body can be remoulded without consequence", the works of Rose, Sasha and Spence clearly demonstrate that such an assumption is deeply flawed. They evoke the metaphor of patchwork to capture both the trauma endured by the body as well as its persisting memory. This mirrors the Japanese art of kintsugi, which exists as a repair method in stark contrast with other, modern Western modes of repair critiqued for seeking to return something to its previous condition. In emphasising the fractured or fragmented body, Rose, Sasha and Spence represent the trauma inflicted upon cancerous

bodies that is so often denied or overlooked by biomedicine. This analysis also gives new meaning to Spence's works that use overlayed paving stones and peeling wallpaper, to create the effect of decay. Instead of merely being read as works that capture the deterioration of Spence's leukaemic body, they can be seen to reflect the fractured identity that persists within cancer patienthood, reclaiming the various medical interventions and surgical cuts her body has endured.

It became evident that it was not solely medical interventions that disrupted one's sense of embodiment; machines and technology also played a significant role, profoundly shaping and often complicating how individuals perceived themselves. In one of my own collages, I explored the uneasy fusion of technoscience and the body, highlighting how medical imaging, by reimagining the body in a digitised form, creates an entirely new representation that we attempt to reconcile with our sense of self. This built on Baglia's reflections on the cyborgian experience of being a cancer patient, where the metaphor of the cyborg extends beyond digital appendages to encompass the impact of medical scans and recorded data. These technological interventions often generate conflicting identities, as the sensations of the body may not align with the clinical statistics that define it. Theoretically, I have also contributed towards shifting the concept of the cyborg from Haraway's metaphorical interpretation to one more grounded in the lived experiences of individuals with illness and disability, who depend on machines and medical technology for survival.

By acknowledging the different ways that the cancerous body is reimagined, I have highlighted how living with the bodily instability caused by cancer and its treatments has led to diverse outcomes for embodiment and selfhood. Not only has the body been experienced as depersonalised and vulnerable, but the loss of identity markers like hair have been transformed into an opportunity for meaning-making. Perhaps even more compellingly, Helena reinterpreted the loss of bodily boundaries, revealing their monstrous dimensions to critique the prioritisation of reproductive futures over the immediate health struggles faced by individuals. Across the works of Fairy, Opal and Helena, the disruption of bodily boundaries reiterated both the impossibility of restoration and the resistance to returning, in body or in spirit, to a prior state. This resonates with Eve Kosofsky Sedgwick's post-mastectomy reflections on identity, where she observes, "if I can fit the pieces of this self back together at all, I don't want them to be the way they were" (1998).

Recognising this resistance, as well as the varying forms of embodiment experienced by individuals with cancer, and how these forms shift and evolve with the ebbs and flows of the

disease, is crucial. This acknowledgment not only deepens our understanding of the illness but also provides a further way to bear witness to and honour the diverse testimonies of people's experiences with cancer. I have explored only a small fraction of the many dimensions of embodiment that cancer and its treatments can evoke, leaving countless others yet to be heard, imagined, or understood. Unlike the reductive universalising approach of the biomedical model, there is a pressing need for nuance in examining the lived experiences of illness and disease—a nuance that is notably absent in previous responses to Spence's *The Final Project* (1991–1992) and that continues to be overlooked in many clinical discussions of cancer healthcare and treatment. This chapter, as with this thesis on a whole, serves to encourage a broader and more empathetic dialogue, one that values complexity, individuality, and the multifaceted realities of living with illness.

Conclusion

In this thesis, I have explored the ways in which photofantasy as an artistic practice provides a unique means for expressing the lived experience of cancer. My research engaged with Jo Spence's *The Final Project,* a body of work created while the artist had leukaemia. In addition to analysing Spence's use of photofantasy within this research, I conducted a series of photofantasy-inspired workshops with five participants, who had all previously been diagnosed with cancer. These one-to-one workshops, conducted between myself as researcher and each participant, involved individual art-making around our experiences of cancer, followed by reflective discussions on imagery, themes and personal experience. I took part alongside my participants within the artmaking workshops, actively engaging with the practice of photofantasy. I then analysed the artworks produced within the workshops alongside Spence's work to explore how the practice of photofantasy had supported the expression of cancer experience within both. Prior to beginning the artmaking sessions, I felt that photofantasy as a practice was uniquely suited to exploring cancer experience, particularly because its very development was shaped by the constraints of Spence's leukaemia. Photofantasy arose from Spence's desire to create art despite the physical limitations imposed by her illness. It allowed her to work with existing photographic material, circumventing the need for travel or strenuous activity, and enabled a fantastical reimagination of reality. For these reasons, I felt that photofantasy could be especially useful when explored by others facing similar challenges due to illness. What my study has revealed is a number of distinctive ways in which photofantasy has allowed my participants to express their experiences of cancer.

In Chapter 2, I introduced how, through its use of layered images, *The Final Project* brings to light some of the often overlooked aspects of leukaemia experience. Within the framework of my own experiences of cancer, I examined how Spence introduced the metaphor of the zombie as a figure of endurance during chronic/terminal illness. I also analysed how the artist reclaimed the aesthetics of medical imaging to explore ideas of agency in relation to the medical encounter and medical imaging software. This analysis explored both published and previously unseen materials side by side. Through this exploration, I established a foundation for further discussions of Spence's work alongside the works of my participants. By introducing the ways in which Spence's works evoke cancer experience, I sought to build upon this analysis through the subsequent study of participants' artworks.

This led me to explore, in Chapter 3, how specifically the cutting aspect of photofantasy supported the expression of illness experience. I wanted to highlight how the physical aspects of the method could be perceived as a tool of empowerment. In this analysis, I drew on similarities between the practice of photofantasy and that of photomontage, based on their process of dissecting and reassembling images. From this practice, both Spence and my participants demonstrated how cutting can serve as an act of defiance against medical authority, as well as a way of re-enacting and processing difficult experiences. By framing photofantasy as a form of metaphorical surgery, I explored how it offers a way to reclaim agency, shifting power dynamics that are traditionally dictated by the medical establishment. At the same time, I explored how photofantasy was used to highlight the violence inherent in surgical action, as well as the impact of failing to acknowledge this violence. By providing participants with the tools to symbolically cut and reconfigure their bodies in artistic form, the practice enabled them to acknowledge the harm of these interventions, even when performed for the purpose of healing.

Further to this, I considered, in Chapter 4, how both my participants and Spence used photofantasy to reflect on their experiences of time while living with cancer. Within this analysis, I proposed the concept of "Cancer Time" as a category of Crip Time. This idea developed from both my participants and Spence's expressions of time as disrupted or ruptured when experiencing cancer. Often this involved cycles of waiting and periods of uncertainty. I revealed how the liquid metaphors, which were a repeated occurrence in the photofantasy works, often attested to notions of suspense, stagnation and liminality. Leading on from this, I explored how the ghost became a figure for representing embodiment in moments of waiting, reflecting the sense of living in a kind of medical purgatory. However, I also challenged the perception of waiting as purely stagnation. Building on Abi Palmer's notion of Mushroom Time, I argued for the generative potential of periods of rest, stillness and wait, which are often intrinsic to life with chronic or critical illness. The mushroom or fungus became a key metaphor for this, symbolising the hidden work and growth taking place during periods of stillness, as well as the unexpected emergence of periods of visible growth and sprouting. Through this lens, I demonstrated how photofantasy not only captures the disorienting temporalities of illness but also reveals moments of quiet resilience and unexpected renewal.

From how the experience of cancer can reshape one's experience of time, I went on to outline, in Chapter 5, several of the ways in which cancer can also reshape one's perception and experience of one's own body. By exploring the body as a hybrid of parts, I argued that both

Spence and my workshop participants sought to capture the fragmented identities that are intrinsic to cancer patienthood. Whether a result of surgical cuts, the use of machines or merely bodily deterioration, I highlighted how the experience of the body can shift when experiencing cancer. Photofantasy, with its composite nature, is particularly well suited to expressing this fragmentation. By collaging images together, the pieces created were naturally fragmented. What emerged from this was a challenge to the biomedical model of disease, which often overlooks the psychological and emotional impact of physical alterations on self-perception. Through the act of reconstructing the fragmented body within their collages, both Spence and my participants were able to acknowledge the lasting effects of bodily trauma as well as to bear witness to these experiences that might otherwise remain unrecognised within the clinical encounter.

Contributions in Meaning and Expression

One of the key contributions of this project was the development of a unique participatory arts workshop for people who have experienced cancer. As well as the suitability of the method of photofantasy to the physical constraints of the disease, this workshop provided critical insight into personal experiences of cancer. These experiences have been applied within this study to enrich existing scholarship in a number of ways. A primary contribution has been to scholarship on Spence's *The Final Project*, offering a more nuanced understanding of how her work illustrates illness experience. By incorporating participants' artworks and discussions, this study has not only expanded critical discourse on Spence's work but also demonstrated how Spence's methods continue to resonate with contemporary experiences of illness. Beyond its contribution to Spence scholarship, this project has also helped to develop a new visual language for articulating the complexities of cancer. Through photofantasy, participants were able to express aspects of their experiences that may have been difficult or impossible to capture through conventional verbal narratives. This process has led to the generation of new conceptual frameworks, such as Cancer Time, which explores the nonlinear, suspended, or distorted temporalities experienced during illness, and hybridity as a way of understanding the fragmented yet reconstructed nature of the post-treatment body. These frameworks not only enhance academic discussions of illness and embodiment but also offer new ways for people to conceptualise and communicate their lived experiences.

In addition to exploring the method of photofantasy as a tool for expressing cancer experience, I have reframed the critical reception of *The Final Project* as a body of work. In the years since its conception, *The Final Project* has been critically engaged with as an exploration of Spence's approaching death. It has been considered a "confrontation of mortality" (Epps in Lee 2013, 79) whereby Spence is "teaching herself a dialectical mode of dying" (Boyer 2016). These interpretations were at odds with what I perceived when viewing *The Final Project* for the first time. As well as seeing Spence's exploration of her terminal illness, I saw various expressions of cancer that resonated with my personal experience of leukaemia. From what I perceived as a significant misinterpretation of Spence's work, I have developed a new analysis throughout this thesis that challenges the prevailing reception. As such, a key contribution of this study is its expansion of the critical framework surrounding *The Final Project*, offering a broader understanding of how it engages with Spence's experience of cancer.

