

Collaborative visual ethnography and breast cancer

Christine Douglass

Faculty of Media, Arts and Design

This is an electronic version of a PhD thesis awarded by the University of Westminster. © The Author, 2015.

This is an exact reproduction of the paper copy held by the University of Westminster library.

The WestminsterResearch online digital archive at the University of Westminster aims to make the research output of the University available to a wider audience. Copyright and Moral Rights remain with the authors and/or copyright owners.

Users are permitted to download and/or print one copy for non-commercial private study or research. Further distribution and any use of material from within this archive for profit-making enterprises or for commercial gain is strictly forbidden.

Whilst further distribution of specific materials from within this archive is forbidden, you may freely distribute the URL of WestminsterResearch:
(<http://westminsterresearch.wmin.ac.uk/>).

In case of abuse or copyright appearing without permission e-mail
repository@westminster.ac.uk

COLLABORATIVE VISUAL ETHNOGRAPHY
and BREAST CANCER

Christine Douglass

July 2015

A thesis submitted in partial fulfilment of the requirements
for the degree of Doctor of Philosophy

University of Westminster

ABSTRACT

The aim of this cross-disciplinary, practice-based PhD was to develop, justify and implement an ethical, collaborative visual research methodology to explore and make visible individual experiences of breast cancer.

Nine women, from different ethnic backgrounds, diagnosed with breast cancer nine-36 months before commencement of the study were given video cameras and invited to film their lives. They filmed for an average of nine months and three weeks.

The practice component of this research comprised nine individual films. Together with a ten-minute single screen compilation, projected diary extracts and notes from the participants, they formed a gallery exhibition, *What if?*

The work has progressed existing debates and practices in shared visual ethnography and cross-disciplinary visual research. It provides an original contribution to knowledge through the development of a methodology that has: challenged the reliance on the interview and prior identification of themes as research interventions; offered new insights into reflexive theorising and positioning of investigators in research relationships; countered homogenising, reductive narrative frameworks; and contested fixed models of consent. It also adds to the literature and practices exploring alternative platforms for exhibiting polyphonic, durational visual ethnographic material and to discussions on filmmaking as a therapeutic intervention.

In investigations into the lives of others diagnosed with illness, the irreducibility of experience, the multiple *truths* that co-exist, and the impossibility of investigators becoming similarly situated, demand a respectful, unexploitative, collaborative research methodology. This research proposed an approach that meets these aims.

CONTENTS

A. ACCOMPANYING EVIDENCE OF PRACTICE

Nine films presented as video files on a memory stick. Duration approximately 46-90.'

Password: author's full name, lower case, no spaces.

B. WRITTEN THESIS

Abstract	2
Acknowledgements	5
Breast Cancer & Definitions	6
Introduction	8
Chapter Outline	12
Research Aims.....	12
Original Contribution to Knowledge	13
1. Contextual Review.....	14
Introduction.....	14
Visual Ethnography	14
A Working Definition.....	14
Jean Rouch.....	15
Ethnographic Film	19
Documentary	30
Illness Narratives.....	40
The Culture of Breast Cancer.....	43
Conclusion	47
Gaps in Knowledge	47
Research Questions.....	49
2. Methodology I: Developing An Ethical Framework & Reflexivity	52
Introduction.....	52
Problematising the Interview	54
The Representational Space and the Participants	59
Visual Ethics.....	64
Emplacement.....	71
Conclusion	84

3. Methodology II: Editing Processes & Representational Platforms.....	88
Introduction	88
Editing	90
The Installation Platform	102
<i>Kuba, Kutluğ Ataman, 2005, The Sorting Office, London</i>	103
<i>Warte Mal! Prostitution After The Velvet Revolution, Ann-Sofi Sidén, 2002,</i> Hayward Gallery London	106
Reflexivity in the Installation Space	108
Audience	111
Conclusion	114
4. Making Visible: Audiovisual Inscription & Participant Benefit.....	117
Introduction	117
The Camera as a Tool of Audiovisual Inscription	118
The Process of Breaking Silences	127
Making Physical Changes Visible.....	133
Conclusion	145
5. Conclusion.....	148
Research Questions	148
Original Contribution to Knowledge	155
Secondary Use of the Research Material	156
Limitations	156
Process versus Product	156
Older Women	157
Silences	158
Further Study	158
Appendices	160
Bibliography	193

ACKNOWLEDGEMENTS

There are nine extraordinary women who embarked upon this experiment with me and who ran with the idea with intelligence and sensitivity, determination and diligence, good humour and great integrity. They never once complained about the intrusion into their lives and were — and continue to be — a constant source of inspiration. Without them this project, and what will follow would not have been possible.

My supervisors at the University of Westminster were Professor Joram ten Brink and Dr. Miriam Dwek; passionate supporters of cross-disciplinary research, they expertly guided me through the PhD process with thought-provoking discussions, encouragement and patience.

I hit the jackpot with my student cohort. Miranda Pennell, Nina Mangalanayagam and Samuel Stevens sustained me with unreserved enthusiasm, rescued me from numerous self-induced theoretical and emotional entanglements, and opened my eyes to new ways of looking at the world.

I am grateful to a number of practitioners, academics, technical experts and colleagues who have shared their expertise; consistently responding to my cries for help in a considerate and thorough manner. Robert Sternberg, Christopher Riley, Aaron Kay, Tony Downmunt, Fergal McGrath and John Smith all generously contributed. Sarah Pink's long distance guidance significantly aided my theorising. I thank her in particular for alerting me to a number of relevant projects and suggesting the significance of feminist art practices to my work. Colleagues, friends and service users at Breast Cancer Care too have kindly shared their valuable knowledge, insights and resources. Beverley van de Molen at Paul's Cancer Support Centre was also hugely helpful in the process of my research. The AVPhD group at Goldsmiths, Lab Meetings at FST UOW, and CREAM Symposia UOW, were fertile grounds for testing and exploring ideas.

Thanks must go to Abir Challah whose unwavering, if somewhat perfunctory advice got me out of many dark holes and to the finishing line. Heather McGregor CBE galvanised and inspired me, as she has so many women. Chloe and George Bustin — gorgeous, brilliant, supportive offspring — I hope I haven't put you off education for life. And PRB, what can I say that hasn't already been said, shouted, muttered or gesticulated?

I declare that all the material contained in this thesis is my own work.

BREAST CANCER AND DEFINITIONS¹

Breast cancer is the most common cancer in the UK with 50,285 new cases of invasive breast cancer and 5,765 of in-situ (early) breast cancer diagnosed in 2011. The life-time risk for a woman developing the disease is 1 in 8, and for a man 1 in 868.

Whilst a single diagnostic label, breast cancer is a highly heterogeneous disease with many variants in tumour type, stage of development and rate of growth, as well as likelihood of spreading beyond the breast tissue.

The cause of breast cancer in most individuals diagnosed with the disease is unknown. Its incidence is most strongly associated with being a woman and age. Some 80% of breast cancers in women occur in the over 50s. It is estimated that 27% of breast cancers are related to lifestyle factors, such as obesity, alcohol and occupational exposures.

It is projected that over half a million people living in the UK have been diagnosed with breast cancer. Eight out of ten people survive breast cancer for more than five years.

Ascites

In secondary breast cancer, if cancerous cells spread to the liver and block the normal blood flow, a build-up of fluid can occur in the abdomen; this is known as 'ascites'.

¹ Statistics from Cancer Research UK & Breast Cancer Care.
<http://www.cancerresearchuk.org/cancerinfo/cancerstats/types/breast>;
<https://www.breastcancercare.org.uk/news/media-centre/breast-cancer-facts-statistics>. Accessed 6 April 2015. The latest statistics for breast cancer incidence are 2011.

ER positive breast cancer

Many forms of breast cancer are stimulated to grow by the hormones oestrogen and progesterone. These cancers are called oestrogen or progesterone receptor (ER or PR) positive.

Genetic breast cancer

Approximately 5% of people diagnosed with breast cancer have inherited a faulty BRCA 1 or 2 gene that predisposes them to increased risk for developing the disease.

Lymphoedema

Lymphoedema is a collection of lymph fluid causing swelling. It can occur from cancer cells blocking lymph nodes or vessels, but it can also occur following surgery. Most commonly in breast cancer it can occur in the arms following removal of lymph nodes from the axillary region.

Secondary breast cancer

Secondary breast cancer occurs when cancer cells from a primary tumour in the breast spread through the blood stream or lymphatic system to another part of the body and form a new tumour. Secondary breast cancer cannot be cured, but it can be treated and controlled.

INTRODUCTION

For some scholars the methodology is a tool through which to achieve research findings, and for them it is the latter that are the most important as a contribution to knowledge. Yet for others... methodology is something that should be critically reflected on as a crucial component in the processes through which we produce knowledge (Pink, 2012a, p4).

This practice-led thesis examined the application of shared visual ethnography as a means of exploring the lived experiences of nine women diagnosed with breast cancer. My research focused on a critical analysis of the *process* of collaboratively producing knowledge.

It responded to calls from within visual anthropology to widen research practices beyond the study of non-Western societies and across disciplinary boundaries; and from healthcare to explore experiences of illness outside clinical models. Visual representations of illness are traditionally dominated by the arguments of filmmakers, broadcasters, institutions or experts; only through their agencies do we learn of the lives of others (MacDougall, 1998, p156).

This research also grew out of issues arising from two short films that I made during my MSc in Science Media Production at Imperial College. *Remember the Day* (2010, London) was a film made with five individuals brought together to discuss a shared pivotal moment in their lives; being diagnosed with breast cancer. *Breath* (2010, London) explored the emotional ambivalence of waiting for an organ donation: of anticipating your own death whilst waiting for someone else to die in order that you might live.

When we made *Remember the Day*, colleagues and I arrived on the day of filming with a thematic script and prepared questions. However, it immediately became evident that — whilst the obliging participants were happy to follow

our guidelines — our assumptions of what would make a good film did not fit their experiences. One key area of divergence was our supposition that the moment of being diagnosed with breast cancer was the ‘worst’ moment of their experiences. This was not the case: one participant explained, “once I knew what it was, once the words breast cancer had been firmly said by the doctor I relaxed into thinking that I am going to deal with this... I’ve got something now to focus on... one bit of uncertainty was over” (2:22). All agreed that the worst moment was finishing treatment and being told to get on with their lives: one participant likened this moment to falling off the edge of a cliff. The breaking of ties with a medical routine and health care support that had dominated their lives for many months was characterised by fear and loss of control. We abandoned the predetermined script and invited the participants to control the dialogue. The production process from that moment on, and the resultant film, was dominated by the persuasiveness of the five individuals’ personal perspectives and the integrity of their arguments.

There is a lack of longitudinal research that focuses on women’s experiences after finishing treatment for breast cancer (Tighe, 2011), and it is on this period that I wanted to focus this research. Audre Lorde highlighted the paradoxical feelings of many individuals on being discharged from medical care:

I was very anxious to go home. But I found also, and couldn’t admit it at the time, that the very bland whiteness of the hospital which I railed against and hated so, was also a kind of protection, a welcome insulation... Going home to the very people and places that I loved most, at the same time as it was welcome and so desirable, also felt intolerable, like there was an unbearable demand about to be made upon me that I would have to meet (Audre Lorde, 1997, p46).

Breath interwove four narratives of individuals and families affected by organ donation. Concerns about how much intervention was ethical surfaced once again. One narrative strand was so acutely sensitive that we struggled to conceive a way to structure an ethical encounter with the people affected. The

“plucking and recontextualization” did indeed feel like a violation (Renov, 1993, p7). In this examination of imminent death, I questioned the capability of representational methodologies for lived experience, in line with Michael Renov and David MacDougall (Renov, 1993, p7; MacDougall, 1999, pp296-7). My colleagues and I decided to organise and record a simulation of occurrences in the hospital; in the context of the whole film this resulted in a “greater truth value for the recreated event” (Nichols, 1993, p176). This is not to make claims to an objective, indexical reality in narrative strands of the film’s subjects and their families – their representations are all “fictive” (Renov, 1993, p7) — but it raised further ethical questions about the process of producing visual knowledge about experiences of illness. What also emerged were concerns about the “ease” with which we, as researchers, enter other people’s lives (Winston, 1988b, p24).

My research sought to acknowledge those with experience of illness as authoritative knowledge producers. I deconstructed the interview and prior identification of themes, gave participants cameras and invited them to film whatever was important to them. I have made no claims to ideologically neutral research; the films are co-productions and the knowledge produced is of a complex, contingent status.

Breast cancer is a conspicuous disease at the level of the population: it is the most common cancer in the UK — a woman’s lifetime risk of developing breast cancer is one in eight — and it is embedded in a discursive regime, the Pink Ribbon Movement, which is arguably not only among the “most popular and influential social movements of the last 25 years” (Klawiter, 2008, p277) but an economy of industrial scale. However, at the level of the individual, breast cancer can be an invisible, silent disease. Whilst Nadine Ehlers and Shiloh Krupar (2012) rightly asserted that we cannot separate the individual from this wider culture, I have proposed that the complexities of individual experience are often obscured by the homogeneous identity promoted by many of the

broader discourses surrounding the disease. These discourses include: the pink ribbon movement; a single diagnostic label for a disease that is medically, as well as experientially, heterogeneous; the paradigm of 'survivorship'; a 'normalising' aesthetic through reconstruction surgery or prosthesis; and autobiographical cancer narratives of fulfilment and resolution (Ehlers & Krupar, 2012, pp1-2). Much knowledge of individual experience therefore goes unsaid and unseen — silenced by cultural, social and medical hegemonies.

Jay Ruby argued that as researchers, we should make our vantage point known (1995, p77). I have three science degrees and have worked in health care and medical publishing, spending much of my career communicating medical and scientific information. Somewhat late in life I returned to University; my MSc immersed me in science communication through film. At the start of my PhD I had been an Ambassador and volunteer for a national breast cancer charity for 12 years. I have not been diagnosed with breast cancer. I can no longer make that statement without experiencing an emotion that is hard to define or put into words. If I fail to articulate my emotions in writing this thesis – it is *not* due to a lack of feeling profoundly changed by the research, and affected by the privilege of being a part of nine extraordinary women's lives for three years.

My research was cross-disciplinary and thus has been exposed to demands and judgments from a number of disciplinary norms. I found this challenging and productive, but also turbulent. I had to learn to "speak" in a number of voices. My work straddles visual anthropology, health care and contemporary art. However, its origins and theoretical base are in visual anthropological projects where cameras were handed over to participants, and the theories and praxis of Jean Rouch. I have been criticised for not more firmly planting my feet in certain disciplinary camps, but have found great benefits from maintaining an interdisciplinary approach. Whilst at times it felt vulnerable, it was also rewarding to develop a practice at the interstices of disciplines.

Eight participants filmed for much longer than anticipated, producing hundreds of hours of footage. Each engaged with the research in different ways, and most expressed benefits to taking part. I have chosen to focus my analysis on the methodology, examining the *process* of producing knowledge, how taking part affected the participants and how my original aims for a single intercut documentary containing all perspectives had to be abandoned.

CHAPTER OUTLINE

Chapter One examines and synthesises published work surrounding the shared praxis of Jean Rouch, projects where the camera has been handed over by ethnographers, and visual texts on illness in general. My initial research questions emerged from identifying the gaps in this literature and are justified at the end of the chapter. Chapter One thus proposes the application of shared visual ethnography to investigating experiences of breast cancer. Chapter Two analyses key aspects of the methodology designed to ethically address representational inequalities. It also considers both the participants' and my own emplacement, and the contingent status of the knowledge produced. Chapter Three problematises the process of editing and displaying the research material. Chapter Four, theorises the ways in which the participants used their cameras as tools of audiovisual inscription, and the impact the research process had on their lives.

RESEARCH AIMS

My principal aim in this research was to investigate, develop and implement an ethical, collaborative visual methodology to explore and make visible individual experiences of illness. Specifically, I sought to challenge existing hierarchical power imbalances and hegemonic practices in visual ethnography, filmmaking and health care research through deconstructing the interview. A further aim was to explore participant and investigator positioning in the research space, theorising how the project was interpreted, how the study and cameras were incorporated into and impacted on lives, and how the cameras were used as

research tools. I wanted also to investigate the importance of feedback screenings and collaborative editing when cameras had been handed over to participants. An additional aim was to publicly present the material produced in a manner that respected both the participants' aims and the nature of production. Finally, I aimed to provide guidelines for future researchers in the field.

ORIGINAL CONTRIBUTION TO KNOWLEDGE

Through my practice and thesis, I propose that my original contribution to knowledge is the production of a novel, ethical, collaborative visual ethnographic methodology that can be used to explore, produce knowledge about, and represent experiences of illness. New insights are offered through the testing of specific research interventions: handing cameras over & not being present during filmmaking (unless invited into the frame by participants); challenging the reliance on the interview and pre-identified themes as investigative tools; contesting reductive models of reflexivity; questioning the positioning of researchers in research relationships; proposing a representational model that counters homogenous, reductive narrative trends; disputing fixed models of consent; and exploring ways of presenting collaborative polyphonic, durational visual ethnography.

The methodology was presented at the National Cancer Research Institute (NCRI) Cancer Conference (Douglass *et al.*, 2013) and received a Prize Award. 'Shared Visual Anthropology and Breast Cancer: Experiences and Perceptions of Tamoxifen Therapy in the Social Context of Women's Lives' (Douglass *et al.*, 2014) was accepted at the same conference in 2014.

1. CONTEXTUAL REVIEW

INTRODUCTION

This contextual review interprets and synthesises published work surrounding the theories and practices of shared visual ethnography, exploring their relevance to developing a methodology for knowledge production by individuals diagnosed with breast cancer. This review examines the shared praxis of Jean Rouch and projects where the camera has been handed over to indigenous people by a visual ethnographer. It provides a critical review of knowledge production in documentaries and visual texts on breast cancer specifically, as well as key illness texts in general. In doing so, it reveals a comparable history of representational practices within visual ethnography characterised by unequal authorial power relationships and passive subjects and notes the rise of subjective filmmaking in the genre. Gaps in the literature are identified and research questions established.

VISUAL ETHNOGRAPHY

A Working Definition

Visual ethnography has a contested, turbulent history from its origins in the late 1890s. It was a colonial phenomenon (de Brigard, 2003, p15) embedded within a hierarchy of Western domination, and has a tradition of engaging in discourse about non-Western cultures. Historically, knowledge has been produced through unequal power relationships, with the “camera being held by a representative of one culture encountering another” (MacDougall, 2003, p125). It was steeped in positivist beliefs about the camera as a scientific object capable of recording a single, objective truth, and the visual ethnographer as a neutral, detached observer.

As a practice, visual ethnography has been characterised by a lack of clear defining criteria and norms. There have been numerous attempts to define it as

a discipline (for example, de Brigard, 2003; Russell, 1999a; Heider, 2006; Henley, 2000; Ruby, 1975, 2000a; Banks, 2001; Fuchs, 1988). In relation to my own research and to *rethinking* methodologies to explore experiences of illness, David MacDougall's proposal to *rethink* anthropology (2006a) resonated. He advocated "a shift from word-and-sentence-based anthropological thought to image-and-sequence-based anthropological thought" (2006a, p225). MacDougall proposed less reliance on science for validity and suggested an emphasis on "how people perceive their material environment and interact with it, in both its natural and cultural forms, including their interactions with others as physical beings" (2006b, p269).

Sarah Pink also provided defining characteristics relevant to my research. Pink proposed that ethnography is a methodology, a process which highlights the influences of the ethnographer's own experiences on knowledge production, making no claims to truth. The text should be as "loyal as possible" to the context and conditions of production; detail intersubjectivities; and, as well as giving insight into observable realities, privilege "the immaterial" and the multisensoriality of experience. Emphasising reflexive, collaborative and participatory practices, Pink stated that the researcher should "recognise the impossibility of 'knowing other minds'... The sense that we make of our informants' words and actions is an 'expression of our own consciousness'" (2007, p22). She questioned the *right* of researchers to investigate and represent the lives of others. Pink argued strongly for the application of visual ethnography across disciplines.

Jean Rouch

The very nature of ethnographic cinema — how it is practiced, how it is talked about, where its limits are deemed to lie — have been profoundly shaped by the work of the late Jean Rouch (Henley, 2009, piv).

Jean Rouch was the first to address the myopic, colonial paradigm, with its unequal power relationships, that shaped knowledge production in early

ethnographic film; this paradigm arguably resonates with Michel Foucault's representation of penal surveillance (Foucault, 1991, pp195-228). Adopting the metaphor of Joram ten Brink (2007), Rouch *built bridges* between cultures in order to both produce and share knowledge. His collective and participatory methodology aimed to produce an "approximate ethnographic reality" while respecting the subjects' own experiential knowledge. He engaged them in "the process of shaping the films' ideas, plots, and characters and he sought their advice and critique of the filmed footage about them" (ten Brink, 2007, p98). Knowledge, Rouch claimed, should not be a "stolen secret" (2003b, p101), but should arise from a mutual understanding; a collaboration. He proposed "a shared anthropology" (2003a, p46), and in doing so "he shrunk the distance and blurred the traditional unequal power relations between ethnographer and subject" (ten Brink, 2007, p98).

Rouch acknowledged two 'forerunners' — Robert Flaherty and Dziga Vertov — whose distinct modes of interaction and authorship influenced the development of his own participatory methodology (Rouch, 2003a, p31). The participatory stance — engagement in production and feedback techniques — adopted by Flaherty in filming *Nanook of the North* was, Rouch argued, a "basic honesty" (2003a, p32). The resulting filmic text was a "celebration" (Feld, 2003, p12) of a relationship between filmmaker and subject. Rouch saw Flaherty's participatory methods as an "indispensable part of filmmaking in the field" as it enabled subjects to "know" the camera and to "understand its capability to see and hear" (2003b, p99).

Vertov's authorial mantra privileged the filmmaker's "sensibilities" (Ruby, 1991, p51) to present a singular vision: "the world as only I can see it... the creation of a fresh perception of the world. I decipher in a new way a world unknown to you" (Vertov, 1984, pp17-18). Rouch praised Vertov's methods of *seeing* life through the "cine-eye", arguing that they created, not a 'pure truth', but a new, "particular truth of the recorded images and sounds – a filmic truth (cine-

verite)" (Rouch, 2003b, p98). In contrast to Flaherty, Vertov was concerned with using unstaged filming to produce pockets of 'reality'. Vertov's reflexive strategies and themed editing style clearly demonstrated the mediated nature of film. The distortion of truth by the filmmaker and the filmmaking process was something that Rouch both acknowledged and addressed.

There were "a number of different stations on 'the path of shared anthropology'" (Henley, 2009, p317). Feedback screenings were an integral part of an ethical process. They encouraged the co-construction of knowledge *with* subjects, rather than the promotion of a single filmmaker's perspective *about* others. They led to greater insights for Rouch as a filmmaker-ethnographer, as well as increasing the participants' understanding of Rouch's aims. In addition, they stimulated ideas for further films (*ibid.*).

Another 'station' is the concept of fieldwork as an ethnodialogue (Feld, 2003, p19) that is used to "show how the filmmaker observer, while recording these phenomena, both unconsciously modifies them and is himself changed" (Rouch, 2003b, p87). This was practiced by Rouch in his work in West Africa with the Songhay-Zarma. As a further example of Rouch's collaborative methodology, he actively engaged in training African filmmakers.

Moi Un Noir (1958, France) was the first example of shared anthropology where the subjects were afforded authorial self-representation. Rouch credited the participants with having done everything (Rouch, 2003c, p221): having become authors and taken responsibility for knowledge production. The participants' voice-overs provided a subjective narration, in combination with Rouch's objective scene-setting. However, the balance of power within the voice-overs, the overall 'voice of the film', was debated by Steven Ungar (ten Brink, 2007, p114) who questioned whether Rouch spoke as a privileged outsider or as an insider collaborating on equal terms. There was certainly collaborative profit-sharing (Rouch, 2003c, p221); a profound and literal shift in film ownership.

Whilst lacking the ethnographic interest of his other films during this period, *La Pyramide Humaine* (1961, France) demonstrated the evolution of Rouch's participatory cinema (Henley, 2009, p100). As in *Moi un Noir*, Rouch shared authorship with the participants. The setting up and viewing of rushes by the protagonists was included in the film. Rouch's presence on- screen attested to his developing reflexivity.

Rouch's practice was not without critics who proposed that some of his work reinforced, rather than broke down, colonial frameworks. *Les Maitres Fous* (1955, France) was condemned for "reinforcing stereotypes of savagery" (Eaton, 1979a, p6). Nwachukwu Frank Ukadike relayed how "objectionable" *Les Maitres Fous* was to Africans (Ukadike, 1994), previously having accused Rouch of treating them like "scientific specimens" (Ukadike, 1987/88, p14). However, the methodology and the form of the film — cinema verite — which Ukadike (1994, p51) admitted had cultural specificity, undoubtedly contributed to the differing readings of this particular film.

In *Chronicle of a Summer* (1960, France), Rouch's last collaborative film, both the camera and filmmaker provoked action. *Chronicle of a Summer* was of particular interest to my PhD as Rouch, with Edgar Morin, turned the camera away from non-Western cultures and engaged in the study of a European 'tribe'. The film opened with a (seemingly) very open-ended question - "How do you live?" Through collaboration, where there was "no moat between either side of the camera but free circulation of ideas" (Morin, 2003, p233), and influenced by Vertov, Rouch as co-participant explored life "within the context of the film" (Hockings, 2003, p126). Ruby noted that *Chronicle* was the first reflexive "social-science film" (2000d, p169). Upon completing the research Rouch and Morin invited all the participants to see the rushes together in conditions conducive to "camaraderie" (Morin, 2003, p234). They requested comments to help illuminate the process of participating and the "truth" that they sought through the film. The film did not seek to offer narrative resolution for viewers,

“but an open “to be continued” for each one” (*ibid.*, p234).

Rouch acknowledged that as a filmmaker it was impossible “to be a witness to things happening around you and not take a stance” (1985, p19). He asserted that the future of participatory cinema, the culmination of collective “dreams”, was that the camera would “automatically pass into the hands of those who, until now, have always been in front of the lens” (Rouch, 2003a, p46). This idea stimulated and informed this PhD.

Despite *Nanook*’s antecedence and Rouch’s body of collaborative work, most filmmakers in the English-speaking world did not build on Rouch’s participatory methodology for some time.

Ethnographic Film

A significant shift in the hierarchy of objective versus subjective knowledge began to emerge in the 1960s. A detailed examination of the broader origins of this shift is beyond the scope of this thesis. Ruby noted three key contributing factors: the end of the colonial era; the challenge to the prevailing positivist assumptions of scientific knowledge exemplified by Thomas Kuhn’s *The Structure of Scientific Revolutions* (1962); and the emergence of a “‘new’ journalism” that blurred the boundaries between fiction and non-fiction (Ruby, 1991, p53). Subjective knowledge prior to this period was “constructed as a kind of contamination, to be expected but minimised” (Renov, 2004a, p174).

A general *unease* about representational practices in anthropology surfaced in the 1970s as challenges to positivist models of knowledge production were mounted (MacDougall, 1998, pp125–139). In visual anthropology, questions were raised about the legitimacy of the dominant paradigm of authorship — the “monologic, observational, and privileged Western Gaze” (Ginsburg, 1995, p74) — and of the camera as a scientific instrument presenting a window of reality.

Considerable academic capital was invested in debating the crisis of representation² by visual anthropologists. A call for more subjective, reflexive ethnographic cinema was articulated by MacDougall, who questioned the current practices of film production where knowledge created was generally only what the filmmaker found significant (1998, p126) and was obtained by the filmmaker's "invisibility and omniscience" (*ibid.*, p129). MacDougall proposed a new mode of engagement to address these unequal power relationships: "a participatory cinema, bearing witness to the 'event' of the film and making strengths of what most films are at pains to conceal" (*ibid.*, p134). Margaret Mead, too, rallied for openness and "the articulate, imaginative inclusion in the whole process of the people who are being filmed - inclusion in the planning and programming, in the filming itself, and in the editing of the film" (2003, p8). The validity (Nichols, 1983; Ruby, 1991) and morality (Ruby, 1995; Elder, 1995) of speaking for others was called into question. Ruby proposed that the traditional role of the ethnographer be modified to that of a facilitator or collaborator, and suggested that ethnographers should start to "filmicly explore their own culture" (1995, p78).

In the tradition of Rouch's shared anthropology and revisiting the epistemological arguments from the documentary film movement some 30 years earlier (MacDougall, 1998), a number of filmmakers in the field began to directly challenge the "inexorably hegemonic and homogenizing" (Ginsburg, 1998, p187) constraints, biases and preconceptions imposed when the representative of one culture constructs knowledge about another. Subjectivity ceased to be considered a pollutant and became "a filter through which the Real enters discourse as well as a kind of experimental compass guiding work towards its goal as embodied knowledge" (Renov, 2004a, pp174–176). Shifting

² Most authors attribute the phrase "crisis of representation" to George Marcus and Michael Fischer, who argued that this crisis arose from "uncertainty about adequate means of describing social reality" (Marcus, 1986, p8). Clearly, though, Rouch and others had been addressing the inadequacies of representational practices prior to this phrase being coined.

to reflexive, dialogical participatory modes, projects sought “not to mask but to recuperate ... collective stories” (Ginsburg, 2002, p40) and to resurrect voices drowned out by the dominant culture.

Richard Chalfen proposed categories to define the emerging subject involvement in knowledge production. He offered a (by no means exhaustive) list including: the appearance of willing, coerced or unsuspecting subjects in films; subject participation in editing processes; subject-selected topics; feedback screenings for participants; and filmmakers following Indigenous filmmaking incentives (Chalfen, 1989, p71-73). Elder (1995, p94) suggested that “the term collaboration has long served as a politically acceptable catch-all description of most joint efforts”. Barbara Myerhoff and Jay Ruby rightly proposed that anthropological knowledge arises from “a collision of two viewpoints” but then rather optimistically concluded that the ethnographers’ and subjects’ views meet “in a middle terrain” (Myerhoff & Ruby, 1982, p20). MacDougall accurately acknowledged the “confusion of perspectives” that participatory methodology can generate (1998, p138). The lack of clear defining criteria remains, with Caroline Bennett more recently concluding, “there is almost no consensus on how the term is used” (2012).

My praxis and theorising was informed by reviewing ethnographic projects where the camera was handed over by anthropologists. Chalfen’s classification recommended two broad types: i) where subjects were asked to make films by/with a filmmaker/anthropologist: researchers asked community members to make a film about whatever they liked, after some instruction in camera use; or they asked subjects to make films on specified topics; or they might have combined footage produced by subjects with their own; or they requested that subjects made their own films within specified anthropological conventions and boundaries; ii) where community members initiated their own projects.

These boundaries may not be as clear-cut as Chalfen suggested with many

anthropologists' incentives leading to community members initiating their own projects in the heritage of Rouch. That said, it has been helpful to use his categorisation to identify projects informing my research. Chalfen provided a detailed historical examination of many of these projects (Chalfen, 1997) which together with Faye Ginsburg's writing on Indigenous Media (i.e., 1991, 1993, 1998) have offered extensive background to the emergence of collaborative practices. I drew from some exemplars.

Sol Worth and John Adair's ground-breaking project with Navajo Indians (1960)³ challenged positivist empirical paradigms of knowledge production. Fulfilling Rouch's vision of putting the native's eye behind the camera they asked "what would happen if someone with a culture that makes and uses motion pictures taught people who had never made or used motion pictures to do so for the first time?" (Worth, 1997, p3). The Navajo were instructed to film whatever they wanted to (the researchers avoided making statements concerning what the films should be about) and encouraged to actively engage in the editing process. The research sought to reveal how the makers constructed knowledge and meaning. Subsequently the term bio-documentary was proposed to describe a film made by a person, who is not a filmmaker "to show how he feels about himself and his world" (Worth, 1997, p25). This methodology provided an opportunity to see how knowledge constructed by indigenous peoples compared to knowledge constructed by anthropologists.

In Western culture, and concurrent with Worth and Adair, Chalfen made 16mm films with culturally diverse teenagers. He observed how varied ways of seeing and the different types of discourse produced were connected to "cultural dimensions surrounding the image production" (Chalfen, 1989, p76). He noted class as the most significant variable (rather than ethnicity or gender). In

³subsequently published in *Through Navajo Eyes* (Worth, et al., 1997).

Philadelphia in 1971 he addressed “how young Black people in an urban poor neighbourhood perceive their world” (Chalfen, 1971, p91) by inviting teenage girls, identified as being at risk from pregnancy, to make 16mm films about themselves, advising them only on technical and not content issues.

The *Fogo Island Project* was a community development programme and cornerstone of *Challenge for Change*, National Film Board of Canada (1967-1980). It “used film as a catalyst to generate local debate — to give local people a voice and even editorial control — and to provide those people with access to people in power, via film” (Low, 2010, p17). Cameras were handed over in some 40 films, with the Canadian Government “replying” through video letters. The researchers taught how to film in a structured way. The product was not a single spectacle and was largely unedited with the film crews becoming a part of the political conflict (Lansing, 1990, p12).

Several prominent projects followed Worth and Adair’s study. Ronald Light and Bradley Henio introduced video filmmaking into a community of teenagers in New Mexico aiming to study the cultural context of filmmaking as well as the “social organisation surrounding the production activities” (Light & Henio, 1977, p10).

A study by sociologists Beryl Bellman and Jules Rosette Bennetta with indigenous groups in Western Africa was influenced significantly by the work with the Navajo a decade earlier (Bellman & Bennetta, 1977). The resultant films - from both rural and urban indigenous filmmaking groups - revealed the emergence of distinct film languages. Notably the overall style of filmmaking was quite different to the Navajo filmmakers who knew that their films would be edited, whereas Bellman and Bennetta instructed subjects to shoot complete sequences with the camera.

Timothy Asch recognised that as an outsider in the process of filmmaking, he

had been “inevitably constructing” his version of the Other’s reality. “Our relative outsider status means that we can never really know enough to be able to represent aspects of another culture the way they are experienced by members of that culture” (Asch *et al.*, 1991, p103). Choosing the role of a ‘catalyst’ he described the difficult process of giving up control as he handed the camera over and taught the Yanomami how to make their own films. Avoiding the paternalistic cliché of ‘giving voice’ by acknowledging, “they have their own voice” he argued “why should North American representation of South Americans dominate” (Asch *et al.*, 1991, p106).

In the projects that Duncan Holaday facilitated (notably in West Java and West Malaysia) he emphasised that the ethnographic video process required a detailed observation within the context of a given culture (Holaday, 1991, p5). He warned against reinforcing “the conceit that if we, as anthropologists, are explicit about the assumptions we are making in describing others, then our descriptions will somehow be more ethical and accurate” (*ibid.*, p6). Indeed Timothy Kennedy, Producer of Challenge for Change, described the need to “draw out community members — to encourage full expression of ideas and opinions without imposing his or her agenda” (Kennedy, 1989, p5).

Terence Turner charted the evolution of media usage in self-documentation programmes by the Kayapo of Brazil (Turner 1990, 1991). He described the associated shift in control and power over the terms of engagement for the Kayapo, the changing role for the anthropologists from “participant observation to observant participation” (*ibid.* p12) and the nature of the reality being documented.

Mark Badger and Asen Balikci (1993) handed cameras over to indigenous groups in Siberia who had expressed an interest “in using video to extend the awareness of Khant culture and to encourage its preservation and revitalisation in context of its emergence from mainstream Soviet society” (Badger & Balikci,

1993, p145). Subjects were instructed in camera techniques, and collective decision making in seminar format led to the selection of topics for films. Unlike the Navajo project, ethnographic 'rules' and filmmaking values were asserted that restricted the potential outcome. Interestingly the students regarded themselves as "active participants" rather than just "passive participants" in the process (*ibid.*, p147).

Brazilian activist Vincent Carelli used photographs and video "to foster indigenous cultural and political self-awareness and autonomy" (Aufderheide, 1995, p83) with a number of Indigenous groups. The Video in the Villages project included both the provision of video equipment and instruction in and encouragement of its use, as well as documenting the impact of the technology.

Eric Michaels set out to replicate the Navajo study in Australia in the 1980s giving greater attention to the documentation of the process (Michaels, 1985). The cultural reality of Indigenous Australians and the political circumstances of the time meant that he adopted an activist approach (Ginsburg, 1993, p565) rather than one of pure research, engaging in training and instruction in the use of video. His focus became the culturally sensitive use of media in the pursuit of human, political and social rights — under the guiding principle of filming life as it unfolds, finding himself walking the line between "facilitator, advocate and cultural broker" (Ruby, 2000e, p227).

More recent examples based on the methodology and experiences of Worth and Adair include Michael Rich and Richard Chalfen's applied visual ethnography in a healthcare setting in Boston's Children's Hospital (i.e., Chalfen & Rich, 2009; Rich *et al.*, 2002, 2000; Rich & Chalfen, 1999). Adolescents with chronic medical conditions were given a specific remit: "Teach your clinician what it means to live with your condition." Whilst the prescribed authorial instructions reinforce power imbalances both in the clinic and in ethnographic authorship models, and indeed run counter to the principles of collective methodology for my work, the

study is the most extensive example of a visual ethnographic methodology being applied in a health care setting to elicit “voices and perspectives through visual illness narratives” (Chalfen *et al.*, 2010, p201). A similar study was conducted by Mara Buchbinder *et al.*, (2005) who gave video cameras to children with diabetes for four weeks to record their lives.