Further to this, my study has contributed to scholarship on Spence through the introduction of new archival research and the discussion of previously unpublished works by the artist. When accessing the various archives that hold Spence's work, I came across pieces from *The Final Project* that had not only remained largely unseen but had also never been critically analysed. One of the most significant discoveries was the variation among several works depicting Spence reclined in a pool, each set against a distinctly different background. By closely examining these variations, I was able to challenge existing understandings of *The Final Project*. Instead, my analysis situates these images within a broader and more complex exploration of illness, embodiment and transformation.

Similarly, my positionality in this research provided unique insight into Spence's works from a perspective that has not been previously explored. While some academic research might strive for objectivity, my approach embraced a Feminist Standpoint Epistemology. Thus, rather than attempting to hide the influence my personal perspective had on the research, my autotheoretical approach has actively engaged with it, making visible when and how my own experiences were shaping meaning-making throughout the study. Further to this, my personal experience with illness served as a valuable tool for engaging with Spence's work from the unique perspective of my lived experience, providing an embodied rather than a detached observation. My experience with cancer allowed me to approach *The Final Project* not just as an academic but as someone who has navigated similar terrain. This perspective also enabled me to explore a visual language of illness in ways that might not have been available from a more objective standpoint. In addition to this, my experience with cancer played a crucial role in how I

was able to conduct the participatory workshops. As my methodology was inspired by Participatory Action Research, I intended to work towards creating a collaborative rather than hierarchical research environment. This was made even more possible based on the fact that I was not merely an observer or outsider to my participants but rather fell into the same demographic as those eligible for my study and participated alongside them. I believe that this led to a greater level of trust and openness in our workshops as well as more authentic expressions of illness experience.

The Future of this Research: Therapeutic Potential?

This thesis demonstrates the vast potential of Spence's work and of her method of photofantasy in expressing the experiences of illness. It also highlights the uniqueness of visual languages in communicating that which cannot be expressed through words, giving further weight to calls from theorists like Susan E. Bell who argue that images are not just beneficial but *necessary* to understanding experiences of illness (Bell 2013, 143). I have highlighted how photofantasy allowed both Spence and my participants to move away from or reframe clinical languages, altering uneven power dynamics and restoring their own senses of agency. As well as demonstrating the necessity for practices like this to support the reclamation of agency, this study has demonstrated precisely how photofantasy accomplishes this transformation.

Thinking towards the future of this study, it feels important to note the personal impact that the artmaking had on my participants. Where I have analysed the representations of cancer experience that were expressed in the workshop artworks, there is an additional dimension to photofantasy that I would like to touch on briefly. As addressed in my methodology, two weeks after each of the workshop sessions were held, I asked my participants to fill in a brief questionnaire on their experiences. These questionnaires provided space for participants to write down their thoughts in relation to the following:

- How did you find the collage based method? (e.g. Were there parts that were challenging? Would you look to try it again?)
- Was there anything that came up in the session that you have since thought about more deeply?
- Is there anything that you have taken away from this session that has been particularly resonant?

- Please share your general feelings on the collaborative art making session…
- Please share your feelings towards the artworks that you produced during this session…

From my participants' answers to these questions, I feel it's important to address how the practice of photofantasy, in addition to affording a new language for experiences of cancer, was also found to be a powerful tool for recollecting and processing these experiences. I believe that this opens up future avenues for collaboration with healthcare professionals and art therapists into the application of photofantasy in clinical settings. By highlighting each of the participant's personal reflections on the practice, taken from their follow-up questionnaires, I hope to draw attention to the exciting opportunity that future research into the therapeutic benefit of the practice of photofantasy could offer.

My first participant, Helena, expressed that although she had not attempted collage since primary school and initially felt she lacked creativity, she did not feel restricted when trying out the practice. Rather she noted "this collage-based method is very well-suited to explore topics such as cancer because it gave me the opportunity to reflect on something deeply personal, whilst at the same time adding a touch of humour – or allowing me to use humour and metaphors… to discuss upsetting and unsettling aspects of my illness". In addition to being able to inject humour into the artistic practice, Helena also reflected on how, within her work, she used "a limited number of images" yet still managed to create "nuanced" pieces. She wrote that "in each of these images I can see the nuances of my experience and the nuances of feelings and emotions that I experienced as I went through surgeries and recovery stages". It can thus appear that for Helena, the practice of photofantasy proved to be an effective means of expression, allowing her to develop a lot of meaning through minimal imagery. Not only did the ability to integrate humour into recollections aid with the processing of these memories but the visual medium allowed her to reference complex experiences with nuance, even when working with simple imagery.

My second participant, Sasha, similarly noted how she had not tried a collage-based practice since school. Although she noted a preference for more time to explore the method, she was immediately struck by the images she found, writing that "their symbolism was immediately apparent". She reflected that this process allowed her to recognise "what the imagery meant to me and what it was saying". Sasha described how the practice gave her a retrospective view of her experience of cancer, allowing her to divide it into "distinct parts". This in turn allowed her to reflect upon how she's changed throughout the different stages of her illness. She noted that "when you're going through a debilitating disease/condition you're caught up in it – but this

exercise allowed me to consider it in total in all its progression". While I theorised that this practice could support people currently experiencing cancer, Sasha's insights suggest that photofantasy is also valuable as a tool for retrospective reflection. In her case, this reflection occurred twenty-two months post-diagnosis, offering a way to unite and make sense of her journey. Part of this retrospective view involved Sasha reflecting on the "awful" parts of her experience. As I previously discussed in Chapters 3 and 5, photofantasy provides several tools that allow for the exploration of challenging experiences. Furthermore, Sasha noted that she felt the artworks expressed her experiences of cancer both "consciously and subconsciously" attesting to the capacity for photofantasy to address otherwise unavailable aspects of our feelings towards cancer.

Rose, my third participant, did highlight that she initially found beginning the workshop "a bit of a challenge", noting that "it was good that Lizzie also created her own collage" as it "made it easier and less daunting". However, this apprehension did not appear to limit the therapeutic potential of the practice. For, when reflecting on her completed artworks, Rose wrote that she felt "quite proud" and even discussed how she took them home and used them to open a discussion with her daughters about how they were affected during her treatment. This highlights an unexpected outcome of the workshop where the artworks became tools outside of the workshop for processing thoughts and feelings about treatment. Rather than being static creations, they became artefacts that facilitated deeper conversations about family, illness and emotional processing, demonstrating the lasting impact of photofantasy beyond the immediate act of artmaking.

For Opal, my fourth participant, her reflections differed significantly from those of the others. As an artist, Opal had made work throughout both of her experiences of cancer. Some of this work even involved similar methods to photofantasy, so, unlike my other participants, this was not Opal's first introduction to using these practices. This meant that the artmaking was not necessarily the most striking aspect of the photofantasy workshop for her. Instead, what appeared to have the greatest impact on Opal was the opportunity for dialogue and shared reflection. In response to the questionnaire prompt, "Is there anything that you have taken away from the session that has been particularly resonant?" she wrote: "Lizzie's experience of cancer resonates with me – even as a child she seemed to have more important things in her life to be getting on with – school work – having fun etc." This response, suggests that Opal found a sense of connection in hearing about my experience, perhaps also seeing parallels with her own. Beyond this written reflection, the depth of Opal's engagement with the workshop was also

evident in the way that that our conversation continued well beyond the formal session. Her eagerness to continue discussing themes explored in the workshop suggests that the act of verbally sharing her experiences was deeply therapeutic also.

Fairy, my fifth participant, reflected that she was "pleasantly surprised by how easy it was just to get stuck in and it flowed very easily. I didn't find anything challenging". Although, she felt that everything to do with her treatment was "all firmly behind [her]", the workshop revealed that there might have been "some areas which weren't". From this she reflected that the workshop allowed her to feel "more at ease" with these areas, suggesting that the process facilitated a deeper sense of closure. Fairy also noted that she enjoyed the method itself and "hadn't realised how striking some images could be once done like that". In addition to recognising how evocative certain images became through photofantasy, Fairy described how "how good it made [her] feel to show [her] history with cancer". She reflected that when looking at her works retrospectively, they revealed her "complete journey from the start until the end". Similarly to Sasha and Rose, Fairy highlighted the value of participating alongside the researcher, describing it as "great" because it allowed her to "talk about it at the same time". This reinforces the importance of the discursive element of the workshop, demonstrating how both the act of creating photofantasy works as well as the dialogue surrounding them can contribute towards a meaningful exploration of cancer experience.

Ultimately, these workshop questionnaires cannot provide a conclusive nor comprehensive account of how my participants truly experienced the workshops in the moment they were taking place. But they have provided an interesting reflection on engagements with the practice of photofantasy. For some participants, such as Sasha and Fairy, the practice offered a retrospective perspective, helping them see their journeys as a whole and uncover aspects of their experiences that had previously gone unexamined. For others, such as Helena and Rose, the method provided a tool for considering difficult aspects of their illnesses. In contrast, Opal, an artist with prior experience of using similar artistic methods, found the discursive aspect of the practice more impactful.

Where this study has focussed on the expressions of illness that arise from engagement with the practice of photofantasy, these questionnaire responses also highlight the broad scope for considering its therapeutic benefits. The overwhelmingly positive feedback from my participants highlights that there is clear potential to expand this work further, particularly in exploring how photofantasy can be integrated into therapeutic and medical contexts to support individuals facing illness. Throughout her career, Spence used art as a means of self-exploration

and emotional processing, developing phototherapy as a way to engage with her complex personal history. Photofantasy evolved directly from this approach, reinforcing the inherently therapeutic nature of her practice. Given this foundation, further research on the practice of photofantasy as a therapeutic tool could provide valuable insights into its potential applications in healthcare and wellbeing contexts. In addition to publishing findings regarding the therapeutic benefit of the practice, there is also significant scope to develop a resource guide for individuals or organisations interested in taking the method further.

Outside of exploring the therapeutic benefits of the practice, there are several other avenues for further exploration that this project generates. One of the most exciting aspects when beginning this study was the abundance of available artistic material from *The Final Project* that has never before been critically explored. During an early conversation about this project, Richard Saltoun noted that hundreds of photographic slides exist from this body of work. Although not all of them were accessible for this thesis, the sheer volume suggests that *The Final Project* extends well beyond the scope of any single monograph. This wealth of material makes clear the need for continued exploration. Whether building on the research here or engaging with new avenues altogether, the breadth of *The Final Project* provides an exciting ground for future studies related to Spence's later works and the practice of photofantasy – whether in art historical analysis, medical humanities research, or participatory arts studies.