Influenced by Pink’s cross-disciplinary applications of visual ethnography, doctor and documentary filmmaker Gretchen Berland spent over a decade handing over cameras to ‘*her patients*’. She challenged the effectiveness of the clinical encounter to elicit knowledge about lived experience of illness: “As nuances of a *patient’s* experience are compressed into standardized responses, statistical power is achieved, but depth is lost” (Berland, 2007, p2533).

Barbara Ellen Gibson invited a group of young men with Duchenne muscular dystrophy to produce video accounts of their lives as part of a broader interview-based investigation into identity (2005). Whilst the participants only filmed for a week, her analysis of her role gives insight into the status of the knowledge produced, which she clearly describes as a co-production.

Using visual research methodologies within a sociological framework, Ruth Holliday handed cameras over to explore the performance of sexual identities in three different spaces — domestic, social, employment (Holliday, 2009, 2004, 2000). She invited participants to make video diaries, and the focus of her research was the construction of identity through the production of these diaries. Also originating from a sociological background is Donna Barnes *et al.*’s work with HIV-infected mothers (1997). They used collaborative visual methodologies to enable the mothers to produce legacies for their children. Whilst cameras were not “handed over” researcher influences on the content of the legacies were minimal and clearly documented.

In other anthropological investigations of illness, Andrew Irving acknowledged

the limitations of conventional approaches to exploring HIV experiences, and “accessing the imaginary” proposing a cross-disciplinary approach (and drawing from Rouch) using collaborative research methods. His research involved performance and photography to explore experiences and memories of HIV within the context of everyday life (Irving, 2007). Christine Lammer’s applied visual ethnography in the health-care setting is informed by narrative medicine, visual anthropology and anthropological theory of visual art. She cited Chalfen and Rich’s work as influencing her practice. Working within the clinic she used video as a tool of “self-reflection” for both *patients* and health care professionals. Her work centred on the mediation of relationship between clinician and *patient*, “communicating and teaching emotional competence to physicians and medical students” (Lammer, 2009a, p266). A particularly pertinent example of her mediations follows one *patient’s* articulation through video of her decision to decline medical advice, putting herself in a situation deemed at-risk by the medical profession.

The ideological intent of handing the camera over has been challenged on many levels. Trinh Minh-Ha problematised how the processes of multiple voices and reflexivity were understood. If only used as self-criticism, or to enhance anthropological knowledge or improve anthropology itself then “what is achieved is either a refinement in the pseudoscience of appropriating Otherness or a mere stir within the same frame”. She argued further that polyphonic perspectives articulated from within specified boundaries do not necessarily provide a solution to “centralised and hierarchical knowledge” (Minh-ha, 1999, p215).

Rachel Moore questioned whether handing the camera over was an adequate solution to the crisis of representation. She acknowledged that this power shift transformed the historical power relations in filming the Other and the associated “unquestionable ethnographic authority” (Moore, 1994, p128), but proposed that handing the camera over “just at the point when our own

methods and theories appear to be exhausted not only defers the critique... but far more importantly pre-empts the creativity... required to change them". The problem that academics and Western practitioners were trying to address has merely been transferred. Like Ruby (1991) and Asch (1991), Moore acknowledged the potential disruptive effects due to the power of the media itself. Minh-ha expressed concerns about the Navajo project serving "white anthropology to further anthropologize man" (1991, p72). Ginsburg noted that the Navajo project, in focusing on semiotics and ways in which meaning was produced, failed to fully consider the social framework of the production (1991, p95). In addition, Moore argued that Asch's work only "presents the reverse side of the positivist coin" (1994, p129). MacDougall warned of the possibility that including indigenous narratives may reinforce the voice of the filmmaker rather than actually "making indigenous statements" (1998, p154).

Furthermore, Catherine Russell argued, "within the arena of ethnographic film 'handing the camera over' to a native filmmaker often simply perpetuates the realist aesthetics that experimental film form has dislodged" (1999b, p11) and that the importance of this methodology lay in the fact that other voices, other perspectives were heard. Ruby (1995, p78) admitted that many of these works could legitimately be seen as paternalistic and warned against the subordination of voices, but concluded (somewhat paternalistically himself) that it may be the only way as "few have the wealth of knowledge to do it on their own".

To conclude that handing the camera over provides unproblematic or indeed unmediated knowledge would thus be naïve. The nature of the encounter and the rendering tendencies — project design, aims and implementation, ongoing interactions, editing and production — will directly influence the knowledge produced. In order to address power inequalities in representations, we must look thoroughly both "at the tools that define ourselves and our own activities" (Minh-ha, 1999, p61). Reflexivity is not just about didactically exposing a

researcher's role.

Ruby defined reflexivity thus: "the producer deliberately, intentionally reveals to his or her audience the underlying epistemological assumptions that caused him or her to formulate a set of questions in a particular way, to seek answers to those questions in a particular way and finally, to present his or her findings in a particular way" (Ruby, 2000d, p156). Winston went further by arguing that for Rouch and Morin "the only subject for documentary film was the making of a documentary film" (1988b, p24). Pink who warned of getting caught up in "a race to be the most reflexive", provided an overview of reflexive practices across disciplines, and defended visual anthropology against accusations that it is an un-reflexive discipline (2006, pp32-38). MacDougall labelled Ruby's proposal as an "external" reflexivity and argued for reflexivity that is "inscribed in the nuances of detail" (Taylor, 1998, p18), in the "very construction of the work" (MacDougall, 1998, p89). The challenge of reflexivity, Minh-ha argued, is "how to keep the process 'alive' so that it becomes integral to the film itself" (1999, p73). Pink, too, stated that reflexivity should be:

integrated fully into processes of fieldwork and visual or written representation in ways that do not simply explain the researcher's approach but reveal the very processes by which the positionality of researcher and informant were constituted and through which knowledge was produced during the field work (2006, p 35).

Paul Basu (2009) analysed how visual ethnographic work is presented. He proposed looking beyond conventional formats, arguing that "other than in its most didactic form, the filmic version of ethnographic thick description is not served well by the 30-minute, 60-minute or even two hour narrative film format" (*ibid.*, p107). Basu's writing alerted me to the work of Kutluğ Ataman (*Kuba* 2005, London) and Ann-Sofi Sidén (*Warte Mal! Prostitution After the Velvet Revolution*, 2002, London) and their use of an installation/exhibition

platform to display durational, polyphonic material.⁴ Similarly, Cahal McLaughlin's documented considerations about the final form of his collaborative research into political violence in Northern Ireland was important for this enquiry as his work gives further insight into resolving the problems of presenting multiple perspectives in conventional documentary form (McLaughlin, 2010).

DOCUMENTARY

Since few visual ethnographic texts exist on breast cancer, or indeed on cancer in general, I will now look to documentary film and other films of fact, to consider how individuals with cancer have been represented and how knowledge has been produced.

The first films made by the medical profession for the medical profession emerged as early as the late nineteenth century, and included studies of the mammalian heart, joint movements and Parkinson's Disease (Essex-Lopresti, 1997). For many decades these films were authored by institutions such as governments, armed forces and pharmaceutical companies. Surgical procedures were recorded on film from the late 1890s; the first example was made by Parisian surgeon Eugene L. Doyen for teaching purposes. These films "dominated the films made in the next four decades" (*ibid.*, p819). Jose Van Dijck has argued that as these films — originally developed by and for professional audience — evolved, authorship diversified and audiences widened; this contributed to the normalisation of the "spectacle of illness" under the guise of "medical information and human interest" (Van Dijck, 2002, p552).

Health propaganda films (so named before the term 'propaganda' acquired its pejorative meaning) emerged from the 1920s on both sides of the Atlantic, in a

⁴ I refer to the specific installations in London for both Ataman and Sidén's work.

wave of enthusiasm for film's potential as a mass education device. Fictional narratives were adopted largely because "a particular set of conventions for cinematic narration" already existed (Kuhn, 1988, p50) in the dominant *Other*, the fictional film. Illness representation was thus wedded to a culturally-validated narrative form. Many educational cancer films, including films on breast cancer, were produced in the USA, and have been extensively studied by David Cantor (2007, 2009), Leslie Reagan (2007), and Kirsten Gardner (2006).

The American Cancer Society used film widely as an educational tool. A number of these films featured breast cancer. Millions of women saw the 1950, and 1960s remake, of *Breast Self-Examination* (1950/1960 USA American Cancer Society), making it one of the most successful and long-running health campaigns of the twentieth century (Reagan, 2007, p164). Conversely extensive research in the Archives of the British Empire Cancer Campaign (1923-1981) and the BBC, NFI and BMA archives has failed to uncover any early British educational films on cancer. Three 'appeal' films were produced for fundraising purposes in 1959, 1958 and 1953. UK medical authorities were very resistant to engaging in lay cancer educational programmes (Toon, 2007). It was not until smoking was linked to cancer that British authorities took a real interest in cancer-related public health programmes.

In the UK, early educational films tended to focus on infectious disease and social hygiene. Authored by institutions these were 'narrow' educational films. Each presented a clear linear narrative or argument, seeking to alter public behaviour and achieve widespread health improvement (Boon, 2005, 2008). Medical authority dominated narratives in these films (Boon, 2005, p49). The authoritative medical voice — either visible or disembodied — and the doctor's 'clinical gaze' (Foucault, 2003) established his superiority over both *patients*, particularly women (Reagan, 2007, p163), and audiences. The gaze has origins in "a reordering of the relation between the visible and invisible which permitted an objectifying gaze authorised as expert knowledge" (Kuipers, 1989,

p104). Consequently, *patients* in these films were subordinated and objectified or became specimens (Reagan, 2007, p179). The arguments presented in early health documentaries were grounded in positivist notions of knowledge and the received-view of science, wherein only scientific knowledge has validity.

Many producers of science and health documentaries were slow to embrace subjective knowledge, and their views remained embedded in scientism (Silverstone, 1985, p4). Mirroring the reductionist approach of the medical profession, they have “tended to focus attention more on disease mechanisms than on those who are suffering from the disease” (Weatherall, 2003, p13). Like medical experts, they have dismissed the *patient’s* voice as being an unreliable distraction, unstable and subjective. Indeed, the camera itself adopts a similar objectifying gaze.

The health documentary was cemented in positivist ground by the views: that documentary film presented “uncontested statements of fact” (Ruby, 1991, p53); the belief that subjectivity had the “potential to colour or subvert objectivity” (Nichols, 1991c, p159); the historical linkage of both the camera as a scientific instrument and the “non-fiction film and the scientific project” (Renov, 2004a, p173); as well as the persistent received-view perspective of medical and scientific professionals. Robert Sternberg’s PhD thesis (2010, University of Westminster) explores positivism in relation to the documentary form and proposes an alternative epistemology and practice.

Whilst the perspective of the more contemporary health documentary film widened from the early origins, a clear linear narrative continued to be the norm. Arguments remained driven by expert interpretation of the verifiable aspects of physiological progression, investigation, or treatment, and linear narrative occupied space that might be allocated to *patients’* responses or interpretations. The voice-of-God narration was replaced by the intermittent introduction of an expert talking-head; but this failed to challenge earlier

hierarchies as “the off screen voice of authority simply moved into the frame” (Ruby, 1991, p54). Positivist predilections still strongly influence issues of authorship, knowledge production and representation of those with illness: medical authority tends to dominate the voices of those with illness, as ‘expert’ testimony provides an interpretation of how subjects feel and often subjects voices are used to support the filmmakers’, experts’ or institutions’ agenda (for example, *Shadow of Breast Cancer*, 1992, BBC; *Caught in the Machine*, 2010, BBC; *Herceptin*, 2006, BBC).

From the end of the 1990s, some mainstream television documentary filmmakers began to explore personal experiences of breast cancer without relying heavily on medical opinion. Personal illness narratives such as *Kissed by Angels* (2003, Channel 4), *Beating Breast Cancer: Marsha’s Journey* (2005, ITV), *Angela’s Dying Wish* (2005, Channel 4), *My Breasts or My Life* (2006, ITV), and *Miranda’s Chest* (1998, Channel 4) provide accounts of illness that relied less on expert testimony. In *Miranda’s Chest* — a documentary about a young, beautiful model and mother of young children who had a bilateral mastectomy — the filmmaker constructed a compelling story manipulated into a conventional dramatic broadcast model. This fit with Bill Nichols’s notion of documentary as fiction where they “offer introductory lacks, challenges, or dilemmas; they build heightened tensions and dramatically rising conflicts, and they terminate with resolution and closure” (1991b, p107). It also echoed Winston’s description of ‘victims’ in documentaries: a “parade of those of the disadvantaged whose deviance was sufficiently interesting to attract and hold our attention” (1988a, p34), a spectacle legitimised by the documentary framework. Textual authority remained firmly with the filmmaker and there was little, if any, evidence of collaboration. It was reminiscent of Dai Vaughan’s warning: “people are having scripts written for them out of their own words, and performances drawn from the repository of their unguarded gestures” (1999, p71). Angela Armstrong-Coster through an analysis of the production processes of two documentaries made about a woman dying from breast cancer, showed how editorial

influences shaped the film “to comply with a contemporary popular ideology on how death should be rather than presenting the actual truth of lived experience” (2001, p287).

The history of factual health films has included notable examples of shifts in authorial power. The feminist health movement, spearheaded in the early 1970s by the Boston Women’s Health Book Collective (now known as Our Bodies Ourselves) challenged head-on the dominance of institutionalised and positivist authorship in 1970s health films. Activist-produced films such as *Taking Our Bodies Back* (1974, USA) and *Healthcaring from Our End of the Speculum* (1976, USA) gave responsibility for the text to the community that it represented. Expert opinion and established medical views were confronted directly as women engaged in active discussion about treatments and diagnostic decisions, challenging normative authorship in health films and film distribution.

In 1973, the American Cancer Society produced a further film on breast cancer, *Breast Cancer: Where We Are*. This film acknowledged how the feminist movement was shifting the paradigm towards women having more control over their bodies by showing a more personalised relationship between doctor and *patient* and, indeed, showing more female physicians. However, it also reinforced certain normative ideals and behaviours, including the ultimate authority of the medical profession, women’s subservience to that power, and the culture of blame surrounding women diagnosed with breast cancer (Gardner, 2006, pp200-203).

A striking divergence from the dominant mode of knowledge production in health films was triggered by the media coverage in the years immediately following the identification of AIDS: coverage was sometimes absent, but more often incomplete or inaccurate. Alexandra Juhasz (1995) charts the emergence of AIDS media from epidemic’s beginnings in the early 1980s.

In her own practice, Juhasz saw collaboration as the “obvious and ubiquitous alternative to victimhood” (2003, p74). Juhasz claimed that her community AIDS videos conveyed, not the truth, but a “better vision of those individuals’ reality” (1999, p207). Exemplified by the film *We Care: A Video for Care Providers of People Affected by AIDS* (WAVE, 1990, USA) these productions allowed “us to speak our needs, define our agenda, counter irresponsible depictions of our lives, and recognise our similarities and differences” (*ibid.*, p212). Knowledge production in this film had a defined purpose for a specified audience (those with AIDS or their carers), and marked a shift in authorship, and indeed audience, from the white, middle-class, heterosexual male.

Catherine Saalfeld (1995) provided a comprehensive videography of (largely) collaborative AIDS media. At the core of these productions was the belief that those affected by the disease are best qualified to produce representations of it.

Around this time, independent documentary films emerged that focused on personal experiences of breast cancer, particularly from North America. The filmmakers often had experienced breast cancer,⁵ for example: *My Left Breast* (2000, Canada), *The Breast Cancer Diaries* (2006, USA) and *Ich Will Ja Leben, Oder?* (2009, Germany). The latter two films, were edited/directed by an outsider. Some films were made by filmmakers whose close family member had been affected by the disease, for example: the experimental short-film *Amazonia* (2001, USA) and *Busting Out* (2004, USA). Other films that originated from personal experience of breast cancer produced in close collaboration with filmmakers/directors who had not had breast cancer, include: for example, *About HER* (2010, Canada) and the highly individualised, experimental

⁵ This thesis has not focused on autobiographical films, but rather has noted their existence as subjective independent ‘documentary’ representations of breast cancer. I have made no claims that my practice is eliciting autobiographical/autopathographical texts, and have been hesitant about including unframed first person filmmaking about illness experiences in my line of enquiry. However, I have referred to some autobiographical examples that highlight important considerations in my work.

interpretation of Jonna Tamases' breast cancer diagnosis — *Jonna's Body* (2007, USA). It is impossible to know the composition of the voices in these films; however, I do have insight into Feustel's documentary, *Ich Will Ja Leben, Oder?* to which I will return. These films demonstrated the emergence of subjective personal filmmaking about breast cancer.

In mainstream television, the BBC also mounted a challenge to prevalent models of documentary authorship with *Video Diaries* (1990) and *Video Nation*. *Video Nation* had its roots in Britain's 1930s Mass Observation project. Described as "an ethnography of the people by the people for the people" (MacClancey 1995, p495), it was an example of anthropology in a home setting. In *Video Dairies* and *Video Nation* knowledge was produced by (heavily vetted) volunteers from the general population.

The appeal of this mode of knowledge production was both political, providing a democratic manifesto for participatory television, and aesthetic, in respect to the camcorder (seemingly) producing "the closet shave yet" — the reduced image quality served only to enhance the text's 'authenticity' (Keighron, 1993, p24). Jon Dovey wrote about the emergence of the "self-made documentary portrait" (2000, p60) in relation to *Video Diaries*, and more generally of the *belief* of a "foregrounding of the individual subjective experience as a guarantor of knowledge" in factual TV (*ibid.*, p21). It is difficult to ascertain the balance of authorship — how self made — the diaries actually were; which the editor of *Video Diaries* admitted was down to the integrity of the editorial team and broadcaster. Institutional guidance was clearly pronounced (*ibid.*, p25). Richard Kilborn concurred that diarists were "operating much more to the broadcasters agenda than they might imagine" (1998, p206). Dovey argued that whilst there was a shift in power relations in *Video Diaries* it was the "formal aspects of the diary" — rather than an egalitarian model of authorship — "that contribute to a strongly embodied sense of authorial presence" (Dovey, 2000, p 61). However, examples from this series do provide a rare instance of collaborative,

consultative production methodology in institutional broadcast settings.⁶

Surviving Memories (1991, BBC2) is an example from the aforementioned series, in which Jo Spence filmed her experiences following her leukaemia diagnosis. In a highly personal account, she showed her sick self in constant flux: isolated, fragmented, unstable, and obsessive. She grounded her illness experience in the political, acknowledging its wider social implications. Despite being a highly reflexive political film, it succumbed to the homogenising and normalising tendencies of a culturally validated narrative form. Again, the degree of self-inscription and outside intervention is impossible to measure.

Beyond this BBC incentive, examples of 'handing the camera over' projects in documentary/films of fact about illness are few. Director Mark Wilkinson gave a camera to a young teenage mother with terminal cancer when making *To Courtney with Love* (2005, BBC). The young mother, Beckie, wanted not only to make a film, but also to leave a legacy for her daughter. Whilst the film appears to be an example of first-person filmmaking, the director told me in an interview that he was present throughout all filming; that only 25% of the text was actually filmed by Beckie, and even that was largely influenced and controlled by Beckie's sister as well as himself, and that when filming he often mimicked Beckie's style in order to fulfil aesthetic requirements, concealing this from the audience (personal communication). Wilkinson also made *You, Me and Cancer* (2010, BBC), where cameras were handed over to three individuals to record their experiences of Hodgkin's lymphoma, testicular cancer and cervical cancer. Again, the resultant film was a combination of self-filming and filmmaker-authored text, relied heavily on voice-overs, and had structured narratives with evidence of the filmmaker's interaction and interventions.

⁶ Sue Dinsmore (1996) provided an overview of the BBC series from 1990 – 1993.

Kris: Dying to Live (2014, BBC3) is a recent documentary film made by Neil Bonner about Kris Hallenga, a young woman with secondary breast cancer. During the filming process, Kris was given a camera; only a few minutes of Kris's hundreds of hours self-filming made the final cut. These isolated moments do not challenge dominant authorship models and are arguably used for effect, to heighten (a sense of) an indexical, authentic relationship with lived experience as Dovey (2000) has described. However, Kris described the filmmaking process as personally beneficial (personal communication).

Through his work in post conflict Northern Ireland Cahal McLaughlin proposed that collaborative, ethical filmmaking could be beneficial for participants (2010, p23). Jolene Mairs Dyer's thesis (2013) explored this suggestion through filmmaking with people also affected by the Troubles. She concluded — through participant questionnaires — that the process of producing and exhibiting the films was beneficial, "if not healing" for most participants (p230). Juhasz similarly found collaborative filmmaking with HIV-positive women a helpful experience for them (1999).

Jo Spence used photography to document her experience of breast cancer, from her diagnosis in 1982 to her death in 1992, "outside the institutions and power relations of conventional medicine" (Watney, 1986, p212). Spence had, since the 1970s, problematised how knowledge was produced in visual texts, questioning both her right to represent others and how others had represented her. She "began to reverse the process of the way I had been constructed as a woman by deconstructing myself visually in an attempt to identify the process by which I had been 'put together'" (Spence, 1986, p83). Her self-representations of illness explored the power relationships in image making, and challenged the cultural politics of health, including: the power imbalances in doctor-*patient* relationships; the privileging of medical knowledge over *patient* knowledge and experiences; the objectification of the *patient*; and social inequalities. Her archives further demonstrate how creating a dialogue "beyond oral and textual

accounts can enlarge and enrich” the understanding of personal illness experiences (Bell, 2002, p23). The therapeutic benefits of phototherapy projects have been theorised (collectively and individually) by Spence (1986, 2005) and Rosy Martin (2001, 2012). The cross-disciplinary work of Pink *et al.*, (2011), Susan Hogan and Pink (2012), and Anna Grimshaw and Amanda Ravetz (2005) draws firm links between visual ethnography and feminist art practices as a way of simultaneously producing understanding for researchers (and participants) and benefits for participants.

Another autobiographical work highlighted a central concern of this research: “The traditional method of composing the life history as a flowing narrative is not only morally dishonest but also intellectually inadequate because it conveys the false impression of chronologically timeless and uninterrupted soliloquy” (Pack, 2012, p43). German actress, Kathrin Spielvogel, borrowed a camera from her filmmaker friend Nicholas Feustel when she found out she had a very aggressive form of breast cancer. She did not start with the objective of making a film, but just wanted to document her treatment. Subsequently Feustel collaborated with Spielvogel and produced the film *Ich Will Ja Leben, Oder?* (2009, Germany). The production was highly edited: often cut sentence-by-sentence, reducing knowledge to sound-bites. Subheadings and storyboards were used to drive the narrative of her cancer experience forwards, producing an unquestionably flowing narrative but one which came at the expense of depth or associated meaning. This resonated with MacDougall’s polemic on the loss of: excess meaning, interpretive space, the sense of the encounter, and internal contextualisation (1999, p299).

A number of projects are taking place in medical settings which involve handing the camera over. Documentary filmmaker Amy Hardie has recently developed a

video intervention project at Strathcarron Hospice⁷ that enables *patients* and their families to create films or video letters for their relatives. The more established Jimmyteens TV⁸ is a non-profit social enterprise in collaboration with Teenage Cancer Trust, where teenagers and young adults with cancer are given camcorders to make films about their lives (or anything they wish). In addition it broadcasts live shows and debates about issues surrounding cancer. The whole project is directed, produced and filmed by those diagnosed with cancer.

Healthtalk.org⁹ is a health experience research group that interviews and videos *patients* to produce narratives. These narratives are available as an on-line support resource for others affected by illness. They are also used to influence policy and decision-making. Whilst important research, easily accessible and widely applied — they have over 3000 interviews and collaborations in place nationally and internationally — the methodology of two researchers being present and conducting interviews, and the presentation as one to two minute thematic sound bites situate this work outside of my field of enquiry, but nevertheless is interesting to note the use of the visual via the internet as a mass educational tool.

ILLNESS NARRATIVES

In examining the narrativisation of illness experiences away from filmic representations, I acknowledge the existence of a culturally-validated narrative ethic of illness, exemplified by the work of Arthur Frank (1995), Elliot Mishler (1984) and Arthur Kleinman (1988). There is increasing interest in illness narratives as an area of inquiry from medical, social and personal viewpoints.

⁷ http://www.amyhardie.com/work_strathcarron [Accessed 20 April 2013]

⁸ <https://jtv cancersupport.com> [Accessed 4 March 2012]

⁹ <http://www.healthtalk.org/peoples-experiences/cancer/breast-cancer-women/topics> [Accessed 12 April 2015]

Personal accounts of illness were extremely rare before the 1900s, and remained uncommon until the 1950s (Hunsaker-Hawkins, 1999, p3). Thomas Couser argued that *Women and Their Bodies*, first published as a booklet in 1970 and later as the book *Our Bodies Ourselves* (1973), and the open discussion of breast cancer experiences by public figures such as Betty Ford, were key influences behind the emergence of breast cancer autobiographies in the 1970s and 1980s. This resulted in the transformation of “breast cancer from a private, even shameful ordeal into a publicly narratable personal crisis” (Couser, 1997, p39).

“Patients’ narratives give voice to suffering in a way that lies outside the domain of the biomedical voice” (Hyden, 1997, p49), and can serve as reflexive and therapeutic tool for those who have experienced illness. Narratives, Gay Becker proposed, “arise out of a desire to have life display coherence, integrity, fullness, and closure” (1997, p12).

Mishler advanced that “the world as a *meaningful* reality is constructed through human interpretive activity”, reliant upon “cultural values, social norms and culturally shared rules of interpretation (1981, p141). He argued that conflict exists between the “voice of medicine” and the “voice of the lifeworld”, with the former often drowning out the *patient’s* voice. The voice of medicine was characterised by lack of the personal; the voice of the lifeworld was the opposite — the very essence of the personal (Mishler, 1984).

As an anthropologist and physician, Kleinman broadened the definition of illness narratives. He recognised that a significant proportion of clinical diagnoses arose from information from *patient* histories, but notes that these utterances have to be contextualised:

each patient brings to the practitioner a story. That story enmeshes the disease in a web of meanings that make sense only in the context of a particular life. But to understand that life and the illness experience it

creates we must relate life and illness to cultural context (Kleinman, 1988, p96).

Kleinman described *patients'* (and their families') perspective of illness as 'explanatory models', which comprise the "knowledge of the beliefs the patient holds about his illness, the personal and social meaning he attaches to his disorder, his expectations about what will happen to him and what the doctor will do, and his own therapeutic goals" (Kleinman *et al.*, 1978, p256). Kleinman noted that they are often littered with contradictions; "they congeal and unravel... our understanding of it firms up in one situation only to dissolve in another" (1988, p122).

Frank argued that "ill people" "are wounded not just in body but in voice" (1995, pxii), and that they need to become storytellers to resurrect the voices lost in their illness experience. He divided narratives into three main themes: restitution, chaos and quest. The restitution narrative was the culturally validated illness account that centred around life returning to a pre-illness state, fulfilling both the individual's wish for restored health and cultural expectation. The chaos narrative was the opposite, characterised by a lack of order it ran counter to cultural norms and told "of how easily any of us can be sucked under" (*ibid.*, p97). This narrative type provoked anxiety, both in those who experience and witness them. Frank contended that the chaos narrative renders the revelation of the self extremely difficult. The quest narrative was defined by the belief that something positive would be gained from illness experience. However, a focus on a classification system such as Frank's arguably homogenises experiences, imposing meta-narratives over individual experiences and fails to account for the many fluctuations that take place over time.

Whilst citing these collective exemplars for contextual purposes, I rarely draw on them for my theorising. I have found it more helpful to visit Paul Stoller's writing of his illness experiences. Following his diagnosis with non-Hodgkin's

lymphoma he revisited his earlier anthropological work with the Songhay people (2004). This, and his more recent writing (2014), combined anthropological and illness experiences in a manner pertinent to this enquiry.

THE CULTURE OF BREAST CANCER

Whilst this PhD did not focus on the culture of breast cancer, an awareness of the culture in which a study population is situated forms an important part of any ethnographic research. The ontological and epistemological considerations of the cultural landscape of breast cancer are complex and riddled with tensions. It was not my intention to provide a detailed history of the culture of breast cancer: comprehensive accounts exist of breast cancer bio-politics and activism (Klawiter, 2008; Sulik, 2011); awareness campaigns (Gardner, 2006); cancer education in the UK (Toon, 2007); the history of breast cancer in relation to the ‘do not delay message’ (Aronowitz, 2001); and medicalisation more broadly (Conrad, 2007). I will give a brief overview of the culture of breast cancer away from filmic representations, to provide an understanding of the broader environment in which the participants were situated.

Using Foucaudian terminology, Klawiter identified two key “regimes” of breast cancer¹⁰ (2008, pp51-104). The first regime was one of ‘medicalisation’¹¹ (and institutionalisation) in which medical dominance remained largely unchallenged. Klawiter located the origins of this power in Foucault’s polemic of

¹⁰ “Regimes of power” was indeed a useful term (adopted by Klawiter) to look at the political culture of breast cancer being “programs of conduct that have both prescriptive effects regarding what is to be done (effects of jurisdiction) and codifying effects regarding what is to be known (effects of veridiction)” (Foucault, 1994, p225).

¹¹ A history of the medicalisation thesis lies outside the scope of this study. It originated with Foucault (1994a) and Illich (1976), who described a professionally-organised medical expansion across society, a “medico-administrative” knowledge (Foucault, 1994, p100). Miller and Findlay suggested that, in the twentieth century, the “male doctor became societies’ accepted experts on the subject of women” (Miller *et al.*, 2002, p186). Like Aronowitz, they saw women as actually complicit in this (*ibid.*, p187), and noted that demedicalisation was (to some extent) occurring (*ibid.*, p203). Klawiter (2008) and Conrad (2007) argued that medicalisation had shifted. It was no longer regarded as imposed from above, by the State and a series of experts, on an uniformed passive public. Rather, it resulted from a myriad of influences — pharmaceutical companies, social movements, managed care, alternative therapist, and the media — with *patients* themselves taking more prominent roles.

the clinical gaze (*ibid.*, p59). *Patient* movements in this period were under the control of medical institutions, exemplified by the American Cancer Society films and the prominent 'Reach to Recovery' moment in the USA which "forbade volunteers from discussing medical information to avoid contradicting doctors" (Sulik, 2011, p38). In mainstream society, breast cancer remained stigmatised and individuals with the disease isolated; nondisclosure of diagnostic and outcome information prevailed, with a one-step consent practice common. A "do not delay" to seek medical help message permeated this period (Aronowitz, 2001). In his extensive examination of how the history of breast cancer has shaped the current culture of breast cancer, Aronowitz noted however that women were not always passive victims.

During the 1970s and 1980s, the second "regime" of breast cancer emerged - the regime of biomedicalisation, dominated by informed consent, challenges to the Halsted mastectomy, alternative therapies and "diffusion of screening technologies" (Klawiter, 2008, p102). A key part of this second regime was the emergence of screening programmes in healthy populations, which Conrad describes as an "expanded form of medical control" (2007, p151), which for some now includes a molecular gaze (Bell, 2013) as well as breast screening. This policing of bodies echoed Foucault's notion of the panopticon of penal surveillance (1991, pp201-2). However, it is unclear who is in the central tower observing the population, as medical professionals are openly casting doubt on screening programmes, in terms of both mortality reduction and over-diagnosis (detection of tumours that would have been of no clinical significance during a woman's life time) (Independent UK Panel on Breast Screening, 2012).

It has been suggested that for numerous chronic illnesses, those who are at-risk of the disease conflate with those who actually have it (Aronowitz, 2009). This convergence has particular relevance in breast cancer, where Klawiter proposed that all women have been united as at-risk of breast cancer "transform[ing] the disease from an either/or condition to a breast cancer

continuum” (Klawiter, 2008, p280). Importantly, however, Griffiths reported that for healthy women, mammography screening was “something that they accepted but which was peripheral to their life” (2010, p661).

This PhD does not examine the screening of healthy women, however of relevance is the surveillance of individuals’ lives after diagnosis and treatment, when “cancer becomes a constant backdrop by which women live” (Davies, 2008, p73). Fear, risk and surveillance dominate the emotional landscape of breast cancer. Fallowfield has extensively studied the personal experiences of individuals with breast cancer and identified that, following diagnosis and treatment, a “pre-eminent worry for women living with breast cancer is the fear of recurrence” which that can result in “crippling anxiety” and depression, and obsessive breast-checking (Fallowfield, 1991, p72-3). Surveillance, both self and medical, takes on heightened significance in the lives of those diagnosed; however, the notion of an *invisible* policing is outdated. Women’s surrender to screening (which, as mentioned, has questionable benefits) resonates with the “homogeneous effects” produced by powerful central surveillance (Foucault, 1991, p202).

The Pink Ribbon movement is “one of the most popular and influential social movements of the last 25 years” (Klawiter, 2008, p277). It has united and empowered millions of women, families and friends who shared information, knowledge, and experiences, and has come to define the public face of breast cancer. Its emergence marked a significant shift in breast cancer politics.

Recently, questions have been raised as to whether the Pink Ribbon movement accurately embodies individual experiences and whether it is ultimately harmful to women’s health (Sulik, 2011). In *Pink Ribbon Blues*, Gayle Sulik identified areas for concern including the commercialisation of voices, dilution of feminist ideals, mass obedience, statistical manipulation and a “tyranny of cheerfulness”.

Audre Lorde's critique from a Black lesbian feminist perspective, argued that the concealment of breast cancer made the disease invisible and women invisible from each other. This still resonates today. Whilst breast cancer is now discussed more and detected earlier in most white communities, silence continues to dominate communities of minority women, as well as research about them. Before the first national analysis of cancer and ethnicity by the National Cancer Intelligence Network (NCIN) in 2009, data on ethnic minorities and cancer was incomplete and of poor quality (NCIN, 2009, p4). Whilst breast cancer incidence is lower amongst Asian, Black, Chinese and mixed-ethnicity groups than their white counterparts (NCIN, 2009, p28; Jack *et al.*, 2009), Asian and Black women in southeast England are more likely to present later, have metastatic disease and have poorer survival rates (Jack *et al.*, 2009; Richards *et al.*, 1999).

For all women with breast cancer, the silence described by Audre Lorde's was perpetuated by the normalising imperative of reconstructive breast surgery to restore the female aesthetic. The prosthesis "reinforces this society's stereotype of women, that we are only what we look or appear, so this is the only aspect of our existence we need to address" (Lorde, 1997, p58).

David Jay's *The Scar Project* shows the physical effects of breast cancer, marking a significant challenge to existing breast cancer culture (Jay, 2012a). Nadine Ehlers and Shiloh Krupar observed that:

the intimacy of the portraiture encourages a particular kind of ethical relation between viewer and subject, and between subject and cancer. This ethical call can be uncomfortable. Even for those with a medical knowledge of the disease, seeing images of bodies marked by breast cancer outside the hospital or clinical setting out of their context jars and provokes a reading that often confirms dominant mythologies of breast cancer (Ehlers & Krupar, 2012, p5).

Susan Sontag (1991) argued that individuals with cancer are stigmatised

through the use of metaphorical imagery resulting in a distortion or even denial of the medical and social experience of illness. Sontag believed the disease should be demystified by adopting a biological understanding of cancer; however, Susan DiGiacomo firmly rejected this idea, stating that we can *only* experience illness through “culturally constructed and socially reproduced structures of metaphor and meaning” (1992, p117). Whilst one cannot separate an illness from its social meaning, some expressions of illness experiences comprehensively incorporate the biological. Both Tom Corby’s and Salvador Iaconesi’s work acknowledged and engaged with the medical body. In Corby’s portrait of his own body¹² whilst undergoing cancer treatment, he took ownership of his clinical data; rather than seeing illness as something that ‘happens to you’, he produced an “individuated experience of pathology” that privileged, shared and interpreted medical information. Iaconesi also wanted to ‘see’ and share the clinical or “industrial” side of his cancer by inviting multi-disciplinary online discourse.¹³ Neither practitioner argued that the complexity of human experience of illness should be ignored — far from it. However, their research did provide some support for Sontag’s aims of demystifying disease by engaging with the biomedical.

CONCLUSION

I have advanced my belief that the theories of shared visual anthropology and practices of shared visual ethnography are applicable to developing a methodology to collaboratively produce knowledge with individuals diagnosed with breast cancer.

Gaps in Knowledge

In reviewing and contextualising the existing literature and practices surrounding shared visual ethnography, cross disciplinary visual research

¹² <http://bloodandbones.org/data/> [Accessed 1 January 2015]

¹³ <http://opensourcecureforcancer.com/> [Accessed 1 January 2015]

practices and documentary films about illness, the following gaps in knowledge were identified and provided the basis for my research questions.

From within visual ethnography: defining characteristics of a collaborative visual ethnographic methodology as best practice for others embarking on visual research to explore experiences of illness; the application, relevance and importance of Jean Rouch's 'shared' praxis when the filmmaker is not present during filming i.e., when the camera is handed over; handing the camera over as an ethical, democratic, sustained research practice to explore experiences of women diagnosed with breast cancer; describing and defining reflexive and reflective practices when the camera is handed over; how in practice we, as researchers, position ourselves in relation to those we study; how cameras are used as a tools of audiovisual inscription when given to research participants; how these cameras are integrated into and impact on lives; exploring alternative means of displaying durational visual ethnographic material in practice.

From within documentary film: challenges to dominant authorship and narrative models of documentary films about breast cancer; handing the camera over in documentary filmmaking as an extended collaborative ethical praxis, rather than as an aesthetic or secondary measure for established authorship models; filmmaking that does not submit to culturally validated narratives or broadcast imperatives; processes of bringing together polyphonic perspectives; filmmaking as a therapeutic practice for those diagnosed with illness.