Moreover, I believe that there is further scope for applying photofantasy as a practice for people with cancer. As I was exploring this method with participants for the first time, I chose to restrict my study to people who were not receiving active treatment for their cancers. This ethical decision was made to minimise emotional risk to my participant group. This choice meant that my participants were either in remission or had chosen not to pursue treatment. Additionally, I considered the amount of time that had passed since my participants had been diagnosed with cancer, ensuring that no participant had been diagnosed too recently. The most recent diagnosis among participants was twenty-two months prior to our workshop taking place, while the others were at least several years post-diagnosis. This precaution was taken to further mitigate potential distress. However, as highlighted in both the introduction and methodology chapters of this thesis, I believe that photofantasy is uniquely attuned to supporting people who are currently navigating a cancer diagnosis and the challenges of treatment. The theoretical framework I developed in this project does not distinguish between recent and past diagnoses, suggesting that photofantasy could provide meaningful support to those actively undergoing treatment. Thus, part of the future I envision for this project involves further research into the

application of photofantasy for people receiving treatment and an exploration of the realities of cancer patienthood that are not solely retrospective. Spence's method was created out of the artist's desire to continue creating art while living with the realities of leukaemia and I believe that this mode of engagement could benefit others who are finding expression or artistic engagement a challenge. Further research into its application for those receiving treatment could expand photofantasy's accessibility and deepen our understanding of its role in fostering agency and self-expression within medical contexts.

Further to this, within the clinical environment, I believe that photofantasy offers the potential to employ visual meaning-making in shaping our understanding of disability and illness representation. Traditional approaches to these topics in healthcare and policy have often prioritised medicalised perspectives, leading to the reduction of people to clinical cases. Photofantasy has demonstrated how visual methods can allow individuals to reclaim agency in environments that frequently marginalise or depersonalise them. This finding suggests that visual methodologies such as photofantasy could play a crucial role in advocacy efforts for people with cancer when developing healthcare policies based on the illness. By encouraging policymakers to engage with patient experience beyond written testimony or statistical data, the gap between lived experience and institutional decision making could be better bridged. Future research could thus consider how photofantasy might be used in consultation with healthcare providers and accessibility initiatives to influence systemic change.

A final thought

When I imagine the potential future scope of this project, I can't help but think back to myself at nine years old. I lost count of the number of times I heard, "it'll be ok", "it won't hurt for long" or "you'll feel better in the morning". Although many of these statements proved to be true, they taught me a very clear lesson – that my pain and my discomfort were not worth acknowledging, that they were just temporary hurdles on the path to healing. What photofantasy gave me was a space to challenge that idea, a place where I could recognise my pain, sit with my discomfort and create visible proof that it was once real. So much is done to our bodies in the name of healing, and yet so much of it is forgotten once treatment is complete, once the outcome is clear. Photofantasy, I believe, provides not just a space for witnessing the various discomforts we accept but also for memorialising them and acknowledging them as part of a broader understanding of what healing really entails. It still astonishes me that for nearly sixteen years, I had nothing to say about my experience of cancer beyond "I remember it really well". That, in

itself, is a testament to the incredible healthcare providers who softened every painful, unpleasant, and violent thing my body endured. But, in the process, I failed to recognise how remission had whitewashed over those experiences. This entire project has been a complete upheaval, a rethinking of the ways that we process treatment and medical care. While I don't believe that acknowledgement alone can soften the experiences of cancer, I do believe we gain a far deeper capacity for understanding and change when we lean into the potential of visual modes of communication. Researching photofantasy has been both an example of the open-ended potential of visual expression as well as a reminder that we'll discover far more if we learn to listen with our eyes as well as our ears.

Appendix 1: Exercise Prompts

- Find a substitute self in the materials as a starting point, this self can be you now or you at any point following your diagnosis, begin adding to and collaging around this self.

- Using either an image of yourself or a substitute image for yourself, identify your cancer using the collage materials.

- Thinking of a moment during your experience of cancer, create a fantastical representation of this time.

- What happened to the internal/external body when you were diagnosed with cancer?

- Try to express, using images, how you visualised your cancer.

- Working from a medical image, begin to map the rest of your body from found materials.

- Re-imagine one of your images using the found materials.

Appendix 2: Participant Information Sheet

My name is Lizzie Merrill, and I am a doctoral research student at the Centre for Women's Studies at the University of York.

PhD Research Project Title: How can Jo Spence's creative practice in 'The Final Project' be applied to help re-evaluate patient perception of self?

Participant Information Sheet

You are being invited to take part in a research study looking at how the artist, Jo Spence's creative practice in her project, 'The Final Project', can be applied as an arts intervention for people who have been diagnosed with cancer. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of this study is to explore the potential usefulness of Jo Spence's artistic methods in 'The Final Project' for those who have experienced a cancer diagnosis. By practicing Spence's collage-based method with participants, in a participatory art-making session, I will test the efficacy of Spence's practice as a potential arts intervention. The intention behind this is to consider alternative ways to support the wellbeing of people who have been diagnosed with cancer, through the arts.

Why is the study being done?

In 1991, Jo Spence's methods of art-making in 'The Final Project' changed significantly to suit the new demands of her leukaemia diagnosis. Spence utilised what was available to her as a seriously ill person to continue making work about her thoughts and desires. She used family photographs, portrait photographs, medical images (from X-ray, ultrasound, MRI, etc.) and various found materials like newspaper and magazine clippings. From these, Spence created collages that represented "the kind of photographs she would have taken if she had been well enough to do so" (Boyer 2019). It is my belief that Spence's practice can be used by those who have been diagnosed with cancer to explore their thoughts, feelings and desires with regard to their experience. The information and the images produced for medical records, during cancer diagnoses, are rarely used in a playful or exploratory way by the patients to whom they belong. Spence's practice of collage challenged this by putting the medical image (from X-ray, ultrasound, MRI, etc.) back into the hands of the patient/artist. It

also allowed Spence to manipulate her medical images through collage to create something that better reflected how she perceived herself. This study aims to set out a framework for employing Jo Spence's creative methods as an arts intervention and to test its potential benefits and limitations.

Why have I been chosen?

You have been considered for the study because you have had a diagnosis of cancer and may have accessed the support services of Paul's. If you have not sought the support of Paul's before, they are a charity who is aware of the project and would be happy to offer support to those taking part. It is preferred that participants who take part in the study have access to support services should they feel they need them and by partnering with the organisation Paul's, that offers such services, I hope to better protect the wellbeing of participants. In addition to this, participants will be provided with a list of alternative, specialised support services if they choose to take part in the study.
About 5-10 participants will be recruited for the study.

What will the study consist of?

If you decide to take part in the study, it will be conducted in two parts, on a one-to-one basis with the researcher. Part one will consist of a 2-hour collaborative art-making session, facilitated by the researcher. There will be a number of breaks throughout the session and the opportunity to take additional breaks wherever necessary. Both you and the researcher will make art following Jo Spence's methods of collaging and discuss the thoughts and ideas behind your work throughout the art-making process. The researcher will bring materials to use in the session and it is up to participants whether they would like to bring additional materials. If participants wish, they can volunteer to bring personal photographs, medical images or medical records to the session to inspire the art-making process. However, this is not a requirement for taking part.

The session will be structured as follows:

Introduction to Spence's 'The Final Project' - 10 mins (10 min)
5 minute work (15 min)
5 minute reflection (20 min)
5 minute work (25 min)
5 minute reflection (30 min)
5 minute break (35 min)
15 minute work (50 min)
5 minute reflection (55 min)
5 minute break (1h)
30 minute work (1h 30)

30 minute buffer for additional breaks (2h)

Two weeks following the art-making session, participants will be asked to complete a survey online to express their retrospective feelings towards the collaborative art-making session. This will be part two of the study.

The researcher will schedule for the art-making session to take place in a public workspace, local to the participant. If necessary for the wellbeing of the participant, the researcher can facilitate workshops in participants' homes.

Do I have to take part?

It is up to you to decide whether or not to take part. You do not have to take part, but your participation in the study is greatly appreciated.

The study encourages its participants to only discuss elements of their diagnosis and cancer experience that they feel comfortable doing so. Therefore, any discussions had as part of this study will be guided by topics that participants desire to explore.

You will not have to talk about anything you do not want to. There will be several planned breaks throughout the session (please refer to the timetable below), and participants can take a break from art-making and discussion at any time they would like. Participants can also terminate the session at any point if they feel it necessary to do so.

The session will be audio recorded, fully transcribed and kept confidentially as a password-protected and encrypted computer file, accessible only to the researcher. You are welcome to have a copy of your file once the interview has been transcribed.

Copies of artworks produced during the session will also be digitally captured. Any identifying information from these artworks will be redacted in copies taken and anonymity will be maintained. Participants will be able to keep original artworks.

(As an extension to this PhD research, I would look to exhibit associated artworks in future, if enough participants consent to their work being shown at a later date. If you would like the opportunity to have your work exhibited in future, please consider carefully storing your original artworks for future use.)

You will receive a copy of this information sheet and the signed consent form to keep.

Will the information the researcher collects be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential, and pseudonyms will be used in the Ph.D instead of real names or any details that could identify you. Where personal photographs or medical images have been used in art-making, any copies taken of these will redact identifying information. An anonymised transcript of the art-making session will be kept as a secure computer file for up to 5 years after the end of the study. While written extracts (verbatim quotations) may be used within publications relating to the study, individuals will not be identified from the details presented. All data will be treated in accordance with the Data Protection Act 1998. This study has received approval from the University of York research ethics committee.

The researcher has a duty of care to inform the relevant agencies of any illegal activity or safeguarding issue disclosed to her.

What if I change my mind after the research begins?

If you change your mind about being part of the study, up to one month after beginning part one (the collaborative art-making practice), your data will be left out of the study and all related information about you erased.

What will happen to the results of the study?

The results of the study will be reported in the PhD thesis and possibly in a subsequent monograph and/or academic articles.

Prior to completion, a draft of the PhD thesis can be disseminated to participants (where they have indicated that they would like this option in the consent form) to confirm that they are comfortable and happy with the analysis of their art-works and discussions. The finished thesis will also be made open-access, so participants will have full access to the results of this fieldwork.

There may be the opportunity, in future, to include art-works completed through this study in an exhibition, however, this will be managed separately to the study and on an entirely voluntary basis.

On what basis will you process my data?

Under the General Data Protection Regulation (GDPR), the University has to identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data.

In line with our charter which states that we advance learning and knowledge by teaching and research, the University processes personal data for research purposes under Article 6 (1) (e) of the GDPR:

Processing is necessary for the performance of a task carried out in the public interest

Special category data is processed under Article 9 (2) (j):

Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes

Research will only be undertaken where ethical approval has been obtained, where there is a clear public interest and where appropriate safeguards have been put in place to protect data.