I sought, through my practice and theorising, to address these gaps by: reducing my own interventions in the filmmaking process by inviting women diagnosed with breast cancer to become authors of their films; challenging the dominance of the interview and prior identification of themes in filmmaking and qualitative research; researching how the camera is appropriated by participants and the impact it has on their lives; rethinking both models of reflexivity when cameras

are handed over and the positioning of researchers in research relationships; offering an alternative narrative structure to broadcast or culturally validated models; exploring ways of presenting collaborative polyphonic visual ethnographic material; defining best practice for researchers embarking in this area of research.

Research Questions

In justifying my research questions, I have linked them to my aims, and the debates and gaps emerging from the contextual review. In presenting my research questions individually, however, I have not wanted to deny their interconnectedness. *Is the methodology an effective, respectful way of producing new knowledge, and new ways of knowing, about illness experiences?* Whilst acknowledging Rouch's "dream" of 'passing' the camera to those who were traditionally subjects of films, the review of the literature from visual ethnography has highlighted (notably Minh-ha, 1999; Moore, 1994; MacDougall, 1998) that this process does not necessarily remove representational and authorial inequalities. Indeed the practice of handing the camera over in documentary filmmaking has often been used as a deceit, mimicking *patient* voices and a vehicle for emotional narrative gain. These 'voices' remain bound by external agencies (i.e. broadcast agendas in the Video Diaries; or filmmaker's POV in Mark Wilkinson's films). A principal aim of this research was to develop a methodology that facilitates participant authorship *outside* of clinical, broadcast, and/or external directorial frameworks; to challenge "centralized and hierarchical" (Minh-ha, 1999, p125), "hegemonic and homogenizing" (Ginsburg, 1998, p 187) agendas. In particular authorship models emerging from some collaborative AIDS projects (i.e. Irving, 2007, Juhasz, *WAVE* 1990, 1999, 2003), visual ethnographic projects where reliance on the interview is reduced (i.e. Barnes, 1997; Lammer 2009a,b; Pink, 2014; Holliday, 2000; McLaughlin, 2010) and individual illness experiences (i.e. Stoller, 2004, 2014) were helpful examples to draw from.

Subsequent research questions were inexorably linked to developing and justifying this methodology. *How did the participants interpret the open-ended research and how were we as co-participants, emplaced in the research?* Rouch's shared anthropology, and the theories and practices of MacDougall and Pink (i.e., MacDougall, 2006b; Pink, 2007) were grounded in the importance of understanding inter-subjective relationships, of an integral reflexivity (i.e., Minh-ha, 1999; Pink, 2006; MacDougall, 1998; Taylor 1998) that was process led (Pink, 2006) and acknowledged the impossibility of a detached observer (Rouch, 1985; Pink, 2007). The open-ended nature of the project lent itself to numerous interpretations, and a clear understanding of individual motives was essential to contextualise the process(es) and product(s) of the research, as well also assisting fulfilment of participants' personal aims in taking part in the research. New considerations and descriptions of a collective, process orientated reflexivity that extended beyond role description were required.

What impact did the research have on the participants' lives? Anticipating and documenting the impact the research would have on individual lives formed a central part of the investigation and ethical planning for the study. The fact that the research could have impacted negatively on the participants, (i.e. of them revealing too much, experiencing emotional discomfort in revisiting past, present and anticipated feelings/events, or withdrawing from the project) had to be identified and mitigated against. Conversely — and not exclusively — the possibilities of benefit for participants emerged from documentary (Juhasz, 1999; McLaughlin, 2010; Mairs Dyer, 2013), feminist (Spence, 1986, 2005; Spence and Martin, 2001, 2012) and cross-disciplinary (Pink, 2011; Hogan and Pink, 2012) literature.

In the literature there is little attention to or theorising about how cameras are appropriated, used as research tools, and integrated into lives when they are handed over. This lends importance to questioning: *How were the cameras used as tools of audiovisual inscription?*

What role was played by the collaborative edit and feedback screenings? Collaborative editing and feedback screenings formed a central part of Rouch's shared visual anthropology and form a central part in fulfilling ethical collaborative filmmaking practices. I wanted to explore the significance attached to feedback screenings and editing collaboratively by participants when they have been responsible for filming the material. Considering this question also incorporated parameters of self-censorship and deliberations of audience by the participants, as well as my own authorial influences through my interactions, the editing processes, and the final structure that brought the contributions together.

How to display and engage with durational polyphonic ethnographic material? I was unsure of how participants would engage with the open-ended guidance. For example: how they would use the cameras? What they would talk about? How much material would be produced? I knew that I would have to respond to the material, the aims and the wishes of the participants during the course of the research. Paul Basu's theorising (2009) and Cahal McLaughlin's theorising and practice (2010), altered me to the possibilities that a single intercut documentary format *may* have to be reconsidered.

In my research I did not intend to provide a history of the culture of breast cancer, nor perform in-depth comparative studies with health care or narrative methodologies. I have not included contemporary community 'participatory' filmmaking in my analysis. Whilst my aim in my thesis was to privilege theorising 'process' over 'knowledge produced' I have highlighted the possibilities for further papers that explore and apply the important experiential knowledge generated, comparing it with existing literature, practices and debates (i.e., tamoxifen, Appendix 5).

2. METHODOLOGY I: DEVELOPING AN ETHICAL FRAMEWORK & REFLEXIVITY.

INTRODUCTION

This chapter theorises key aspects of my methodology and highlights relationships between theory and practice. My research design focused on creating an ethical framework in which the participants can “structure *their* view of the world — *their* reality — through film” (Worth & Adair, 1997, p7, my emphasis), by moving away from the singular authorial perspective of a filmmaker, expert, or institution. The research recognised the importance of seeking a wide range of experiences in visual representations of illness, as “the human condition is too complex to be filtered through the eyes of a small group of people” (Ruby, 2005, p219).

This critical reflection focuses on methodology — the *process* through which knowledge has been produced — drawing on insights derived from Rouch’s shared filmmaking praxis, ethnographic projects initiated by visual anthropologists in which the camera was ‘handed over’ and other contemporary collaborative interdisciplinary practices in visual research discussed in the contextual review. However, as I noted above, the practice within visual anthropology of simply handing the camera over did not necessarily fulfil its ideological intent of ameliorating ethical problems such as objectification or power imbalances. As Trinh Minh-ha argued, polyphonic practices do not necessarily address “centralised” hierarchical knowledge production; polyphonic projects therefore have to be motivated by something besides anthropological gain if participatory practices are to fully address representational inequalities (Minh-ha, 1999, p215).

A salient example is Rich and Chalfen’s visual ethnographic research into chronic child and adolescent illnesses (e.g., 1999, 2000, 2002). Despite the

extensive analytical framework, their research failed to fully consider the context of knowledge production and power imbalances that it perpetuated. Their claim that the methodology “eliminates the problems of reactivity to an outside observer” (Rich *et al.*, 2000, p164) did not acknowledge the effect of the camera, the researchers facilitating the filming, or the participants’ interpretations of the research. As Gibson (2005, p36) noted, Rich *et al.*’s statement that “[t]he indiscriminate and uncompromising gaze of the camera was able to show what the selectivity of perception and memory may have filtered out of the patient’s verbally reported medical history” (Rich *et al.*, 2000, p162) was misguided. The authors failed to either address or explore the motivations for the participants’ choice of what to film for the research — indeed, they attributed an indexical relationship between the visual images and the lives of the filmed subjects. They did not explore the bias of knowledge being produced for clinicians, under instruction by clinicians; nor did they fully acknowledge the ethical implications related to the hierarchical ‘surveillance’ imposed on the lives of participants by the camera. This surveillance was justified by the fact that the films would only be available to a medical team. Rich *et al.*’s claims about increased *patient* advocacy were therefore misguided, as their study reinforced the unequal power positions between healthcare workers and *patients*. The *patients* remained very much the ‘object’ under scrutiny of the medical gaze, albeit mediated through the camera. The *patients*’ voices never escaped the “identified boundaries” (Minh-ha, 1999, p215) of the biomedical context, despite Chalfen’s otherwise-expressed hopes (Chalfen, 2010).

As well as calls in visual anthropology for research practices to be widened beyond the study of non-Western societies (Ruby, 2008; Picton, 2011) and across academic boundaries (Pink, i.e., 2001, 2003, 2006, 2009, 2012a), a need has been identified to explore experiences of illness away from clinical models (Dow & Lafferty, 2000; Bredin, 1999; Arman & Rehnsfeldt, 2003; Rich *et al.*, 1999, 2000, 2002). James Brennan emphasised the limitations of what existing

clinical analytical frameworks can reveal:

There has been a tendency in psycho-oncology to examine emotional distress in isolation, rather than binding it to the social context within which it occurs. People exist within complicated changing lives, so research that relies on purely categorical data and cross sectional snapshot designs often fails to capture the most important information. Responses are plucked from individuals and then interpreted out of the context in which they arose (2004, pxxii).

MacDougall noted that “[f]ilm can never replace the written word in anthropology, but anthropologists are made conscious by their field experience of the limitations which words impose on their discipline. We are beginning to discover how film can fill in some of the blind spots” (1978, p424). In the same way, collaborative visual ethnography may be able to illuminate blind spots about lived experiences of breast cancer by challenging the hegemonic practices of more commonly adopted clinical and qualitative investigative research.

I do not agree with Klawiter’s argument that, as all women are at-risk from breast cancer, the disease has become a continuum (2008, p280); rather, I contend that it very much remains an ‘either or condition’. I have not been diagnosed with breast cancer and respectfully acknowledge that researchers not diagnosed with illness “are all outsiders in the lives of others” (Pryluck, 2005, p197) with “substantially different notions of the self” (MacDougall, 1998, p55).

PROBLEMATISING THE INTERVIEW

Understanding should be achieved through a gradual process of discovery, that is, through engagement with the everyday lives of the subjects rather than by placing them within predetermined matrices, whether a script in the case of the filmmakers or a questionnaire in the case of anthropologists (Henley, 2000, p218).

Key elements of my methodology have been to neither interview the participants, nor be present during filming unless invited into the frame. To re-

situate the voices of those diagnosed with breast cancer, it was necessary to address [deconstruct] the interview. There is a reliance on the interview to elicit information from *patients*, both in the clinical setting and in visual texts about cancer. The interview is “probably the most widely used method of investigating the social world” (Aull Davies, 2008, p 105). Furthermore, it forms a part of most clinical encounters between *patients* and medical/allied professionals; this is exemplified by, but not restricted to, the case study. This methodology, which Hunsaker Hawkins regarded as myopic (1992, p174), is “inextricably and unavoidably historically, politically, and contextually bound” (Fontana & Frey, 2005, p695). Silverman called for researchers to rethink the idea that the interview is a “gold standard” (2013, p319) of qualitative research.

I revisited Foucault’s question, “can one articulate the production of truth according to the old juridico-religious model of confession and the extortion of confidential evidence according to the rules of scientific discourse?” (Foucault, 1998, p64). In his historical examination of the confessional in relation to sexuality, Foucault gave insight into how the interview operated within the context of ‘medical professional/client’ relationships. Foucault traced the origins of confession to the medieval practice of penance; he proposed that by the nineteenth century, society had “put into operation an entire machinery for producing true discourses concerning [sex]” (*ibid.*, p69), a machinery inexorably linked to the juridico-religious model of confession. In this model, utterances by the “client” were incapable of being revealed “wholly formed” and were thus extorted and given validity by a “master of truth” (*ibid.*, p66). Nichols projected that this existed in film too, for without the *objective* voice of the filmmaker, we risk “accepting the voice of the subject as the truth” (1983, p19, p25). This is a rationale that has dominated conventional ethnographic and documentary film practices characterised by an authoritative voice over or the participation of experts as interview subjects.

Atkinson & Silverman argued that this hierarchical power structure was a

“terrible” asymmetry that led to “the interviewer’s gaze” fixing “the self of others” (1997, p314). Minh-ha described the process of filmmakers getting caught “in their own framing being too eager to proceed with their list of preformed questions, regardless of what the answers given are and where these are heading ... based on answers they have already assumed ahead of time” (1999, p266). The subject thus became “an element that may be placed, moved, articulated on others”, a ‘docile’ body (Foucault, 1991, p164) unable to return the gaze.

This controlling and fixing of identity by the Outsider’s interviews created a disciplined, regulated storytelling that operated on “a reversal of the political axis of individualization” (Foucault, 1991, p44). I do not claim that knowledge produced in the absence of interviews (or other predetermined methods) escapes the societal or researcher-imposed pressures creating the docile body; nor would I argue that the interview cannot elicit important information. Rather, my point is to demonstrate that in exercising control over narratives, the interview is often employed “for assuring the ordering of human multiplicities” (*ibid.*, p218) that are “ordered towards a terminal stable point” (*ibid.*, p160) rather than acknowledging the possibilities of a fluid self, capable of self-expression.

Applying Foucault’s interrogation to the clinical setting, “[t]he paradigm of modern social-scientific reportage is the rationally ordered, systematic narrative that makes a coherent argument” (Blumenthal, 1999, p377). Similarly, in visual ethnography, critics noted the need to package knowledge for easy, accessible consumption (Minh-ha, 1999, p4 & p216), for filmmaker empowerment (Taylor, 1998, pp5–6), or for ‘maximum efficiency’ on the filmmaker’s part; this is the opposite of Rouch’s praxis (Henley, 2009, p316).

The common practice whereby researchers identify themes in advance is a further example of the restrictive practices regimenting knowledge production.

Pre-identified trends prioritise knowledge, impose assumptions, and promote generalisations that belie the complexities of the voice of those diagnosed with illnesses. Mary Bredin extended this notion to the pre-identification of themes in clinical research, which can be in direct conflict with lived experience and “detract from the gravity of facing a life threatening illness” (1999, p1114).

By problematising the interview I wanted to avoid making the participants’ narratives simply responses to external stimuli; I sought to allow participants to explore “anything that emerges at a specific moment in one’s thinking process, that related back to one intimate experience and then proceed slowly from there ...” (Minh-ha, 1999, p34). As Minh-ha noted, the objective is to let “things come to you rather than seizing or grasping them” (*ibid.*).

As interventions in social research, interviews exist on a continuum: some theorists have classified informal conversation in the research setting as an ‘interview’ (Hammersley & Atkinson, 2007, p108) since conversations “are never *simply* conversations, because the ethnographer has a research agenda and must retain some control over the proceedings” (*ibid.*, p117). Like most researchers (Hammersley & Atkinson, 2007; Fontana & Frey, 2005, p696), I believe that neutrality is impossible in this respect. Each encounter and conversation I had with participants was, of course, bound to the context of the research. I tried to not ‘control’, probe, or actively seek knowledge about their experiences; rather, I tried to be an empathetic listener and to support them in their chosen process of knowledge production. However, as my filmed interactions with one participant, PA show (i.e., 18:17, 47:45)¹⁴, in all of the

¹⁴ My on-camera interactions with PA were unique. I was invited to film with her far more frequently than with other participants. I was not present during filming with most participants, and most did not invite me into the frame. However, the cademes/edemes with PA provide insight into my relationships and interventions.

encounters knowledge was a co-construction.¹⁵

Some practitioners have used methodologies to reduce direct interview intervention in their research, to shape, stimulate and guide “different types of intentionality, interaction, and understanding of people’s everyday thinking and being” (Irving, 2007, p187). Holliday (2000, 2004, 2009) invited participants to use ‘dress’ as a stimulant for exploration of identity; Cahal McLaughlin (2010) used ‘the materiality of spaces’ to inform knowledge production and performance of memory of political violence; Barnes *et al.*, (1997) invited participants to make a legacy; Pink & Mackley (2014) used performing laundry; and Irving (2007) used journey and performance.

Worth and Adair’s work offered a very open line of research: “You can make any kind of movie you want to; you can make it about anything you want to; I won’t tell you what to do” (1997, p78). It is their approach that informed my decision to simply guide participants: “you know you have been invited to take part because you have had a diagnosis of breast cancer. You are being given a camera for three to six months to film whatever is important to you”.^{16, 17}

¹⁵ It is interesting that the participants reported that they never felt that I influenced them; in some conversations following our exchanges, I expressed concerns that I had influenced them and they disagreed, leading to an amusing back-and-forth.

¹⁶ Each participant was given a Panasonic HC - V700 HD camcorder (with 32GB SDHC UHS-I SanDisk cards) and instructed in its use. A significant amount of time was invested in selecting cameras. I required inexpensive camcorders without built-in memory — the University Network Security Team advised that any cameras with built-in memories used would have to be destroyed after the project — with excellent image quality, 1920 x 1080 HD, good performance in low light, and an external jack for a microphone. They also needed to be low weight, as participants who have had lymph nodes removed may suffer from lymphoedema, discomfort, or weakness. We tested a number of cameras and selected the Panasonic HCV700 HD, which has proved to be generally reliable and high quality. A criticism of the camera is that the on/off button is next to the button to switch recording modes from 50i to 50p; if pressed accidentally, this necessitates converting footage before it could be ingested into FCP. In addition, although the camera is excellent for night-time filming, with one participant low light led to grainy images. All participants were given an external microphone, but these proved to be unpopular; three requested tripods, and these were provided.

¹⁷ A sustained period of time for filming was deemed appropriate in order to allow participants to become familiar with the camera and fully explore their experiences, which are often characterised by fluctuations and instability over time (Tighe, 2011, p231). Visual ethnography is particularly well suited to the study of illness experiences in this respect.

I was not present during filming unless invited into the frame by a participant, nor did I 'train' the participants as informers. I was always cognisant of Asch's warning that the information we want as researchers is not necessarily what the participants want to share (Asch *et al.*, 1991); this principle guided my research. However, I requested that participants not delete any footage they recorded until we reviewed it together. The significance of trust in the research relationships cannot be overstated. Safeguards of respectful positioning in the research relationship; a visibly accountable role for researchers; control of veto of the final research material remaining with the participants; and feedback screenings, need to be in place. I return to and elaborate on these important points.

All were given my mobile number and email address, and invited to contact me at any time should they have concerns, questions, and/or technical queries. They were also provided with my second supervisor's contact details should they have any complaints about me, or the research in general. It was stressed that any criticisms would be treated as confidential. The Breast Cancer Care helpline number was also made available to discuss any emotional reactions to making the films or indeed any aspect/issues that the participating in the project raised. The helpline was fully briefed in advance about the study.

THE REPRESENTATIONAL SPACE AND THE PARTICIPANTS

I wanted to locate this study outside of clinical practice, not only in response to calls from the field of healthcare research, but also because I sought to visually explore breast cancer experiences as part of the life in which they occurred. I hoped, by not abstracting the research space or exploring the illness in isolation, to counteract the "dulling sense of familiarity" (Geertz, 2000, p14) which comes when experiences of illness are examined or interpreted within a clinical framework. Researching breast cancer in the context of everyday life,

looking at the ordinary in places where it takes unaccustomed forms

brings out not, as has often been claimed, the arbitrariness of human behaviour ...[,] but the degree to which its meaning varies according to the pattern of life by which it is informed (Geertz, 2000, p14).