In line with ethical expectations and in order to comply with common law duty of confidentiality, we will seek your consent to participate where appropriate. This consent will not, however, be our legal basis for processing your data under the GDPR.

How will you use my data?

Data will be processed for the purposes outlined in this notice.

Will you share my data with 3rd parties?

No. Data will be accessible to the project team at York only.

How will you keep my data secure?

The University will put in place appropriate technical and organisational measures to protect your personal data and/or special category data. For the purposes of this project we will capture data on encrypted, password-protected devices and store it in a password protected folder on an online drive that requires two-factor authentication.

Information will be treated confidentiality and shared on a need-to-know basis only. The University is committed to the principle of data protection by design and default and will collect the minimum amount of data necessary for the project. In addition, we will anonymise or pseudonymise data wherever possible.

Will you transfer my data internationally?

No. Data will be held within the UK in full compliance with data protection legislation.

Will I be identified in any research outputs?

No, we offer full anonymity to participants.

How long will you keep my data?

For 5 years; data will be retained in line with legal requirements or where there is a business need.

What rights do I have in relation to my data?

Under the GDPR, you have a general right of access to your data, a right to rectification, erasure, restriction, objection or portability. You also have a right to withdrawal. Please note, not all rights apply where data is processed purely for research purposes. For further information see, https://www.york.ac.uk/records-management/generaldataprotectionregulation/individualsrights/.

Questions or concerns

If you have any questions about this participant information sheet or concerns about how your data is being processed, please contact Lizzie Merrill (ejm625@york.ac.uk) in the first instance. If you are still dissatisfied, please contact the University's Acting Data Protection Officer at dataprotection@york.ac.uk.

Right to complain

If you are unhappy with the way in which the University has handled your personal data, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.

Who can I talk to for more information or advice about the study?

If you have any queries about this research, please do not hesitate to contact Lizzie Merrill at:

Centre for Women's Studies, Law and Management Building, University of York, YO10 5GD

Email: ejm625@york.ac.uk

Research Project Supervisors: Dr Clare Bielby and Dr Boriana Alexandrova

Email: clare.bielby@york.ac.uk , boriana.alexandrova@york.ac.uk

Chair of ELMPS, Tony Royle, email: tony.royle@york.ac.uk

What do I do now?

If you would like to hear more about the study or think you might like to take part, just approach the researcher by emailing the address above.

Thank you for your time.

Appendix 3: Questions from Follow Up Questionnaire

- How did you find the collage-based method? (e.g. *Were there parts that were challenging? Would you look to try it again?*)

- Was there anything that came up in the session that you have since thought about more deeply?

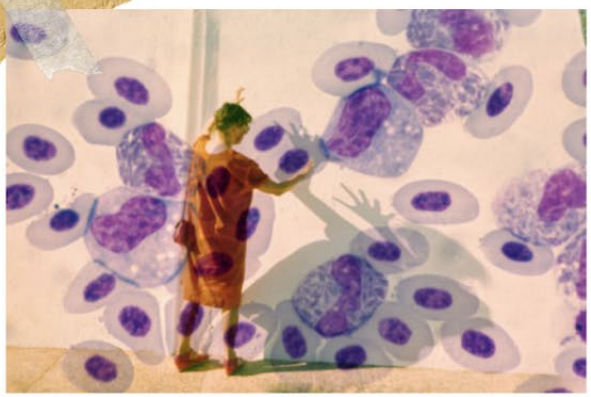
- Is there anything that you have taken away from the session that has been particularly resonant?

- Please share your general feelings on the collaborative art making session…

- Please share your feelings towards the artworks that you produced during this session…

Appendix 4: Participant Recruitment Poster

Participants needed



We are investigating how the artist Jo Spence's creative practice in her project, 'The Final Project', can be applied as an arts and health intervention for people who have been diagnosed with cancer.

Our study will test this intervention with participants, using Spence's collage-based methods for art-making. The intention behind this research is to consider alternative ways to support the wellbeing of people who have been diagnosed with cancer, through the arts.

We invite participants who are:

- At least 18 years old
- Have been diagnosed with cancer
- Are not in active treatment for a cancer diagnosis

If you would like to find out more about the study please contact Lizzie Merrill at ejm625@york.ac.uk

UNIVERSITY of York

White Rose College of the Arts & Humanities
Universities of Leeds, Sheffield & York

Appendix 5: Participant Consent Form

Have you read, or has someone read to you, the 'Information Sheet' about the project?
Yes / No

Do you understand what the project is about and what taking part involves?
Yes / No

Do you understand that if you take part in the research your words will be used but you will not be identifiable in any way; a pseudonym will be used instead?
Yes / No

Do you understand that the information you provide may be used anonymously in future research?
Yes / No

Do you understand that including any personal photographs or medical images within the study's art making process is entirely voluntary and that doing so is not a requirement for taking part in this study?
Yes / No

Do you plan to use medical images/records to support your art-making?
Yes / No

If yes, would you like us to allow 4-6 weeks (from signing this consent form) for you to gain access to these before sessions begin?
Yes / No

Do you consent for digital copies of any artwork that you produce during the study to be taken? (These copies will have personal data redacted).
Yes / No

Do you consent for these anonymised copies to be printed in future research publications?
Yes / No

If no, do you consent to the researcher verbally describing the content of these artworks in future research publications?
Yes / No

Do you understand that if you decide to take part and later change your mind, you can leave the project up to one month after part one without giving a reason?
Yes / No

Would you like to take part in the project 'How can Jo Spence's creative practice in 'The Final Project' be applied to help re-evaluate patient perception of self?'

Yes / No

If yes, is it okay to record your sessions?
Yes / No

If you have chosen to take part, would you like access to a draft of the thesis prior to its publication?
Yes / No

Please write your name here (in BLOCK letters): _____
Please sign your name here: _____

Appendix 6: Participant Resources

Paul's: https://pauls.org.uk/

Cancer Specific Support:

Macmillan Support Line (telephone line) 0808 808 00 00 available 7 days a week, 8am to 8pm

Look Good Feel Better (workshops and information) https://lookgoodfeelbetter.co.uk/

Cancer Support UK (coaching groups) https://cancersupportuk.org/cancercoach/

Location-specific NHS services https://www.nhs.uk/service-search/other-services/Cancer-information-and-support/LocationSearch/320

Maggies https://www.maggies.org/

(support groups) https://www.maggies.org/cancer-support/our-support/our-support-groups/

(professional teams) https://www.maggies.org/cancer-support/our-support/our-professional-staff/

(courses and workshops) https://www.maggies.org/cancer-support/our-support/courses-and-workshops/

Marie Curie (comprehensive list of further services, specific to different types of cancer) https://www.mariecurie.org.uk/help/support/support-directory/health-organisations

Non-Specific Support:

Mind (signposting telephone line) 0300 123 3393 available 9am to 6pm Monday to Friday

(Online Peer Community) https://www.mind.org.uk/information-support/side-by-side-our-online-community/

(General Support Information) https://www.mind.org.uk/information-support/guides-to-support-and-services/

Urgent Contacts:

Call Samaritans on 116 123 (UK-wide)

Text SHOUT to 85258 (UK-wide)

Call C.A.L.L. on 0800 132 737 (Wales only)

Appendix 7: Exhibition Consent Form

Name of Researcher: Elizabeth Merrill

PhD Project: How can Jo Spence's creative practice in 'The Final Project' be applied to help re-evaluate patient perception of self?

Contact details: ejm625@york.ac.uk

Following on from the interviews/workshops I have conducted with you in the past year, I would like to organise an exhibition to display the works produced through these sessions. The purpose of the exhibit is to showcase the outcomes of this research project and to introduce the workshops as a community-based method for approaching discussions of cancer experience.

Informed Consent: I would be honoured to display your artwork. However, there is no obligation to participate in the exhibition. There will be no repercussions for refusing to participate, or for withdrawing consent at any time.

Confidentiality: In order to continue to maintain confidentiality, your artwork will be displayed under a pseudonym. No personal information or any information that would in any way reveal your identity will be shared with the public.

Do you give consent for the art that you made on _____ (date of workshop), as part of this research study, to be exhibited publicly in an exhibition, put together by the researcher?

Yes / No

Do you give consent for audio excerpts taken from your workshop to be exhibited in a public exhibition, put together by the researcher?

Yes / No

Do you give consent to be quoted, in written form, from the workshop transcripts, in a public exhibition, put together by the researcher?

Yes / No

References

Abranches, Maria, and Elena and Horton. 2024. ‘Heritage through Collage: A Participatory and Creative Approach to Heritage Making’. *International Journal of Heritage Studies* 30, 1: 81–102. https://doi.org/10.1080/13527258.2023.2277780.

‘Adolf The Superman. Famous Adolf Hitler Portrait. John Heartfield AIZ’. n.d. *John Heartfield Exhibition* (blog). Accessed 6 January 2025. https://www.johnheartfield.com/John-Heartfield-Exhibition/john-heartfield-art/famous-anti-fascist-art/heartfield-posters-aiz/adolf-the-superman-hitler-portrait.

Alice Wong, Ashley Shew, and Jillian Weise. n.d. ‘Cyborgs’. Disability Visibility Project. Accessed 28 November 2024. https://disabilityvisibilityproject.com/2019/12/18/ep-66-cyborgs/.

Anderson, Elizabeth. 2024. ‘Feminist Epistemology and Philosophy of Science’. In *The Stanford Encyclopedia of Philosophy*, edited by Edward N. Zalta and Uri Nodelman, Fall 2024. Metaphysics Research Lab, Stanford University. https://plato.stanford.edu/archives/fall2024/entries/feminism-epistemology/.

Andrews, Molly, Corinne Squire and Maria Tamboukou. 2013. *Doing Narrative Research*. Second edition. Los Angeles, California ; London: SAGE.

Audre Lorde. 2017. *A Burst of Light*. United States: Ixia Press.

Ayuso, Sullivan A. 2023. ‘Numb to the Violence: Five Years as a General Surgery Resident’. *The American Surgeon*, 31348231180913–31348231180913. https://doi.org/10.1177/00031348231180913.

Baglia, Jay. 2023. ‘The Ontology of Oncology: Navigating Cyborgs and Assemblages Through Cancer Treatment’. *Health Communication* 38, 12: 2592–2603. https://doi.org/10.1080/10410236.2022.2093554.

BBC News. 2019. “‘I Am 22 and I Want a Hysterectomy”’, 1 September 2019, sec. Glasgow & West Scotland. https://www.bbc.com/news/uk-scotland-glasgow-west-49510858.

———. 2021. ‘Endometriosis: Young Woman “pleading” for Hysterectomy’, 14 April 2021, sec. Northern Ireland. https://www.bbc.com/news/uk-northern-ireland-56737353.

Bell, Susan E. 2002. ‘Photo Images: Jo Spence’s Narratives of Living with Illness’. *Health (London, England : 1997)* 6, 1: 5–30. https://doi.org/10.1177/1363459302006001442.

———. 2006. ‘Living with Breast Cancer in Text and Image: Making Art to Make Sense’. *Qualitative Research in Psychology* 3,1: 31–44. https://doi.org/10.1191/1478088706qp052oa.

———. 2013. ‘Seeing Narratives’. In *Doing Narrative Research*, edited by Molly Andrews, Corinne Squire and Maria Tamboukou,142–58. SAGE Publications, Ltd. https://doi.org/10.4135/9781526402271.

Benjamin, Walter, and Michael W. Jennings. 2010. ‘The Work of Art in the Age of Its Technological Reproducibility [First Version]’. *Grey Room* 39: 11–38. https://doi.org/10.1162/grey.2010.1.39.11.

Biber, Sharlene Hesse. 2011. *Handbook of Feminist Research: Theory and Praxis*. 2nd Edition. Thousand Oaks: SAGE Publications, Incorporated. https://doi.org/10.4135/9781483384740.

Bielby, Clare, Mererid Puw Davies, Katharina Karcher, Evelien Geerts, Seán Allan, Martin Brady, Jonathan J. Long, Ernest Schonfield, and Katherine Stone. 2024. *Violence Elsewhere 1: Imagining Distant Violence in Germany 1945-2001*. 1st ed. Vol. 238. Rochester: Boydell & Brewer, Incorporated.

Biro, Matthew. 2009. *The Dada Cyborg: Visions of the New Human in Weimar Berlin*. Minneapolis: University of Minnesota Press.

Blanchard, Enka, and Ashley Shew. 2022. ‘Disabled Dimensionalities: Normative Expectations’ Impacts on Disabled Perceptions and Spatialities’. *L’espace Politique* 45. https://doi.org/10.4000/espacepolitique.10518.

Blanco, María del Pilar and Esther Peeren. 2013. *The Spectralities Reader: Ghosts and Haunting in Contemporary Cultural Theory / Edited by Maria Del Pilar Blanco and Esther Peeren*. New York: Bloomsbury Academic.

Bolaki, Stella. 2016. *Illness as Many Narratives: Arts, Medicine and Culture*. Edinburgh: University Press.

Boyer, Anne. 2016. ‘The Kind of Pictures She Would Have Taken: Jo Spence’. *Afterall* 42, 1: 4–11. https://doi.org/10.1086/689799.

———. 2019. *The Undying*. London: Penguin.

Bradbury, Hilary. 2015. *The SAGE Handbook of Action Research*. Third edition. Los Angeles: SAGE Publications.

Brown, Georgia E. 2015. ‘Cutting, Sticking, and Material Meaning in a Book of Passion Cycle Engravings’. *The Journal of Medieval and Early Modern Studies* 45, 3: 543–56. https://doi.org/10.1215/10829636-3149155.

Brown, Nicole, and Jennifer Leigh. 2020. *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education*. 1st ed. London: UCL Press. https://doi.org/10.2307/j.ctv13xprjr.

Butler-Kisber, Lynn. 2018. *Qualitative Inquiry: Thematic, Narrative and Arts-Based Perspectives*. Second edition. Los Angeles: SAGE.

Cabrera Jaime, Sandra, Cristina Martinez, Verónica Gonzalo Bachiller, Nuria Zarza Arnau, Luis Martin Maldonado, Ana Belén Manrique Palles, Inmaculada Artiga Sarrion, et al. 2023. 'Participatory Action Research Intervention for Improving Sleep in Inpatients with Cancer'. *Journal of Clinical Nursing* 32, 7-8: 1218–29. https://doi.org/10.1111/jocn.16279.

Call, Josep, Malinda Carpenter, and Michael Tomasello. 2005. 'Copying Results and Copying Actions in the Process of Social Learning: Chimpanzees (Pan Troglodytes) and Human Children (Homo Sapiens)'. *Animal Cognition* 8, 3: 151–63. https://doi.org/10.1007/s10071-004-0237-8.

Caraffa, Costanza. 2019. 'The Photo Archive as Laboratory. Art History, Photography, and Materiality'. *Art Libraries Journal* 44, 1: 37–46. https://doi.org/10.1017/alj.2018.39.

Cardona, Carmel, and Taey Iohe. 2023. 'When Our Time Is No Longer Ours: Temporality, Productivity and Reciprocity in Migrant Motherhood and Cancer Survivorship'. In *GenderErträge V*, edited by Hazal Kaygusuz and Daniela Petrosino, 34: 4–24. Berlin: Humboldt-Universität zu Berlin. https://www.gender.hu-berlin.de/de/publikationen/gender-bulletin-broschueren.

Caulfield, Jon. 1996. 'Sociology and Visual Representation / Cape Breton 1952 / Shooting Back from the Reservation / Visual Culture / Picturing Us'. *Contemporary Sociology (Washington)* 25, 3: 403-.

Cederved, Catarina, Jon Back, Charlotte Ångström-Brännström, Gustaf Ljungman, and Gunn Engvall. 2022. 'Co-Creation of a Serious Game About Radiotherapy: Participatory Action Research Study With Children Treated for Cancer'. *JMIR Human Factors* 9: 34476. https://doi.org/10.2196/34476.

Charmaz, Kathy. 1991. *Good Days, Bad Days: The Self in Chronic Illness and Time.* New Brunswick, N.J.: Rutgers University Press.

Charon, Rita. 2006. *Narrative Medicine: Honoring the Stories of Illness.* New York; Oxford: Oxford University Press.

Chenaud, Catherine, Paolo Merlani, and Bara Ricou. 2007. 'Research in Critically Ill Patients: Standards of Informed Consent'. *Critical Care* 11, 1: 110. https://doi.org/10.1186/cc5678.

Clerselier, Claude. 1664. *De l'homme et de La Formation Du Foetus*. Paris.

Conley, Katharine. 2013. *Surrealist Ghostliness.* Lincoln: University of Nebraska Press.

Couser, G. Thomas, and Nancy Mairs. 1997. *Recovering Bodies: Illness, Disability and Life-Writing*. Madison: University of Wisconsin Press.

Creed, Barbara. 1993. *The Monstrous-Feminine: Film, Feminism, Psychoanalysis.* Popular Fiction Series. London: Routledge.

Davis, Lennard J.1995. *Enforcing Normalcy: Disability, Deafness, and the Body*. London/New York: Verso Books.

Dennett, Terry. 2011. 'Jo Spence's Auto-Therapeutic Survival Strategies'. *Health (London, England: 1997)* 15, 3: 223–39. https://doi.org/10.1177/1363459310397973.

Descartes, René. 1998. *Descartes: The World and Other Writings*. Edited by Stephen Gaukroger. Cambridge; New York: Cambridge University Press.

DeShazer, Mary K. 2013. *Mammographies: The Cultural Discourses of Breast Cancer Narratives*. Illustrated edition. Ann Arbor: University of Michigan Press.

Dijck, José van. 2005. *The Transparent Body: A Cultural Analysis of Medical Imaging*. In Vivo (Seattle, Wash.). Seattle: University of Washington Press.

Edelman, Lee. 2004. *No Future: Queer Theory and the Death Drive*. E-Duke Books Scholarly Collection. Durham: Duke University Press, Duke University Press.

Elizegi, Rebeka editor. 2019. *Collage by Women: 50 Essential Contemporary Artists*. Barcelona, Spain: Promopress.

El-Sheikh, Tammer. 2020. *Entangled Bodies: Art, Identity and Intercorporeality*. Wilmington, DE: Vernon Press.

Ettinger, Bracha Lichtenberg. 2001. 'Wit(h)Nessing Trauma and the Matrixial Gaze: From Phantasm to Trauma, from Phallic Structure to Matrixial Sphere'. *Parallax (Leeds, England)* 7, 4: 89–114. https://doi.org/10.1080/13534640110089276.

'Executioners As Surgeons'. 1908. *British Medical Journal* 2: 850–51.

Fadiman, Anne. 1998. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors and the Collision of Two Cultures*. New York: Farrar Straus & Giroux.

Fazeli, Taraneh. 2016. 'Notes for "Sick Time, Sleepy Time, Crip Time: Against Capitalism's Temporal Bullying" in Conversation with the Canaries'. *Temporary Art Review*. https://temporaryartreview.com/notes-for-sick-time-sleepy-time-crip-time-against-capitalisms-temporal-bullying-in-conversation-with-the-canaries/.

Ferguson, Laura. n.d. 'Galleries: A Narrative of the Body'. Accessed 1 December 2017. www.laurafergusonart.squarespace.com/body-narrative-galleries.

Fernández-Morales, Marta. 2013. '"Is Anybody Paying Attention?": Breast Cancer on Stage in the Twenty-First Century'. *Tulsa Studies in Women's Literature* 32/33, 1-2: 129–46.

Ferris, Alison. 2003. 'Disembodied Spirits: Spirit Photography and Rachel Whiteread's "Ghost"'. *Art Journal (New York. 1960)* 62, 3: 44-. https://doi.org/10.2307/3558520.

Finch, Alison, and Michela Quecchia. 2025. 'Relational Knowledge and Young People's Cancer Care: How Community-Based Participatory Research Promotes Learning and Directs Action in Practice'. *Educational Action Research* 33, 1: 96–114. https://doi.org/10.1080/09650792.2024.2420901.

Fingeret, Michelle Cororve, Irene Teo, and Daniel E. Epner. 2014. 'Managing Body Image Difficulties of Adult Cancer Patients: Lessons from Available Research'. *Cancer* 120, 5: 633–41. https://doi.org/10.1002/cncr.28469.

Foucault, Michel. 2020. *Discipline and Punish: The Birth of the Prison; Translated from the French by Alan Sheridan*. Penguin Classics. UK: Penguin Books.

Fournier, Lauren. 2021. *Autotheory as Feminist Practice in Art, Writing, and Criticism*. The MIT Press. https://doi.org/10.7551/mitpress/13573.001.0001.

Fox, Alice. 2021. 'The (Possible) Future of Cyborg Healthcare: Depictions of Disability in Cyberpunk 2077'. *Science as Culture* 30, 4: 591–97. https://doi.org/10.1080/09505431.2021.1956888.