Ehlers & Krupar, (2012) offered a stark example of the importance of making experiences of breast cancer visible outside of the clinic following a doctor's reaction to seeing a photograph exhibited in the street of a young pregnant woman who had undergone a bilateral mastectomy. The photograph, taken by David Jay, was being used to advertise the SCAR project (Jay, 2012). The doctor, Domhall Macauley, recalled his response: "the reality of the disease had escaped from the consulting room, and without the usual professional defences, it was scary" (Macauley, quoted in Ehlers & Krupar, 2012, p5). He also reverted to an unquestioning diagnostic generalisation by incorrectly assuming that the woman's distended abdomen was due to liver ascites.

In situating the research away from the clinic, I also wanted to minimise the potential for the regulatory powers that dominate hospitals' institutional regimes to influence the participants' testimony. I proposed that the "clinical codification of the inducement to speak" (Foucault, 1998, p65) could influence participants when 'scientifico-medical' interviews or research is conducted by clinical staff. Further, I questioned whether the coding effects and politics imposed by the hospital space itself could affect testimony (Foucault, 1991, pp143–4). So even if I as a non-clinical researcher, invited participation from a hospital — the space itself may 'code' and impose a particular way of understanding the research.¹⁸ To lessen these clinical influences, participants were invited to take part through community groups, cancer support groups, cancer charities, and word-of-mouth.

¹⁸ McLaughlin's research shows how memory and testimony is formed by location. He describes how "location has a profound affect on story telling" (2010, p18) in the same way I speculated that situating the research in a hospital setting would directly influence the memories, thoughts and feelings evoked during filming.

I do not claim that this '*invitation strategy*' eliminates other cultural and social codifying effects of testimony, but acknowledge that other "regimes of practices" (Foucault, 1994b, p225) and "cultures of action" (Klawiter, 2008, p44) will exert influences on the participants. As already mentioned, pharmaceutical companies, social movements, managed care and *patient*-driven incentives are all loci of power, activism, and authority within the culture of breast cancer.

In the early planning stages of my research I used certain words and concepts that were strongly positivist. One word was 'recruitment' in reference to asking participants to take part in the project. It is a standard phrase used in medical research, and as such was possibly an ingrained setting from my previous work, but it was fundamentally positivist in outlook. There is an implicit power hierarchy within 'recruitment' that requires submission to the person who is recruiting, and I quickly substituted it with the term 'invitation'. I had to consciously check against similar pejorative habitual phrases such as 'drop out' and 'compliance' with treatment/research. In addition, the working title for this research included the descriptive noun '*patient*'.¹⁹ This labelling contradicted my expressed desire to remove the research from the clinic, confining and homogenising all participants into a medically descriptive group.

Community and support groups and breast cancer charities were selected to obtain the widest possible representational base of experience, ethnicity, sexual orientation, and age (Appendix 1). Individuals from within the groups were self-selecting. Whilst I began with a single contact in each group, I tried to avoid using 'gatekeepers' to recommend individuals, requesting that anyone who wanted to take part should do so voluntarily. Banks noted how selecting

¹⁹ Subsequently I have become hesitant about using the term '*patient*' at all in my writing. In my thesis if the work I refer to had used the term, I too adopt it. I mark it in italics because it now feels uncomfortable to use it.

gatekeepers can lead to a politicised filmmaking (Banks, 2001, p125).²⁰

Invitations to participate were sent using email, websites, word-of-mouth, and discussions. The inclusion criteria were that each subject must have had a breast cancer diagnosis during the nine to 15 months prior to the study's commencement, and must have completed active treatment.

“Much of the research on breast cancer also reifies dichotomies of health and illness through assumptions that once breast cancer treatments have been completed, women have few concerns” (Thomas-MacLean, 2004, p629). However, the cessation of active treatment and the transition from *patient* to ‘survivor’ has been identified as being problematic — indeed a crisis (Arnold, 1999) — for many individuals diagnosed with cancer. This transition poses discrete on-going physical, physiological, and interpersonal challenges (Stanton, 2006, p5132; Arnold, 1999; Pelusi, 1997; Fallowfield, 1991, pp72–73). Stanton identified several expectations of completing treatment that may characterise this period: individuals often feel that they should ‘be celebrating’, ‘feel well’, ‘be the pre-cancer me’ and ‘should not need support’ (Stanton *et al.*, 2005a, p2609). Instead, at the end of active cancer treatment, *patients* often feel “lost in transition” (Ganz *et al.*, 2008, p209). They describe a sense of isolation (Stanton, 2005a; Arnold, 1999), uncertainty (Garofolo *et al.*, 2009) and a lack control over their lives (Bell *et al.*, 2010). Many feel less protected (McKinley, 2000) and supported (Arnold, 1999; Mahler, 1982), continue to experience ongoing physical symptoms and fear recurrence (Vickberg, 2001, 2003; Mahler, 1982). My experiences making *Remember The Day* (2010, London) and BI’s statement “I have found this part, the aftermath of it all, harder I think than dealing with the actual disease”(53:15), confirmed the vulnerability of this transition for individuals.

²⁰ Banks pointed to the research of Carelli, who used certain politicised groups which led to certain aspects of life being prioritised: for example, male “perspectives” dominated both films and filmmaking.

Initially, the greatest number of responses came via a charity that focuses on young women with breast cancer. Despite much dialogue, there were no volunteers from Black and Minority Ethnic (BME) communities. This is partly due to the lower incidence of breast cancer in minority groups, but there are also political, religious, social, and emotional reasons why participation from BME communities was less likely (Remennick, 2006). The barriers to BME women seeking medical help (resulting in delayed diagnoses) extend beyond a clinical understanding of the disease into a culturally imposed unwillingness to speak openly about it. Audre Lorde brought to attention the imposition of silence amongst Black women, citing “the mockeries of separation that have been imposed upon us” (2000, p21) as a cause. My communication with Betterdays Cancer Support, a group for African Caribbean women with breast cancer, confirmed the strong political reasons for the disinclination to speak openly about their experiences through me as an ethnic Outsider.

In order to address the underrepresentation of women from minorities with breast cancer, I widened the criteria for participation to nine to 36 months post-diagnosis. The medical literature suggested that the feelings that characterise the period after treatment ceases can continue for several years (Stanton, 2006; Bell *et al.*, 2010).

I researched more BME support groups and found three participants: two from an African-Caribbean support group, and one who contacted me after hearing about the study by word-of-mouth. The widened criteria also allowed for the inclusion of DE, a young woman with secondary breast cancer, who expressed great interest in taking part when she heard about the project.

Despite targeting specific support groups for older women, I was unsuccessful in inviting women in their mid to late 50's or older to participate. Notwithstanding their growing numbers, the elderly also form a marginalised group within healthcare provision. Age Concern felt that the self-filming nature

of the project would not appeal to this age group. In addition, there is evidence that older women prefer face-to-face contact to discuss issues (Better Access Better Services (BABS) Project 2009). With nine individuals already filming, and resources stretched, I decided not to include any more participants.

In summary, all participants had been diagnosed with breast cancer nine to 36 months prior to study commencement (October 2011) and were aged 26-51 years at diagnosis. One participant had secondary breast cancer, and eight had been diagnosed with primary tumours. I collaborated closely with each participant to write up the medical details they agreed to disclose (Appendix 2).

VISUAL ETHICS

At the start of my project, I took Pink's advice for inter-disciplinary investigators: "researchers from different disciplines will need to refer to the guidelines of the professional association that they feel more closely aligned to" (2007, p49). In my ethical planning and application, I adopted the dominant norm in healthcare research: a single fixed consent form, completed in advance of the study and anticipating its outcomes. I took guidance from the National Research Ethics Service and the Department of Health (2011).

In this preparatory process, I gave thorough and careful attention to explaining the study design and methodology with the participants, discussing its goals and 'anticipated' outcomes and predicted impact of the research. I was committed to a respectful relationship; to not withholding any information; to anticipating possible harm and mitigating against it; and to emphasising participants' autonomy by advising that they could withdraw or question what is being asked of them at any time. However, it became evident that I had not been reflexive or critical *enough* about my own healthcare background in regard to the 'fixed, single' nature of consent, and that consent and ethical issues had to be an on-going, two way process that continued throughout the research.

Informed consent is a central tenet of visual research (Barbash & Taylor, 1997; Aull Davies, 2008; Clark *et al.*, 2010; Pink, 2007). However, it is difficult to negotiate truly informed consent at the start of a project, due to problems both in predicting outcomes of research and in the conflation of understanding between researcher and participants of research aims; these are reasons for ethical planning and implementation to be an ongoing process (Pink, 2007, p53; Ruby, 1991, p55). Furthermore, fixed consent does not allow for participants to offer feedback or have their ethical values incorporated into the process. Early in my research, it became apparent that participants interpreted the guidance in different ways, and that any outcomes for the research should be decided collaboratively with participants in response to these interpretations and to the material produced.

Whilst I am critical of the fixed model I initially adopted, I disagree with Clark's binary assumption that all biomedical frameworks fail to consider an ethics of care (Clark, 2010, p82), as 'care' was something that was thoroughly planned in my original ethics proposal. I also agree with Murphy and Dingwall (2007) that *rigid* anticipatory models can be restrictive, however, I do not want to dismiss the notion of an anticipatory framework, for there is clearly an imperative in advance of starting a study, to understand and be sensitive to a research community, predict possible negative responses or outcomes, prevent harm, and put in place safeguards.²¹ Nevertheless, anticipatory frameworks should not be rigid. McLaughlin (2010) and Pink (2007) emphasised the importance of clarity over ownership of data, and I should have been clearer about this from the start.

The research protocol also included planning for the intervention's potential to

²¹ The possibility of undesired emotional reaction to the research was mitigated by the planning described above: filming lay in the participants' control; there was access to the Breast Cancer Care Helpline; I frequently visited and contacted participants; and material was kept confidential until participants had approved it.

impact negatively on the lives of the participants, not only during the study but also after its end. This was of particular concern because, as already discussed, the post-treatment time is a vulnerable period, characterised by a sense of abandonment and uncertainty about the future. It was proposed that the project may temporarily 'fill this gap'; this could risk causing attachment to the project and making withdrawal difficult.

A flexible cut-off point for filming was in place, where participants themselves decided when to stop. The average duration of filming was nine months and three weeks, but some continued for much longer. Whilst two participants anticipated that they might 'miss' the camera when it went (BE & WA), both of them felt (at the time and retrospectively) that their self-determined endpoint was right.

In reviewing my original consent process, a balance was struck between fulfilling the ethical (and indeed legal) obligations to the participants regarding full disclosure of research aims and objectives, data protection and the prevention of exploitation, whilst also accepting that consent had to be a process in which the participant's views were sought and added to the research rather than aiming for a fixed binary agreement.

The original consent and release forms were replaced by on-going collaboratively produced aims; ethics became a "part of the process of knowledge production ... [that was] intrinsic to the entire research process ... [and] part of an on-going negotiation" (Clark, 2012, p29). These were resubmitted to the Ethics Committee and approved.

For two of the participants there was a complex, fluid relationship between self-censorship, revealing the '*truth*', and revealing too much in the first few weeks of filming. My absence during filming, and therefore lack of probing, would, I thought, lessen any tendency to stray beyond the natural limits of self-

censorship. However, one cannot ignore (and indeed the research relies upon) the potential for the camera to act as a “stimulant” (Rouch interviewed by Yakir, 1978, p7) or “accelerator” (Rouch quoted in Eaton, 1979b, p51), even without the presence of an observer (Renov, 2004b, p203). Two participants said that they were disclosing information that they felt they might later delete, or only make available for my PhD, to healthcare professionals, or people affected by breast cancer. In this respect, the prospect of being watched, valued, and respected by a “dedicated audience” (Chalfen *et al.*, 2010, p208) was unproblematic, but the possibility for some of their films being interpreted out of context was a concern voiced in the first few weeks of filming. Indeed, two other participants expressed concern over the possible unfavourable reaction of *known or familial* audiences to previously private disclosures. This echoed other visual research, such as Barnes *et al.*’s (1997) work with HIV positive women, Mairs Dyer’s (2013) audiovisual storytelling research in post-conflict Northern Ireland, and Kutluğ Ataman’s *Kuba* (2005, London). Whilst there was a selective porosity of public/private²² boundaries in relation to knowledge production, it was a fluid process that lessened over the research period.

This reaction is in line with the following example from my earlier film, *Remember the Day* (2010, London). In this project, one participant did, in the group setting and in the moment, stray beyond what they felt comfortable saying. She disclosed something during filming that she had never shared with her family, and did not want it to be included. I made a rough cut for her to see, which she then chose to show her family. After an emotional, immensely cathartic dialogue with her family, she decided to include it in the final film.

The final consent form containing all participants’ suggestions and listing the anticipated outcomes for the films was signed only on completion of the films.

²² Jon Dovey provided a comprehensive review of the shifting public/private domains in factual television and first-person media in *Freakshow* (2000).

Although the participants own the material, I have their permission to use it as outlined (Appendix 3) and they retain the right of veto. While eight of the participants consented to their material being made available in all forms to all audiences, each will be consulted as opportunities arise. One remained hesitant about future use. Despite initial concerns about audience, eight of the nine participants want the films to reach as wide an audience as possible. I invited anyone who was (& still is) interested to engage in dissemination projects (in line with Banks, 2001; Pink, 2007).²³ Participant involvement continued in preparing for the installation and the Gallery Talk. The fact that participants were motivated to take part, at least in part, by the hope that their films would help others imposes a strong ethical responsibility upon me to ensure that the films are extensively distributed.

However, the way in which I ethically interpreted and produced knowledge through my written theorising and analysis raised concerns about disclosing information provided to me during the research period. I kept a diary during the research period. I was cautious about the possibility of it becoming covert, detached surveillance; thus my aim was that it should be an open, experiential and immersive record rather than a secretive observational process. At the same time as making the process of my note taking transparent to participants (and ultimately to the reader of the thesis and viewer of the films), I did not want to physically write during our meetings, feeling this would connote an interview. So generally I wrote immediately after each meeting, recording my own emotions and responses, our interactions, and also noted aims and ideas that the participants expressed (I anticipated that the latter could function as an aide memoire for them should they 'run out' of things to film later in the process). Occasionally I did record 'direct quotes'. We also shared knowledge in emails and telephone calls.

²³ For example, I am writing a collaborative paper to be submitted to the *British Medical Journal*, and have given a presentation with one participant to Trojan's Cancer Support Group on 18/6/14.

I propose that the diaries should be read as highly subjective, selective and recontextualised documents. Importantly, they are not intended to be read as a 'expert voice' — but rather as the voice of a co-participant in the research process. The diary extracts form Appendix 4.²⁴

Whilst I have anonymised the participants in my writing, when the thesis is read with the films the participants will be identifiable and I do not want to break their trust. In looking at ethnographic research in healthcare settings, Murphy and Dingwall noted that, due to the protracted nature of ethnographic research:

The line between researcher and friend or confidante becomes blurred and hosts may disclose information that they do not recognise as relevant to the research but which the researcher considers to be so. This raises questions about the extent to which the hosts' prior consent justifies the use of such disclosures as data (2007, p2226).

Knowing as much as I do is the most profound privilege, as well as an ethical burden.

In his writing on intimacy and the visual in anthropology, Peter Biella sought to overcome racist and sexist attitudes and prejudicial Othering, a point to which I will return to and draw from. But in terms of research relationships where there are "intimate confidences between anthropologists and informants" there also exists, he asserted, the possibility that intimacy can make individuals vulnerable: "intimacy is a dangerous condition in which each individual exposes truths that the other could exploit" (Biella, 2009, pp144-145).

Duncombe and Jessop highlighted the ethical dilemmas of using rapport as a methodological tool to gain access to 'knowledge' through reciprocal disclosure in research (2012). They argued that "the skills of 'doing rapport' have become

²⁴ The diary extracts exhibited in What if? are also included in Appendix 4.

commodified” (*ibid.*, p108) and described a “disturbing ethical naivety” in not recognising the motivations of researchers (*ibid.*, p110). They cautioned that “at the heart of our outwardly friendly interviews, lay the instrument of purpose of persuading interviewees to provide us with data for our research, and also (hopefully) for our future careers” (*ibid.*, p107).

Any dangers or vulnerability in relation to exposing intimate truths in the films were addressed through the filming methodology (above), collaborative editing and right of veto remaining with participants (Chapter Three). However, in my writing, the problematic possibility arose that I could inadvertently break the trust that is at the heart of this collaborative research and upon which its success depends.

I discussed my thesis-writing process with the participants, asked for their consent to write about our meetings and interactions, and have shared the diary extracts used with them — seeking their approval and feedback. All but one of the participants did not express concern, and encouraged me to explore my readings. As BR said:

I know you are not wanting to impose anything on it ... but I think it would be interesting to see your interpretation because you might pull parallels out between people's different experience that we might not know about ...” (Diary, 1/3/14).

One participant asked to read all my analysis and theorising, which I have shared with her on an ongoing basis. I have found her feedback very instructive. She expressed finding the process both interesting and indeed helpful by encouraging her to think retrospectively about many of the issues her filmmaking raised.

In negotiating my writing position I have found Minh-ha’s guidance of speaking “nearby” helpful. Working “nearby” as a practice however, is not a guarantee of

unexploitative, ethical research relationships. I use the term with caution and in reference to Minh-ha's *descriptions* of her practice:

In other words, a speaking that does not objectify does not point to an object as if it is distant from the speaking subject or absent from the speaking place. A speaking that reflects on itself and can come very close to a subject without, however, seizing or claiming it (1999, p218).

I have sought participants' approval for anything I think may be sensitive — for example, their medical details and diary extracts. I do not agree with Murphy and Dingwall's pejorative assertion that collaborating in this way provides an opportunity to "suppress findings they [the participants] find unpalatable" (2007, p2226) — although if they did, it is their right to choose what they reveal. Instead, this presents an opportunity to complete a research process ethically.

EMPLACEMENT

Rouch's voice-over in *La Pyramide Humaine* (1961, France) asserted the importance of understanding intersubjective relationships in ethnographic filmmaking. This priority is central to much theorising on visual ethnography (Pink, 2007; MacDougall, 1998; Banks, 2001). Pink stated that examining "the intersubjectivity between researchers and their research contexts" is crucial to understanding the lives and worlds being researched (2007, p24). I will provide a critical appraisal of the research relationships, acknowledging our individual and collective positioning in the research environment.

I have not located my practice or my reflexive analysis in an anthropology of the senses; however, in theorising our engagement as co-participants in the research, I have found it useful to draw from Pink's proposal of sensory ethnography in its broadest application (i.e. focusing on perception, emotions, and place rather than an exact Aristotelian understanding of the five senses). I have considered us all "part of the social, sensory and material environment"

whilst recognising the “political and ideological agendas and power relations integral to the contexts and circumstances of ethnographic process” (Pink, 2012b, p23). Pink’s description of emplacement and her insistence that ethnography is a “reflexive and experiential process” (*ibid.*, p8) — a “coming together and entanglement of persons, things, trajectories, sensations, discourses and more” where “places are constantly changing and open” (*ibid.*, pp41-42) — has been useful in analysing research roles and positioning.

Pink argued this is a two-fold process: “we need to investigate the emplacement of the people who participate in our research. It is equally important for ethnographers to acknowledge their own emplacement as individuals in and as part of specific research contexts” (2012b, p25). Whilst these two points are interrelated, I shall focus on the latter first, before examining the participants’ emplacement. I rejected Pink’s belief that we should, or rather can, become “similarly situated” (*ibid.*, p50) with research participants as outsiders.

My intuitive positioning in this research inevitably draws on my healthcare background and previous research relationships, which acknowledges that as an ‘Outsider’ one cannot ‘*know*’ what it feels like to have had or to have a disease. From many years working across a number of healthcare sectors, and from listening to the participants in this research,²⁵ I am ambivalent about proximity in research relationships. The anthropologist Paul Stoller, writing on his own experience of being diagnosed with and living with cancer, explained the profound intensity of shared experience that *would* enable being “similarly situated” in research. He wrote of “a silent bond, though, with other cancer patients. They knew the emotional horror of a cancer diagnosis, the strange fraternity of treatment, and the intractable uncertainty of remission. They knew what I knew...” (Stoller, 2014, p114). Someone who has not been diagnosed

²⁵ For example: BI states her belief that there is a ‘knowing’ that can only be achieved through experience of breast cancer highlighted by “unless you have been through it you don’t know...” (1:39:36) and (45:54).

with cancer cannot manufacture this bond, and it would be disrespectful to attempt to do so.

Importantly, in their study of older women and images of aging, Susan Hogan and Lorna Warren (2012) argued for the benefits of the co-construction of knowledge by researchers and participants who do *not* share direct experiences. Quoting Gillies and Alldred (2002), they posited that shared experiences between the researcher and the researched should not be considered as an “authoritative basis” when conducting research (Hogan & Warren, 2012, p333); commonality of experience can be restrictive and compromising in what it reveals. For example, Gilles and Alldred stated, even though shared experience may permit both empathy with participants and may have provided the inspiration to produce research about a particular issue, “when emphasis is placed on sameness, power differences are highlighted in terms of whose version of the account is eventually told, even if the research is presented as a co-construction” (Gilles & Alldred, 2002, quoted in Hogan & Warren, 2012, p 333).

Whilst Biella rightly argued that witnessing intimate research relationships has profound effects upon viewers (2009, p144), as I have already proposed intimacy in research relationships can also expose people and make them vulnerable. My concerns are reinforced by Winston’s analysis of Rouch and Morin’s discussion at the end of *Chronicle of a Summer* (1960, France). Winston drew attention to ethical considerations of “the ease with which he or she [the filmmaker] could penetrate other peoples’ lives” (1988b, p24); this, too, has contributed to my hesitancy about proximity.

Significantly, though, I have not been located “in the margins of our professional discourse” (Stoller, 2014, p176). I would describe my positioning as close, respectfully close, and fluid with my “self-awareness developing relationally” with each individual (Pink, 2012b, p53) – both in the shifting contexts of the

research and, to a lesser extent, in my own life. MacDougall too described the anthropologist's process of "feeling out his or her position, experiencing differences in levels of understanding, as well as the shifts of moods and rapport" (1998, p89). I proceeded with caution though. Fundamentally, my positioning was based on feelings of profound respect for the participants, an inability to "*know*" what it must feel like to have been diagnosed with cancer, and an ethical vulnerability due to concerns that I may (inadvertently) exploit them or their experience through knowledge gained. Finally, as both Pryluck and Ruth Behar acknowledged, at the end of the day we finish our research, leave, and go home to our lives (Pryluck, 2005, p197; Behar, 1996, p51).

As BR relayed, respecting space and creating distance can be helpful:

I had a short time where I kind of pulled back and said 'well I am not certain' maybe I can't fit it all in as well as everything else I am trying to do. You were fantastic about that you didn't put me under any pressure. You just said 'it is fine it is fine' you can think about it for as long as you want and because you took the pressure off me I was then able to think about what benefits there would be and how much I would enjoy doing it and from that moment on I was completely into the idea so that was really helpful (Diary, 1/3/14).

In line with MacDougall's proposal, I believe that there is a deep reflexivity inherent in my work that represents the nature of our relationship "in the very construction of the work", which is "accurately encoded in the materials of the film" (MacDougall, 1998, p89). I will return to this idea in more detail in Chapter Three.

Accepting MacDougall's criticisms of the impossibility of impartiality in any internal assessment of roles in research (1998, p89), I will try to describe aspects of my emplacement. I am cognisant of Ruby's warning that "knowing how much of the self it is necessary to reveal... is the most difficult aspect of being reflexive. When successfully mastered, it separates self-indulgence from revelation" (2000d, p155). I hope to convey the privilege I felt as a co-

researcher in the participants' lives. I will first focus on some general aspects of my emplacement, and further examples emerge later in the thesis.

My relationships were predicated on a similar pattern: I met with the participants in a place of their choice,²⁶ which included coffee shops, homes, the university, even an unused railway platform. Initially we met quite frequently, but I was guided by how each participant responded to the research and to being left 'alone' with the camera.²⁷ All were given the same initial guidance, but each participant and each encounter was different, and each relationship took on a life of its own.²⁸ As mentioned I kept notes from our meetings.

I felt anxious about the ethics of meeting in public places to discuss health-related issues. This undoubtedly related to my professional background where medical information was confidential and confined to enclosed spaces. None of the participants shared my concerns, and they discussed their experiences confidently; nevertheless, I found myself simultaneously deeply moved, acutely aware of their vulnerability, and anxious. For example, when TO described the intimate details of her surgery whilst we were sipping frappuccinos at Starbucks, I listened with empathy and focus, but my responses were guarded — I did not want to encourage her to expose more than she chose to, or betray previous confidences by mentioning medical details back to her. In another cafe, BR apologised to me: an expression I gave clearly conveyed shock, and she asked if she was being too blunt, too open in her descriptions and contemplations of possible death. Now, in writing, I recall the ambivalences I vividly felt: the noisy staff and coffee machines irritated me, but I was also grateful for how they masked our conversations from others. I was conscious

²⁶ In my research what mattered about the meeting location was that the participants chose. I have not analysed the places we met in terms of knowledge production (see Herzog, 2005; Elwood, 2000).

²⁷ Some participants confidently and quickly started filming; others were hesitant, requesting more frequent meetings and feedback.

²⁸ Space does not permit a full description of each relationship.

that life was going on for others uninterrupted by cancer, but I was aware of the disease's invisibility, and wondered about eavesdroppers and their motives. In analysing this iteratively, I wonder to what I was actually reacting. Surely the making public of experiences was at the heart of my research? But the ethical safeguards (reviewing the material with participants, collaborative edits, right of veto) seemed beyond control in the coffee shop. But it was only beyond control for *me*, not for them. The participants continued to choose our meeting places, but it did shake my confidence. What was I inviting them to do? Was it right? Where and how should the films be screened? My consciousness was frequently flooded by the inescapable nature of cancer, and the way we take life for granted.

As the research continued and we wanted to watch footage, I was invited to participants' homes or they came to the university. Meeting in participants' homes, and meeting families, was a privilege only they could offer. But I was unsure whether it constituted an intrusion.

As mentioned above, Pink also emphasised the importance of considering the participants "emplacement" (2012b, p25). Although each participant was given the same guidance at the start of my research project, each interpreted the project in distinct ways. The complex multiplicity of ways in which the participants understood and connected with the research will be analysed, and any interconnectedness will be highlighted.

At the start of the participants' filmmaking, the final representational form of the research material was unknown. Whilst I envisaged that it would probably be a single intercut documentary, discussions with participants about the final outcome were very open-ended.

Each participant expressed aims of imparting experiential knowledge to others diagnosed with breast cancer. Frank ²⁹ noted the “responsibility” that individuals who have experienced illness feel to “guide others who will follow them” (1995, p17). This, he argued, is achieved not through the provision of didactic instructions, but rather through making visible the process of constructing and navigating one’s own path. This responsibility, Frank maintained is “the core morality of the postmodern” (*ibid.*).

Each of the participants was aware of the possibility that their films would reach a wider audience than other people affected by breast cancer. Indeed, for some participants this was a key factor in their taking part in the project (for example, TO wanted to raise awareness of hereditary breast cancer, DE secondary breast cancer, ³⁰ and EN Black lesbian perspectives). The responsibility that Frank describes, extends I argue to informing the wider public of the less well known variants of the disease on behalf of others.

A reciprocity of the positive benefits of sharing knowledge was also acknowledged in the filmmaking process; in part the participants were making the films for themselves. The degree of interest in each of these beneficiaries varied between participants; furthermore, each participant’s audience was not fixed, but fluctuated during the course of the filmmaking.

Several factors were used to examine each participant’s engagement with and understanding of the research, including: their initial understanding of the project; their individual motivation for participating; and the audiences identified by the filmmaker, both the initial primary audience and any

²⁹ I found Frank’s generalised descriptions of narrative types unhelpful. They reify and reduce the complexities and fluidity of individual experiences. I question the need and value of his prescriptive, diagnostic frameworks. Historically his theorising marked an important shift in legitimising marginalised voices — if only then to subject them to his own pedagogy. It was however, helpful to visit aspects of his work in my analysis.

³⁰ The need for which was made very clear in DE’s radio interview (45:48).

subsequent audiences added.³¹

BE's initial interpretation of the project was that she was being invited to make a film that would focus on her experiences of cancer.³² Her motivation for participating was to use her experiences to help others who had been similarly diagnosed. She wanted to share information that she wished she had known during her own treatment. "If other people can see some of the actual effects and hear how it affects them ... then by making this film hopefully other people will realise that they are not alone and what they experience is just typical of someone who is facing life after cancer" (00:54).³³ She was particularly keen to focus on the small things that remain unspoken — things that healthcare professionals may regard as insignificant.

Whilst her motivation to help others remained throughout the research, BE was also making the film for herself. As the project progressed she began to feel personal benefits from participating. She anthropomorphised the camera as her "invisible friend", who she could "off-load to" without burdening anyone [Diary, 8/5/14]. The *process* of participating was therefore important; particularly given that she was facing uncertainty regarding an abnormal finding on an ultrasound scan soon after the research started. As she notes in her film, documenting this process for herself became increasingly significant:

What I am going to do this time round though is I am going to try and make a note of how I feel when I go along to the appointments and between the tests and the results. It is something that people suggest should be done and I didn't do it when I was diagnosed with the breast cancer (18:18).

³¹ Pink was right to be critical of Holliday's failure to undertake this analysis (Pink, 2001).

³² I subsequently directly influenced her filming when I asked if she wanted to take her camera with her on holiday. Somewhat surprised, she replied that she had not realised that she could film non-cancer footage.

³³ This statement was set against the moving reality that *she* was still experiencing and encountering uncertainties alone: "I don't actually know who I am anymore" (5:48); "I don't know who to talk to" (12:35).

The film was also meaningful to her as an archival product:

The film fills a huge section my life where there are no photographs. I avoided being photographed when I was ill. I'd often say to friends or family "oh no don't put me in the photo" or "I'll take the picture" at gatherings because my hair had fallen out, or I looked too unwell, or too grim. So this film fills a gap in my life (Diary, 8/5/14).

TO's initial interpretation of the project and motivation to participate was that it was an opportunity to both raise awareness about hereditary breast cancer to a wide audience (Diary, 1/6/12 and 12/6/12), and to use her own experiences to help others diagnosed with the disease. She also acknowledged that she was making the film for herself, and partly to help me obtain a doctorate.

As filming progressed after her risk-reducing surgery, she focused on her new breastless identity as a vehicle through which to help others confidently challenge the aesthetic disjunction that frequently occurs in breast cancer between public and private bodies. "I hope that other young women out there can look at me and get some sort of inspiration and feel that life can move on after a mastectomy because your life is more than a pair of boobs" (6:07, reiterated at 27:16, 42:05).

In stating that the film was made — at least in part — for herself, TO made it clear that she did not want to see any of the footage, or become involved in the editing. She prioritised the *process* of filming and exploring her own identity (as well as projecting it for others), rather than creating a filmic product for herself.

BR interpreted her research as a creative art project. She had heard about the project through a Fine Arts PhD student at the Media Arts and Design Faculty, who had attended a symposium where I first presented my work. BR gave this as her reason for assuming that the project was grounded in the Arts. She is a practicing artist herself. She was aware that the films would be made visible to external audiences, and this affected her decision-making and filming — for

example, she asked that one cademe be removed.

However, BR was not making the films *for* an external audience. From the start of the project she stated that she was making the film for herself. She had been actively contemplating a creative project to explore her experiences of having breast cancer:

It was something that my counsellor suggested that I should do ... well, not the filming specifically but the ... she said try and do something creative around your experience, and for a while I didn't know which direction I would go with it ... whether it would be painting or a performance of some kind, and nothing came to mind and it wasn't until we had actually started doing this project that I put the two things together and that this was the creative thing I should do and it was exactly how I should be doing it — so it was a great process for me (Diary, 1/3/14).

EA never considered her breast cancer diagnosis to be problematic. However, like BR, from the commencement of the study she identified the project's potential to help her negotiate her response to her breast cancer diagnosis, in the hope that “over the next few months you help me come to terms with my ... own personal, I don't know shall I call it problem — it is not a problem any more” (1:35). Like BE, EA anthropomorphised the camera; instead of a friend, she saw the camera fulfilling the role of a listening therapist she called Princess: “we will speak again and you have to listen to me. I know you can't talk back. But I am afraid you are in here with me for the duration and you are going to help me come to terms with this problem ... and anything else that crops up in between” (7:50).

Whilst imagining herself as the audience, she acknowledged the fact that the films would be shown to a wider audience: “God ... you're mad talking to yourself ... people will soon realise how mad you are” (8:44; also recognised at 13:55 & 21:50). She expressed to me her desire to help others diagnosed with the disease (Diary, 10/7/12).

From the beginning, WA interpreted the project as an opportunity to explore her experiences of cancer. Rather than focusing on breast cancer in isolation, she understood the project as incorporating her experiences of living with and beyond breast cancer in the wider context of her life. WA had been helped enormously by Breast Cancer Care Voices³⁴ when she was first diagnosed with breast cancer, and she placed high value in sharing experiential knowledge. Her principal motivation in participating was to help others as she had been helped. She wanted to inspire people, though she did not presume that she would. She recalled how, when she was diagnosed, she was shown pictures of the women who were just a torso; she remembers craving to see the person behind the image, and this has inspired both her filming and her subsequent life modelling:

Like when I was shown pictures before my operation... you are just shown this like torso, and these kind of... scarred breasts ... and I remember thinking, I don't want to look like that, I don't want to look like that, and I just got really upset... I think part of that maybe was because that there was no person attached to it. I was literally just shown boobs and a tummy scar to kind of say that is what you will look like — there was no person there, there was nobody smiling or ... So I suppose I'd like... to be the person that belongs to those scars and I want people to be able to see me smiling (1:14:37).

However, WA experienced an anxiety underlying her communications and encounters with other women who have experienced breast cancer: because she did not have chemotherapy or radiotherapy, she worried that the validity of her experience might be called into question (Diary, 5/7/12).

WA was also making the film for herself. She described to me how she wanted to use the camera to explore her metamorphosis; to explore the person that she has become as a consequence of her cancer experience. She wanted to use her cancer experience to transform and reinvent herself, to become a more

³⁴ Breast Cancer Care Voices is a charity forum where many hundreds of people affected by breast cancer share experiences.

confident person. She felt that taking part in this research and making a film would help her achieve this. Like BR and EA, from the start she identified with the project as “a tool for healing” (Diary, 13/7/12).

DE was very clear that her principal motivation for participating was to create a legacy for her husband and son:

I made the film for my husband Graham and my son Devon. I wanted Graham to remember who I was and I wanted Devon to know who I was when I was gone. I wanted a record of what we went through together as a family, what we did together as a family, and who we were together as a family. It is a record (Diary, 31/8/14).

Whilst this remained her main aim and her family continued to be her primary audience, DE was aware that the film was part of a larger project that would be seen by wide audiences. She hoped that the film would educate others and help people diagnosed with secondary breast cancer. She feels there is much positive bravado surrounding primary breast cancer that simply is not relevant to, and indeed is unhelpful to, those with secondary breast cancer. She was frequently told by others who heard that she has breast cancer that it must be “OK as the prognosis is good” (Diary, 5/7/12). She wants people to understand that secondary breast cancer is a life-limiting disease.

BI, too, had been active in sharing her experiences of breast cancer prior to the project. She had started an online blog shortly after her diagnosis, entitled ‘Life, Death, and Everything in Between’. She saw the project as an opportunity to build on that blog’s ideals, as a means of sharing experiences to help others diagnosed with the disease: “it is like being involved in this project, I hope that doing this will help somebody, inspire somebody .. just make somebody feel less alone” (1:31:29).

She also envisaged that healthcare professionals, family and friends, and a wider public would see the film. Indeed, BI addressed healthcare professionals

directly in her film: “I just don’t understand health care professionals, why that is not a standard thing that you would do, because if you did you wouldn’t have us coming back every five minutes with problems” (22:40). But then,

It got to a point where I realised that act of recording, of speaking to the camera, was helping me. With the best will in the world, I believe that it is hard to talk to and be understood by people who haven’t been through it. With the camera there was never any need to explain — you could just talk. Also, often when you want to talk, there isn’t always someone there — the camera was always there. It was good to get things off my chest when I wanted to. You also don’t want to burden people with your concerns or worries (Diary, 18/8/14).

EN’s interpretation of the project was that “it was about filming your life over a six month period and how cancer continues to have an impact even though you are post active treatment” (Diary, 5/3/14). EN carefully laid out the aims, content, and style of her participation. She chose to focus on the impact her diagnosis and treatment had, and continues to have, on her relationships, within the context of the intergenerational losses within her family to breast cancer. The medical side of experiencing breast cancer, she felt, was often the most visible; but is not necessarily the most consequential, and she did not want to focus solely on that aspect. She also filmed in a structured way, watching footage back and re-recording aspects (something that few people did) and taking an active directorial role.

Her motivation for participating was multifaceted. She thought that she would enjoy learning a new skill, as she had never made a film before. The opportunity to explore her experiences of breast cancer in a different way was also appealing. She had already been documenting her treatment for breast cancer by taking photographs, and this project presented her with the opportunity to add to this ‘album’. Indeed, some of her filming was only for her private archive. Like BE and DE, the film as a record was important.