Frank, Arthur W. 2013. *The Wounded Storyteller: Body, Illness, and Ethics* / 2nd ed. Chicago, Illinois ; London: The University of Chicago Press.

Garland-Thomson, Rosemarie. 2006. 'Ways of Staring'. *Journal of Visual Culture* 5, 2: 173–92. https://doi.org/10.1177/1470412906066907.

———. 2017. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Twentieth anniversary edition. New York: Columbia University Press.

Gatenby, Bev, and Maria Humphries. 2000. 'Feminist Participatory Action Research: Methodological and Ethical Issues'. *Women's Studies International Forum* 23, 1: 89–105. https://doi.org/10.1016/S0277-5395(99)00095-3.

Gibson, Neil. 2017. 'Therapeutic Photography: Enhancing Patient Communication'. *Journal of Kidney Care* 2, 1: 46–47. https://doi.org/10.12968/jokc.2017.2.1.46.

Gill, Rosalind, Róisín Ryan Flood, Tracey Jensen, Meg Barker, Darren Langdridge, Heidi Nast, Elspeth Probyn, Miriam Glucksmann, and Dag Heede. 2008. 'Secrecy and Silence in Research'. *Feminism & Psychology* 18, 3: 381–83. https://doi.org/10.1177/0959353508092091.

Ginsburg, Faye, and Rayna Rapp. 2013. 'Disability Worlds'. *Annual Review of Anthropology* 42, 1: 53–68. https://doi.org/10.1146/annurev-anthro-092412-155502.

Goody, A. 2007. 'Dada, Cyborgs and the New Woman in New York'. In *Modernist Articulations*. United Kingdom: Palgrave Macmillan UK.

Gray, Chris. 1995. *The Cyborg Handbook*. 1st edition. New York Abingdon: Routledge.

Grover, Jan Zita, and Jo Spence. 1990. '"Sharing the Wounds": Jan Zita Grover Interviews Jo Spence'. *The Women's Review of Books* 7, 10-11: 38–39. https://doi.org/10.2307/4020831.

Gubar, Susan. 2012. *Memoir of a Debulked Woman: Enduring Ovarian Cancer*. Illustrated edition. New York: W. W. Norton & Co.

Guignery, Vanessa, Catherine Pesso-Miquel and François Specq. 2011. *Hybridity: Forms and Figures in Literature and the Visual Arts*. Newcastle upon Tyne, U.K.: Cambridge Scholars Pub.

Gunning, Tom. 2007. 'To Scan a Ghost: The Ontology of Mediated Vision'. *Grey Room* 26: 94–127. https://doi.org/10.1162/grey.2007.1.26.94.

Haddow, Gill, Emma King, Ian Kunkler, and Duncan McLaren. 2015. 'Cyborgs in the Everyday: Masculinity and Biosensing Prostate Cancer'. *Science as Culture* 24, 4: 484–506. https://doi.org/10.1080/09505431.2015.1063597.

Hajian, George. 2022. 'Revealing Embedded Power: Collage and Disruption of Meaning'. *Revista GEMInIS* 13, 2: 94–104. https://doi.org/10.53450/2179-1465.RG.2022v13i2p94-104.

Halberstam, Jack. 2005. *In a Queer Time and Place: Transgender Bodies, Subcultural Lives*. Sexual Cultures. New York ; London: New York University Press.

Hall, Matthew. 2011. *Plants as Persons: A Philosophical Botany*. State University of New York Press.

Hammersley, Martyn. 2016. *Ethics in Qualitative Research: Controversies and Contexts*. London: SAGE.

Haraway, Donna. 2016. 'A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century'. In *Manifestly Haraway*. Minnesota: University of Minnesota Press.

Hatherley, Frances. 2020. *Class Slippers: Jo Spence on Fantasy, Photography & Fairytales*. Bristol: RRB Photobooks.

Hawkins, Anne Hunsaker. 1998. *Reconstructing Illness: Studies in Pathography*. 2nd edition. West Lafayette, Ind: Purdue University Press.

Heard, Catherine. 2010. 'Automata: Hybrid Collage Bodies'. *Brock Review* 11, 1: 74–80. https://doi.org/10.26522/br.v11i1.109.

Heath, Charlene. 2017. 'In Search of "Red": Remodelling the Jo Spence Memorial Archive'. *Photography & Culture* 10, 3: 289–98. https://doi.org/10.1080/17514517.2017.1362771.

Hedva, Johanna. 2024. Instagram Post. *@bighedva*. https://www.instagram.com/p/C_0j_A1sAzH/?igsh=MWJkbHVpNWc0cWo4eg==.

———. 2022. 'Sick Woman Theory'. *Topical Cream*, March. topicalcream.org/features/sick-woman-theory/.

Hefferon, Kathleen. 2017. 'Reconceptualizing Cancer Immunotherapy Based on Plant Production Systems'. *Future Science OA* 3: FSO217–FSO217. https://doi.org/10.4155/fsoa-2017-0018.

Helmick, Linda. 2023. 'Expressing Trauma Through Therapeutic Art-Based Trauma-Informed Practice With/in a Collective Happening'. *Studies in Art Education* 64, 3: 324–43. https://doi.org/10.1080/00393541.2023.2220100.

Hershey, Laura. 2005. *Survival Strategies for Going Abroad: A Guide for People with Disabilities*. Mobility International USA.

Hevey, David. 1992. *The Creatures Time Forgot: Photography and Disability Imagery*. London: Routledge.

Hirsch, Erin A., Kaitlyn Hoover, and Jamie L. Studts. 2024. '"They Need to Feel Non-Judgmental": Results of Participatory Photovoice Research to Inform Lung Cancer Screening Imagery'. *Cancer Control* 31:10732748241292567-. https://doi.org/10.1177/10732748241292567.

Hitchings, Russell. 2003. 'People, Plants and Performance: On Actor Network Theory and the Material Pleasures of the Private Garden'. *Social & Cultural Geography* 4, 1: 99–114. https://doi.org/10.1080/1464936032000049333.

Hoffman, Katherine. 1989. *Collage: Critical Views*. Studies in the Fine Arts. Criticism ; No. 31. Ann Arbor, Mich.: UMI Research Press.

Hofrichter, Frima Fox, and Midori Yoshimoto. 2021. *Women, Aging, and Art: A Crosscultural Anthology*. New York: Bloomsbury Visual Arts.

Holland, Patricia, Jo Spence, and Simon Watney, eds. 1987. *Photography/Politics: Two: V.2*. s.l: Routledge.

Hollway, Wendy, and Tony Jefferson. 2012. *Doing Qualitative Research Differently: A Psychosocial Approach*. Second edition. London, England: SAGE Publications. https://doi.org/10.4135/9781526402233.

Ing, Jane. 1992. Interview with Jo Spence. Jo Spence Box. Goldsmiths Women's Art Library.

Jain, S. Lochlann. 2013. *Malignant: How Cancer Becomes Us*. Berkeley: University of California Press.

Johnson, Samantha. 2016. 'Dust to Dust: The Photographer Who Stared Death in the Face – in Pictures'. *The Guardian*, 2016, sec. Art and design. http://www.theguardian.com/artanddesign/gallery/2016/feb/16/photographer-jo-spence-the-final-project.

Kafer, Alison. 2013. *Feminist, Queer, Crip*. Bloomington: Indiana University Press.

Karnilowicz, W. 2011. 'Identity and Psychological Ownership in Chronic Illness and Disease State'. *European Journal of Cancer Care* 20, 2: 276–82. https://doi.org/10.1111/j.1365-2354.2010.01220.x.

Kevles, Bettyann. 1998. *Naked to the Bone: Medical Imaging in the Twentieth Century*. Reading, Mass.: Addison-Wesley.

Kim, Elizabeth, and Richard J. Levy. 2020. 'The Role of Anaesthesiologists in Lethal Injection: A Call to Action'. *The Lancet* 395, 10225: 749–54. https://doi.org/10.1016/S0140-6736(19)32986-1.

Kirby, Kim. 1991. Interview with Jo Spence. Jo Spence Box. Goldsmiths Women's Art Library.

Klugman, Craig M. 2001. 'From Cyborg Fiction to Medical Reality'. *Literature and Medicine* 20, 1: 39–54. https://doi.org/10.1353/lm.2001.0007.

Kosofsky Sedgwick, Eve. 1992. 'White Glasses'. *Yale Journal of Criticism* 5, 3: 193.

Kriebel, Sabine. 2014. *Revolutionary Beauty: The Radical Photomontages of John Heartfield*. Berkeley: University of California Press.

Kristeva, Julia. 1982. *Powers of Horror: An Essay on Abjection; Translated by Leon S. Roudiez*. European Perspectives. New York: Columbia University Press.

———. 2014. *The Severed Head: Capital Visions; Translated by Jody Gladding*. European Perspectives. New York: Columbia University Press.

Kuppers, Petra. 2014. 'Crip Time'. *Tikkun*. San Francisco: The Institute for Labor and Mental Health. https://doi.org/10.1215/08879982-2810062.

Laird, Carobeth. 1979. *Limbo*. Chandler & Sharp Pub.

Lakoff, George, and Mark Johnson. 2003. *Metaphors We Live By*. New edition. Chicago: University of Chicago Press.

Lapum, Jennifer, Suzanne Fredericks, Heather Beanlands, Elizabeth McCay, Jasna Schwind, and Daria Romaniuk. 2012. 'A Cyborg Ontology in Health Care: Traversing into the Liminal Space between Technology and Person-Centred Practice'. *Nursing Philosophy* 13, 4: 276–88. https://doi.org/10.1111/j.1466-769X.2012.00543.x.

Lara, Jose Alvarez, and Abigail Muller. 2023. 'Zombie Work Force: Capitalism, Sacrifice, and the Virtual Afterlife of Labor'. *Symploke (Bloomington, Ind.)* 31, 1: 397–404. https://doi.org/10.1353/sym.2023.a914671.

Larson, Katie. 2020. 'Alberto Burri and the Image of the Body in Post-Fascist Italy: Reconsidering the "Wound" Motif'. *Art Journal (New York. 1960)* 79, 3: 42–57. https://doi.org/10.1080/00043249.2020.1801096.

Launer, John. 2009. 'Power and Powerlessness'. *Postgraduate Medical Journal* 85, 1003: 280–280. https://doi.org/10.1136/pgmj.2009.081885.

Lauro, Sarah Juliet. 2017. *Zombie Theory: A Reader*. Minneapolis, Minnesota: University of Minnesota Press.

Le, Annie, Kara Miller, and Juliet McMullin. 2017. 'From Particularities to Context: Refining Our Thinking on Illness Narratives'. *AMA Journal of Ethics* 19, 3: 304–11. https://doi.org/10.1001/journalofethics.2017.19.3.msoc1-1703.

Leder, Drew, ed. 1992. *The Body in Medical Thought and Practice*. Vol. 43. Philosophy and Medicine. Dordrecht: Springer Netherlands. https://doi.org/10.1007/978-94-015-7924-7.

Lee, Louisa. 2013. *Jo Spence: The Final Project*. London: Ridinghouse in association with the Jo Spence Memorial Archive.

Leonzio, Dr Elisa, Prof Dr Lorella Bosco, Prof Dr Micaela Latini, Dr Anna Cappellotto, Prof Dr Francesca Di Blasio, Prof Dr Sharon Ruston, Prof Dr Flora de Giovanni, et al. 2015. *Monstrous Anatomies: Literary and Scientific Imagination in Britain and Germany during the Long Nineteenth Century: 10*. Göttingen: V&R unipress GmbH.

Lobo, Patricia. 2016. 'Collages for Cancer'. *The Lancet Oncology* 17, 2: 149–149. https://doi.org/10.1016/S1470-2045(16)00019-X.

Loecher, Nele, Abbie Jordan, Sheri L. Spunt, Pamela Simon, Laura E. Simons, Gary Dahl, Kristin Kosyluk, and Lauren C. Heathcote. 2023. '"You Don't Accept He's Completely Ok": A Reflexive Thematic Analysis of Parents' Roles in Monitoring Their Child's Health and Symptoms after Finishing Childhood Cancer Treatment'. *Journal of Cancer Survivorship*. https://doi.org/10.1007/s11764-023-01353-w.

Lorde, Audre. 1980. *The Cancer Journals*. 1st ed. Argyle, N.Y.: Spinsters, Ink.

Lorenz, Laura S. 2010. 'Visual Metaphors of Living with Brain Injury: Exploring and Communicating Lived Experience with an Invisible Injury'. *Visual Studies (Abingdon, England)* 25, 3: 210–23. https://doi.org/10.1080/1472586X.2010.523273.

Lupton, Deborah. 2015. 'Donna Haraway: The Digital Cyborg Assemblage and the New Digital Health Technologies'. In *The Palgrave Handbook of Social Theory in Health, Illness and Medicine*, 567–81. https://doi.org/10.1057/9781137355621.0045.

Majmudar, Amit. 2015. 'Elitism and American Poetry « Kenyon Review Blog'. The Kenyon Review. 14 October 2015. https://kenyonreview.org/2015/10/elitism-and-american-poetry/.

Malone, Tyler. 2018. 'The Zombies of Karl Marx: Horror in Capitalism's Wake'. *Literary Hub* (blog). 31 October 2018. https://lithub.com/the-zombies-of-karl-marx-horror-in-capitalisms-wake/.

Manfred E. Clynes and Nathan S. Kline. 1995. 'Cyborgs and Space'. In *The Cyborg Handbook*, edited by Chris Hables Gray, 29–33. New York: Routledge.

Maria Mäkelä and Paul Dawson. 2022. *The Routledge Companion to Narrative Theory*. Routledge Literature Companions. Milton: Taylor and Francis. https://doi.org/10.4324/9781003100157.

Matthews, Eric. 2002. *The Philosophy of Merleau-Ponty*. Continental European Philosophy. Chesham: Acumen.

McCreaddie, May, and Sally Wiggins. 2009. 'Reconciling the Good Patient Persona with Problematic and Non-Problematic Humour: A Grounded Theory'. *International Journal of Nursing Studies* 46, 8: 1079–91. https://doi.org/10.1016/j.ijnurstu.2009.01.008.

McIntyre, Alice. 2008. *Participatory Action Research [Electronic Resource]*. Qualitative Research Methods 52. Los Angeles, Calif. ; London, Los Angeles ; London: SAGE, Sage Publications. http://srmo.sagepub.com/view/participatory-action-research-qrm/SAGE.xml.

McRuer, Robert. 2006. *Crip Theory Cultural Signs of Queerness and Disability*. Cultural Front. New York: University Press.

Merrill, Lizzie. 2022. 'Candy Darling on Her Deathbed: Subversive Memorial in the Photography of Peter Hujar'. *Aspectus* 4. https://doi.org/10.15124/yao-637q-5x45.

Millen, D. 1997. 'Some Methodological and Epistemological Issues Raised by Doing Feminist Research on Non-Feminist Women'. *Sociological Research Online* 2, 3: 1–15. https://doi.org/10.5153/sro.1351.

'Misbehaving Bodies: Jo Spence and Oreet Ashery'. 2019. Wellcome Collection. 29 May 2019. https://wellcomecollection.org/exhibitions/misbehaving-bodies--jo-spence-and-oreet-ashery.

Monahon, Catherine, and Elizabeth Jameson. 2020. 'Intimate Visions: Representations of the Imperfect Body in the Age of Digital Medicine'. *Leonardo (Oxford)* 53, 3: 281–87. https://doi.org/10.1162/leon_a_01745.

Monemian, Sharifeh, Mohammad Reza Sharbafchi, and Fariba Taleghani. 2021. 'Empowerment of Women to Provide Home-Based Supportive and Palliative Care for Patients with Cancer: Participatory Action Research Protocol'. *International Journal of Cancer Management* 14, 11. https://doi.org/10.5812/ijcm.118019.

Morrison, Tricia L., and Roanne L. Thomas. 2014. 'Survivors' Experiences of Return to Work Following Cancer: A Photovoice Study'. *Canadian Journal of Occupational Therapy (1939)* 81, 3: 163–72. https://doi.org/10.1177/0008417414534398.

Mullen, Carol A. 1999. 'Chapter 10: Carousel: A Metaphor for Spinning Inquiry in Prison and Education'. *Counterpoints (New York, N.Y.)* 89: 281–314.

Mumin, Nasra. 2019. 'Ghostly Subjects: Towards a Cultural Analysis of the Abjected Self'. University of Guelph. http://hdl.handle.net/10214/14773.

Nead, Lynda. 1992. *The Female Nude: Art, Obscenity, and Sexuality / Lynda Nead*. London; New York: Routledge. http://site.ebrary.com/lib/york/Doc?id=5005049.

O'Brien, Martin. 2016. 'Flesh-Eaters: Notes toward a Zombie Methodology'. *Leonardo (Oxford)* 49, 3: 264–65. https://doi.org/10.1162/LEON_a_01273.

O'Connor, Erin. 1999. 'Camera Medica: Towards a Morbid History of Photography'. *History of Photography* 23, 3: 232–44. https://doi.org/10.1080/03087298.1999.10443326.

Oliver, MarilÈne. 2004. 'The MRI Scanner: An Ideal Instrument for Portraiture'. *Leonardo (Oxford)* 37, 5: 374–374. https://doi.org/10.1162/leon.2004.37.5.374.

Palmer, Abi. 2022. ‘Self Portrait as a Mushroom in the Damp and Leafy Forest’. In *This Book Is a Plant: How to Grow, Learn and Radically Engage with the Natural World*. London: Wellcome Collection.

Paz, Octavio. 2005. *The Labyrinth of Solitude*. Penguin Classics.

Pollock, Griselda. 2007. *Encounters in the Virtual Feminist Museum: Time, Space and the Archive / Griselda Pollock*. London: Routledge.

———. 2009. ‘Art/Trauma/Representation’. *Parallax (Leeds, England)* 15, 1: 40–54.

———. 2010. ‘Aesthetic Wit(h)Nessing in the Era of Trauma’. *EurAmerica* 40, 4: 829–86.

Polo, Katie, Amy Ragle, Gabrielle Ingram, Nicole Scholl, Tamzyn Mather, and Taylor Welch. 2020. ‘"It Takes a Village to Get Through Cancer": A Photovoice Study Exploring the Lived Experiences of Community Cancer Survivors’. *The American Journal of Occupational Therapy* 74: 7411505263-7411505263p1. https://doi.org/10.5014/ajot.2020.74S1-RP304C.

Potier, Rémy. 2011. ‘Medical Imaging and Modern Art: Encounters over a Virtual Body’. *Recherches En Psychanalyse* 12, 2: 131–39.

Poudrier, Jennifer, and Roanne Thomas Mac-Lean. 2009. “‘We’ve Fallen into the Cracks”: Aboriginal Women’s Experiences with Breast Cancer through Photovoice’. *Nursing Inquiry* 16, 4: 306–17. https://doi.org/10.1111/j.1440-1800.2009.00435.x.

Prentice, Rachel. 2013. *Bodies in Formation: An Ethnography of Anatomy and Surgery Education*. Experimental Futures. Durham, NC ; London: Duke University Press.

Price, Elizabeth. 2016. *Elizabeth Price Curates: In a Dream You Saw a Way to Survive and You Were Full of Joy*. London: Hayward Gallery Publishing.

Pryce, Anthony. 1996. ‘Visual Imagery and the Iconography of the Social World: Some Considerations of History, Art and Problems for Sociological Research.’ In *Methodological Imaginations*, 95–111. London: Macmillan.

Radley, Alan, and Susan E. Bell. 2007. ‘Artworks, Collective Experience and Claims for Social Justice: The Case of Women Living with Breast Cancer’. *Sociology of Health & Illness* 29, 3: 366–90. https://doi.org/10.1111/j.1467-9566.2007.00499.x.

Rainey, Lawrence S. 1998. ‘Taking Dictation: Collage Poetics, Pathology, and Politics’. *Modernism/Modernity (Baltimore, Md.)* 5, 2: 123–53. https://doi.org/10.1353/mod.1998.0043.

Ramazanoğlu, Caroline, and Janet Holland. 2002. *Feminist Methodology*. SAGE Publications Ltd. https://doi.org/10.4135/9781849209144.

Reason, Peter. 1994. ‘Three Approaches to Participative Inquiry’. In *Handbook of Qualitative Research,* edited by Norman K Denzin and Yvonna S Lincoln, 324–39. London: Sage Publications Inc.

Reason, Peter, and Hilary Bradbury-Huang. 2007. *The SAGE Handbook of Action Research: Participative Inquiry and Practice*. Second edition. London: SAGE Publications.

Reinharz, Shulamit. 1992. *Feminist Methods in Social Research*. New York; Oxford: Oxford University Press.

Rich, Michael. 2002. 'Show Is Tell'. *Narrative Inquiry : NI* 12, 2: 405–12. https://doi.org/10.1075/ni.12.2.12ric.

Rijke, Victoria de. 2024. 'The And Article: Collage as Research Method'. *Qualitative Inquiry* 30, 3-4: 301–10. https://doi.org/10.1177/10778004231165983.

Robertson, Eden G., Claire E. Wakefield, Joanne Shaw, Anne-Sophie Darlington, Brittany C. McGill, Richard J. Cohn, and Joanna E. Fardell. 2019. 'Decision-Making in Childhood Cancer: Parents' and Adolescents' Views and Perceptions'. *Supportive Care in Cancer* 27, 11: 4331–40. https://doi.org/10.1007/s00520-019-04728-x.

Rosqvist, Hanna Bertilsdotter, Hisayo Katsui, and Janice McLaughlin. 2017. '(Dis)Abling Practices and Theories?: Exploring Chronic Illness in Disability Studies'. *Scandinavian Journal of Disability Research : SJDR* 19, 1.

Roth, Michael S. 2012. *Memory, Trauma, and History: Essays on Living with the Past*. New York: Columbia University Press.

Samuels, Ellen. 2017. 'Six Ways of Looking at Crip Time'. *Disability Studies Quarterly* 37, 3. https://doi.org/10.18061/dsq.v37i3.5824.

Santini, Céline. 2019. *Kintsugi: Finding Strength in Imperfection*. Kansas City, US: Andrews McMeel Publishing.

Schechtman, Marya. 1996. *The Constitution of Selves*. Cornell University Press.

Schultz, Jane E. 2009. '(Un)Body Double: A Rhapsody on Hairless Identity1'. *Literature and Medicine* 28, 2: 371-.

Schwalbe, Will. 2013. *The End of Your Life Book Club*. Two Roads.

Sedgwick, Eve Kosofsky. 1998. 'A Dialogue on Love'. *Critical Inquiry* 24, 2: 611–31. https://doi.org/10.1086/448887.

Sheldrake, Merlin. 2020. *Entangled Life: How Fungi Make Our Worlds, Change Our Minds and Shape Our Futures*. London: Vintage.

Sherwin, Susan and Feminist Health Care Ethics Research Network. 1998. *The Politics of Women's Health: Exploring Agency and Autonomy / the Feminist Health Care Ethics Research Network*. Philadelphia: Temple University Press.

Shew, Ashley. 2017. ‘Technoableism, Cyborg Bodies, and Mars’. *Technology and Disability* (blog). 11 November 2017. https://techanddisability.com/2017/11/11/technoableism-cyborg-bodies-and-mars/.

———. 2019. ‘Stop Depicting Technology As Redeeming Disabled People’. *Nursing Clio* (blog). 23 April 2019. https://nursingclio.org/2019/04/23/stop-depicting-technology-as-redeeming-disabled-people/.

Shildrick, Margrit. 2002. *Embodying the Monster: Encounters with the Vulnerable Self*. London, United Kingdom: SAGE Publications, Limited. http://ebookcentral.proquest.com/lib/york-ebooks/detail.action?docID=254770.

———. 2008. ‘Contesting Normative Embodiment: Some Reflections on the Psycho-Social Significance of Heart Transplant Surgery’. *Perspectives: International Postgraduate Journal of Philosophy* 1, 1: 9–22.

———. 2015a. ‘Staying Alive: Affect, Identity and Anxiety in Organ Transplantation’. *Body & Society* 21, 3: 20–41. https://doi.org/10.1177/1357034X15585886.

———. 2015b. *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)Ethics*. London: Routledge.

Slatman, Jenny. 2004. ‘L’imagerie du corps interne’. *Methodos. Savoirs et textes*, no. 4 (May). https://doi.org/10.4000/methodos.133.

Sontag, Susan. 1983. *Illness as Metaphor.* Harmondsworth: Penguin.

Spence, Jo. 1986. *Putting Myself in the Picture: A Political, Personal and Photographic Autobiography*. London: Camden Press.

———. 1995. *Cultural Sniping: The Art of Transgression; Literary Editing by Jo Stanley, Picture Editing by David Hevey, Foreword by Annette Kuhn*. Comedia. London ; New York: Routledge.

Spence, Jo, Terry Dennett, Experimental Arts Foundation (Australia), George Paton Gallery, and Tin Sheds Art Workshop. 1990. *Jo Spence: Collaborative Works; Australian Tour 1990*. Sydney: Tin Sheds Gallery.

Stacey, Jackie. 1997. *Teratologies: A Cultural Study of Cancer.* International Library of Sociology. London ; New York: Routledge.

Steinberg, Paul. 2015. *A Salamander’s Tale: My Story of Regeneration Surviving 30 Years with Prostate Cancer*. Skyhorse Publishing.

Strawson, Galen. 2004. ‘Against Narrativity’. *Ratio (Oxford)* 17, 4: 428–52. https://doi.org/10.1111/j.1467-9329.2004.00264.x.

Stuhlmiller, Cynthia M. 1996. ‘Narrative Picturing: Ushering Experiential Recall’. *Nursing Inquiry* 3, 3: 183–84. https://doi.org/10.1111/j.1440-1800.1996.tb00036.x.

Sulik, Gayle A. 2011. '"Our Diagnoses, Our Selves": The Rise of the Technoscientific Illness Identity'. *Sociology Compass* 5, 6: 463–77. https://doi.org/10.1111/j.1751-9020.2011.00374.x.

Tembeck, Tamar, Carl Bouchard, Pascal Dufaux, Chantal duPont, Angela Ellsworth, Tina Takemoto, Christina Lammer, et al. 2014. *Auto/Pathographies*. Québec: SAGAMIE édition d'art.

'The Constitution of Selves by Marya Schechtman | Hardcover'. n.d. *Cornell University Press* (blog). Accessed 9 June 2023. https://www.cornellpress.cornell.edu/book/9780801431678/the-constitution-of-selves/.

'The Executioner Surgeon'. 1913. *British Medical Journal* 2, 2757: 1177–78.

Thomas, Roanne, and Ryan Hamilton. 2016. 'Composing Hope through Collage: A Community-Based Intervention for Cancer Survivors Living with Lymphedema'. *Health Psychology Open* 3, 2: 2055102916657674. https://doi.org/10.1177/2055102916657674.

Verceles, Avelino C., and Waqas Bhatti. 2018. 'The Ethical Concerns of Seeking Consent from Critically Ill, Mechanically Ventilated Patients for Research – A Matter of Possessing Capacity or Surrogate Insight'. *Clinical Ethics* 13, 3: 107–11. https://doi.org/10.1177/1477750918762350.

Visser, Irene. 2011. 'Trauma Theory and Postcolonial Literary Studies'. *Journal of Postcolonial Writing* 47, 3: 270–82. https://doi.org/10.1080/17449855.2011.569378.

Wang, Caroline C., Wu Kun Yi, Zhan Wen Tao, and Kathryn Carovano. 1998. 'Photovoice as a Participatory Health Promotion Strategy'. *Health Promotion International* 13, 1: 75–86. https://doi.org/10.1093/heapro/13.1.75.

Weise, Jillian. n.d. 'Common Cyborg'. *Granta*. Accessed 29 October 2024. https://granta.com/common-cyborg/.

Wellcome Collection. 2022. *This Book Is a Plant: How to Grow, Learn and Radically Engage with the Natural World*. Main edition. London: Wellcome Collection.

Wendell, Susan. 2001. 'Unhealthy Disabled: Treating Chronic Illnesses as Disabilities'. *Hypatia* 16, 4: 17–33. https://doi.org/10.1111/j.1527-2001.2001.tb00751.x.

Whyte, William Foote. 1991. *Participatory Action Research*. Sage Focus Editions 123. Newbury Park, Calif. ; London, Newbury Park, Calif.: SAGE, Sage Publications. http://ezproxy.york.ac.uk/login?url=http://SRMO.sagepub.com/view/participatory-action-research/SAGE.xml.

Wilde, Mary H. 1999. 'Why Embodiment Now?' *Advances in Nursing Science* 22, 2: 25–38. https://doi.org/10.1097/00012272-199912000-00004.

Williams, Brandon. 2000. 'Collage Work as a Medium for Guided Reflection in the Clinical Supervision Relationship'. *Nurse Education Today* 20, 4: 273–78. https://doi.org/10.1054/nedt.1999.0393.

Willig, Carla, and Luisa Wirth. 2018. 'A Meta-Synthesis of Studies of Patients' Experience of Living With Terminal Cancer'. *Health Psychology* 37, 3: 228–37. https://doi.org/10.1037/hea0000581.

———. 2019. 'Liminality as a Dimension of the Experience of Living with Terminal Cancer'. *Palliative & Supportive Care* 17, 3: 333–37. https://doi.org/10.1017/S1478951518000536.

Wong, Alice. 2020. *Disability Visibility: First-Person Stories from the Twenty-First Century.* New York: Vintage Books, a division of Penguin Random House LLC.

Woods, Angela. 2011. 'The Limits of Narrative: Provocations for the Medical Humanities'. *Medical Humanities* 37, 2: 73–78. https://doi.org/10.1136/medhum-2011-010045.

———. 2012a. 'Beyond the Wounded Storyteller: Rethinking Narrativity, Illness and Embodied Self-Experience'. In *Health, Illness and Disease: Philosophical Essays*, edited by Havi Carel and Rachel Cooper, 113–28. Acumen Publishing. https://www.cambridge.org/core/books/health-illness-and-disease/beyond-the-wounded-storyteller-rethinking-narrativity-illness-and-embodied-selfexperience/E7AA99606B1799FD303C646B2B10F40B.

———. 2012b. 'Rethinking "Patient Testimony" in the Medical Humanities: The Case of Schizophrenia Bulletin's First Person Accounts'. *Journal of Literature and Science* 6, 1: 38–54. https://doi.org/10.12929/jls.06.1.03.

Woolf, Virginia. 2021. *On Being Ill; Introduction by Hermione Lee ; with Notes from Sick Rooms by Julia Stephen ; Introduction by Mark Hussey ; Afterword by Rita Charon.* Ashfield, Massachusetts: Paris Press ; Wesleyan University Press.

Yi, Jaehee, Min Ah Kim, and Sangmin An. 2016. 'The Experiences of Korean Young Adult Survivors of Childhood Cancer: A Photovoice Study'. *Qualitative Health Research* 26, 8: 1044–54. https://doi.org/10.1177/1049732315599374.

Yuen, Felice. 2016. 'Collage: An Arts-Based Method for Analysis, Representation, and Social Justice'. *Journal of Leisure Research* 48, 4: 338–46. https://doi.org/10.18666/JLR-2016-V48-I4-6922.