PA was motivated to take part in the project by a firm desire to help others

diagnosed with the disease. Like WA, she had personal experience of the benefits of attending a local support group and wanted to share her own experiences more widely, particularly her belief in the importance of maintaining a positive outlook. However, PA initially struggled to interpret the best way to use the camera and engage with the project: “When you gave me the camera I thought, ‘oh my god, what I am going to do with this’” (Diary, 6/9/14). In consultation with me, she subsequently decided to focus her filming on her cancer experiences in relation to friends, family, and individuals she had met since she was diagnosed.

Like BI and BE, over the course of the research PA increasingly experienced participation as a personally helpful act: “It released things inside that you haven’t talked about before or had the chance to talk about before” (Diary, 6/9/14).

CONCLUSION

Nine self-selecting women, who had been diagnosed with breast cancer nine to 36 months before the study’s commencement date, were given video-cameras with the invitation: “You know you have been invited to take part because you have had a diagnosis of breast cancer. You are being given a camera for three to six months to film whatever is important to you”. The participants filmed for an average of nine months and three weeks.

This chapter offered a description and critical appraisal of key aspects of my methodology. Whilst each of the remaining chapters continues to address aspects of the research questions regarding collaborative methodology, ethical engagement and collective reflexivity, this chapter began the process. In addition, it raised and answered further questions.

Is the methodology an effective, respectful way of producing new knowledge, and new ways of knowing, about illness experiences? In seeking to reduce

representational and authorial inequalities and develop a collaborative methodology that places authorship with participants *outside* of clinical, broadcast, and/or external directorial frameworks I have adopted and justified key strategies. I identified the interview and prior identification of themes as problematic interventions that reduce, homogenise and regulate experiences. Instead I used open-ended guidance, inviting participants to film whatever was important to them. Unless invited into the frame, I was not present during filming. I acknowledged my role in the co-construction of knowledge, which remained conditional, situated and temporal.

I proposed that inviting participants to take part from a clinical environment may have codified responses. Instead I issued invitations via word of mouth, and through community and support groups, and health care charities. I made no claims that my decision to invite participants in this way was ideologically neutral and eliminated external agendas or researcher influenced input. I have however justified it as a significant step in researching illness in the context of the life it occurs in. In situating the research outside of the clinic, it has not been the purpose of this thesis to perform a comparative study of research methodologies.

How did the participants interpret the open-ended research and how were we as co-participants, emplaced in the research? An analysis of reflexive practices and processes forms part of each chapter in this thesis. In this chapter, I recommended and defended the following main elements. Firstly, I undertook an analysis of each participant's personal aims for taking part and the ways they interpreted the research. Their discrete responses attest to the importance of examining participants' motivations and understanding of research projects. Their aims for taking part tended not to be fixed but fluctuated during the filming period. Whilst all acknowledged a wider audience for the films, and indeed for many making their lives visible *for* others was a principle reason for participating, the possibility of beneficially producing knowledge for 'self' was

anticipated by some. The value of the research as a 'process' and the research as 'archival product' for participants tended to be fluid.

Secondly, my positioning in the research was scrutinised. The proposed methodology was predicated on an exceptional amount of trust. In seeking to reduce my interventions, the impossibility of a neutral researcher was acknowledged. Intimacy in research relationships was problematised as potentially exploitative. The integrity of the researcher's role carries particular significance as participants were asked not to delete any footage and will be discussed further. A model that recognised (from my own experiences, the participants views, and Stoller, 2014) the impossibilities for 'outsider' researchers to become 'similarly situated' (Pink 2012b, p50) with subjects was proposed. This model also advanced the importance of sensitively seeking out a respectful proximity and supporting participants during the course of the research in response to *their* needs. The research relationship would become exploitative if, for example, cameras were simply handed over to produce 'visual data' purely for investigative gain.

Ethical planning and implementation required revision during the course of the research, and necessitated asking a further research question: *What ethical guidelines arose from this research?* The fixed anticipatory framework initially adopted did not allow for the participants to feed their ethical values back into the research process and failed to consider the impact of uncertain research outcomes. Anticipatory frameworks however remain an important part of research planning and implementation, but these should be flexible. Subsequent use of research material, decided in consultation with participants, should be incorporated into the consent forms and clarity of ownership from the outset established.

What impact did the research have on the participants' lives? As mentioned anticipating and documenting the impact that the research could have on

individual lives formed a central part of the ethical planning for the study. However, few problems were encountered. Initially some hesitancy was expressed by two participants about revealing more than they felt comfortable with. Whilst these feelings were transient, issues relating to self-censorship will be discussed in more detail in Chapter Three. Revisiting the past — whilst at times emotionally charged — was credited with being beneficial, and this effect will be theorised in Chapter Four. Withdrawing from filming was, as described, carefully structured and participant involvement continues with dissemination activities.

During the filming process multiple truths about life following a breast cancer diagnosis emerged, rather than any singular, generalised truth. The knowledge produced has a complex status formed from shifting, divergent motivations and interpretations of the project, and my own intermittent encounters with the participants. In the following Chapter, I theorise the process of editing and displaying this complex visual material.

3. METHODOLOGY II: EDITING PROCESSES & REPRESENTATIONAL PLATFORMS

INTRODUCTION

Having outlined, analysed, and justified my methodological approach to investigating experiences of breast cancer, and offered insight into the status of the knowledge produced, I will now problematise the editing and presentation of the research material. In doing so I focus on two further research questions: *What role was played by the collaborative edit and feedback screenings? And, how to display and engage with durational polyphonic ethnographic / visual material?*

Nine women diagnosed with breast cancer were given cameras to film whatever was important to them. They filmed for an average of nine months and three weeks. The resultant material was a multifaceted, situated co-production. These “thick” representations of living with breast cancer provided: a “multiplicity of complex conceptual structures, many of them superimposed upon or knotted into one another, which are at once strange, irregular, and inexplicit” (Geertz, 2000, p10). How, then, can these representations be grasped and rendered in a way that privileges their individuality and the individual interpretations of the research, whilst also acknowledging their interconnectedness?

In the first half of this chapter I will discuss how my initial plans to assimilate all nine perspectives into a single intercut documentary had to be changed. I will explore key influences — from both existing theory and practice, as well as my own practice. In this decision-making process MacDougall’s observations of the “discrepancy between the experience and the existing paradigms for representing it” (1999, pp296-7) became evident.

In response to this seemingly intractable dilemma, I have principally drawn on the editing theories and practices of Jean Rouch and David MacDougall,

focussing on three key considerations: respecting the collaborative nature of this research; the act of editing while respecting the gap or cavity between the moment of filming and the final film; and privileging the speaking subject and their filmed cademes — “the shot as it comes out of the camera” (Worth & Adair, 1997, p89).³⁵

The decision to move away from a single intercut documentary was dictated significantly by the nature and diversity of the participants ‘rushes’ themselves which in addition to revealing divergent illness experiences, were characterised by distinct styles of filmmaking. Lila Abu-Lughod argued for a form of anthropological writing that brings “closer the language of everyday life and the language of the text” and that does not impose a hierarchy through generalisations (1991, p474–5). These are the aims I adopted in editing. I will describe the participants’ ambivalent responses to feedback screenings and collaborative editing; however, their unanimous requests for minimal reduction in the quantity of material — a common request in collaborative projects (Elder, 1995) — have also significantly guided my decision-making.

In the second half of the chapter I will propose an installation, with nine individual edited films, is the best-suited platform to fulfil the aims of the research and of the participants. I will explain my decision-making process, drawing from Paul Basu’s theorising (2009), Cahal McLaughlin’s use of a multi-screen, interactive exhibition for his collaborative filmmaking in Northern Ireland, and the polyphonic installations of Kutluğ Ataman (*Kuba*, 2005, London)³⁶ and Ann-Sofi Sidén (*Warte Mal! Prostitution after the Velvet*

³⁵ Worth and Adair described the “unit” from the time the start button is pressed until it is turned off as a “cademe” and edited version of this becomes an “edeme”.

³⁶ I refer here to the specific installation site of *Kuba* and *Warte Mal!* both in London. I have studied the archives for both installations at Artangel (*Kuba*) and the Hayward (*Warte Mal!*). I acknowledge Paul Basu’s writing for altering me to both these artists/practices.

Revolution, 2002, London).³⁷Ataman and Sidén's projects, while focusing on divergent groups of people, share a number of features with each other, with the films produced in my research, and with aspects of McLaughlin's work. Experiential knowledge was privileged — however complex or incomplete, partial or problematic, iterative or contradictory. They presented a number of competing and contesting perspectives that privilege the speaking voice, and they foregrounded realist documentation while problematising single-screen conventions. The subjects in each work were all bound by a collective identity or have shared experiences, and their intimate testimonies existed outside of official, sanctioned versions. The practitioners adopted collaborative research methodologies/approaches, through protracted periods of engagement and documentation with research participants that sought to overcome hierarchical power imbalances.

I therefore argue that the gallery can be used as a public space to explore social issues and an installation is an appropriate platform for the films that have emerged from my research. Basu (2009) proposed that:

[t]he future of ethnographic film — of the use, that is, of moving image technologies in the service of the anthropological project — lies therefore beyond the narrative frame that typifies the established canon, and rests, I suggest in the continued experimentation with archival modes of articulation and distribution within online and offline exhibitionary contexts (ibid., p107).

EDITING

Rouch described editing as “the fixing of the truth” (quoted in Henley, 2009, p292). We must therefore consider Mak's question: “If facilitators resort to editing the material away from the people who filmed it, does this count as

³⁷ Researching past installations is problematic as films in installations should not be read as a single, cinematic event, but in the context of their display in a specific space. I spent protracted periods researching through archives, visiting publications and online material.

being non-participatory behaviour?" (2012, p194)

Flaherty's practice in *Nanook of the North* (1922, USA) initiated a form of participatory editing characterised by feedback screenings. Critical opinions vary as to whether collaborative processes that also incorporate consultations in filming, training technicians as well as feedback screenings, achieve more authentic, less exploitative films. These practices did little to prevent Ukadike from making accusations of "paternalism and prejudice" (1990, p38) or Fatimah Tobing Rony from concluding that *Nanook* — like other ethnographic subjects — was presented "to be scopically possessed by the camera/filmmaker and audience as well" (1996, p102). Ruby, by contrast, contended that Flaherty successfully embarked on a partnership, was open about the constructed nature of the project, and was accountable to his subjects (2000c, pp83–91).

Feedback screenings were a central part of Rouch's praxis, for example in *Jaguar* (1957–67), *Petit a Petit* (1968–69), *La Pyramid Humaine* (1961), *Chronicle of a Summer* (1960), and *The Lion Hunters* (1957–64). Critics have questioned whether the resultant mediation from the screenings is an open, two-way process. It arguably gave greater knowledge about participants to the researcher, and perhaps to the participants themselves, but the research remained *about* the other — information is not 'shared' between both parties (Rothman, 1997, p105). Thus, Rothman claimed that, whilst the feedback session in *Chronicle of a Summer* did reveal greater insight through the revelation of motivation and 'truth' value, it was not actually a reciprocal relationship as it revealed little about Rouch and Morin and their views.

However, there was evidence that feedback screenings can and did lead to active authorial changes. For example, when directing *The Lion Hunters*, Rouch explained that, "the hunters themselves said, 'No, it is not good for us'. And I went and re-shot the film, and that version met with approval" (Rouch quoted in ten Brink, 2007, p101). Further, at the end of *Chronicle of a Summer*, Morin and

Rouch openly acknowledged: “I think we are in trouble”. They were clearly disturbed by the ethical implications of making the film, particularly by the probing of participants to produce ‘knowledge’, and were concerned about the status of the knowledge produced through filmic representations.

Feedback screenings for Rouch were largely seen as a “long term” process (Henley 2009, p254); to collaboratively plan further films and projects. In this respect my praxis differed. My primary aim was more short term. I wanted to enable the participants to play an active role in determining the content of their films.³⁸ Whilst like Rouch I gained greater insight from the process of the feedback screenings, I afforded greater authorial control to the participants than he did.

Rouch warned of the potentially restrictive impact of showing films only to those who made them, arguably aiming only to satisfy those individuals and creating “a closed information circuit”. While issuing a rallying cry for collaborative feedback, he also called for “ethnographic films to become films” (Rouch, 2003a, p44) that appeal to a wider and commercial audience.

Rouch’s desire for a single ethnographic film that satisfied diverse audiences is contentious. Carelli’s practice with Brazilian Indians (reported by Aufderheide, 1995) responded in part to this question. He edited a film on male initiation and produced two cuts: one largely unedited (and extremely repetitious) version intended for the local audience, and a second, highly edited version for those outside of the village. Carelli described the process: “we work more with the idea of just cleaning up the material and making the exhibitor’s work easier, grouping together the parts best liked by the local audience” (quoted in Aufderheide, 1995, p91). Asch took this notion further by proposing that, to

³⁸ Although, like Rouch I have actively sought their advice on future projects for us collectively as well as for them individually.

make a ‘complete view of a culture’ (in so far as any representation will allow this), archive copies of unedited rushes should be made available for research purposes (2000, pp199-200). But this begs the question — will they ever be watched?

Whilst Sarah Elder did not hand the camera over in her work with the Alaska Native Heritage Film Centre, her editing praxis invited a high degree of native participation. As Elder noted, she attempted to follow “Yup’ik ways of eliciting and presenting knowledge” (1995, p95). She consulted her collaborators about what footage to include and what should be left out, finding that there were surprisingly few requests to exclude footage (this was unsurprising in some respects, as her filming praxis was highly participatory). There were some exceptions: in *On the Spring Ice* (1975), the Alaskan collaborators wanted a scene where a walrus foetus was killed removed for political reasons, since they were in negotiation with the government about ethical marine “harvesting”; and in *Every Day Choices* (1985), someone who was filmed drunk asked for that footage’s removal (*ibid.*, p99).

Of greater concern to Elder were instances when collaborators asked her to include scenes that conflicted with, or challenged, her own ethical stance. For example, one scene she felt uncomfortable including in *Every Day Choices* featured a man who had drunk excessively and was also suffering from a seizure, being “hauled” into an ambulance. Local counsellors told Elder to include this footage, arguing that “the time for covering up was over” (*ibid.*, p99). Another example, in *The Drums of Winter: Uksuum Cauyai* (1988), related to the diary of a local Catholic missionary, who wrote: “These people are so disgusting on the exterior that nature itself must stand up and take notice”. Elder was concerned about the impact this would have on the young Eskimo children she was trying to enable and inspire (*ibid.*, p100). She confessed that her editing praxis meant that some projects took up to four years to successfully complete.

Rouch's contradictory stance on editing highlights the problems in trying to establish a fixed methodology, and justified leaning towards responding to the material in the editing suite. On the one hand, he advocated editing with the camera – “shoot so as not to edit” (Henley, 2009, p279); Bellman and Bennetta (1977) took this approach in Western Africa. On the other hand, Rouch acknowledged the need for material to be “radically manipulated to make it conform to highly conventional editing procedures” (Henley, 2009, p171).

Whatever the fluctuations and inconsistencies in his actual praxis, Rouch, like MacDougall, associated editing with loss, and both resisted the reduction of rushes. Likening the loss of material in the editing suite to the amputation of a limb, Rouch recognised that much “authenticity” — and hence value — “lay in ‘redundant moments’ which inevitably did not survive the initial edit” (Henley, 2009, p167). MacDougall did not argue that the unedited rushes contained a greater degree of “truth” or that editing could not impose greater understanding, but rather that the “centring of meaning” which occurred in the editing process was at the cost of the conditions of production (MacDougall, 1999, pp298-9).

There was an intense honesty displayed by all participants in that they did not, as requested, delete any material (or indeed pre-edit) when recording. In fact, few watched the footage back before passing it on to me. I was moved by the trust this implied, but also in discussing this with participants, they felt control over the process and rarely strayed beyond limits in their filming they were comfortable with (as mentioned previously).

I propose that the significance of the feedback screenings for participants who had shot their own footage is different than in Rouch's praxis where he held and controlled the camera. In ‘our’ feedback screenings there was anticipated awareness and familiarity of the material as it came onto the screen. Even so for

some there was a self-consciousness or occasional misrecognition about seeing themselves on celluloid. For example, in one feedback screening DE expressed that she saw a confident person on the screen but had not and did not feel confident herself. Both BI and BR acknowledged that if they had watched their footage back on an on-going basis, it might have affected how they behaved on camera. They were concerned that it may have induced a self-consciousness that would have modified their behaviour or inhibited them from future recording.

Knowledge of what has been filmed, however, does not negate the need for feedback screenings. The value of the feedback screenings was as an ethical safeguard in light of the fact that the participants had been asked not to delete anything when recording. The screenings also facilitated prioritising footage for their films and reinvesting meaning when edited together. The fact that not everyone chose to participate, again does not justify its exclusion from a research methodology.

Consequently, I invited each participant individually to engage in feedback screenings of *all* their material. This entailed showing each participant their original rushes and inviting them to contribute to the editing process — selecting which scenes should be included, which left out, and what priorities they had for the remainder (I shall return to this later). In developing an editing style my focus became preserving intact cademes as far as possible, privileging the speaking voice, avoiding jump cuts, and accepting that narrative gaps and repetitions were in themselves revelatory (trusting audiences to read this and fill in the gaps as necessary). Preserving material was a key factor for each of the participants.

Using the rushes selected and prioritised by the participants, my initial edit focused on a thematic, intercut construction undertaken in Rouchian style of ‘successive approximations’. However, it soon became apparent that so much of

the material did not fit into themes, and also when trying to intercut between different perspectives, meaning was lost and dispersed.

For example, during one intercut between perspectives about concerns or fear of recurrence of their cancer (a concern for eight of the nine participants), the iterations became reified, polarised and contained within a specific filmic moment. This failed to represent their nature as uncontained, hard to control, on-going, and iterative in response to different circumstances within the women's lives. When intercut, these fears became comparative between the women and their relative situations, rather than appearing in context of them as individuals. In an attempt to fit testimony into a collective frame, important information that highlighted difference ended up on the 'cutting room floor'. I sometimes had to cut into and shorten cademes — often stripping them to the bare minimum — to keep only essential information that suited the overall narrative, rather than the individual participant's narrative.

This loss of "excess meaning" (MacDougall, 1999, p299) seemed inherently dishonest — even a betrayal. Centring meaning in order to drive forward the overarching narrative had the effect of homogenising the material, at the expense of the individuality and spontaneity of the experience. The chronology of filming was interrupted; consequently, the multiple character functions played by, for example, cancer and tamoxifen (Propp, 2009) (sometimes diurnally) were blurred. Again the "sense of the encounter" (MacDougall, 1999, p299) was eroded, as perspectives were combined and codified into a thematic format. It became as Abu-Lughod described:

[t]he effort to produce general ethnographic descriptions of people's beliefs or actions tends to smooth over contradictions, conflicts of interest, and doubts and arguments, not to mention changing motivations and circumstances. The erasure of time and conflict make what is inside the boundary set up by homogenization something that is essential and fixed (1991, p475).

In editing *Chronicle of a Summer*, Rouch considered the problems of assimilating “heterogeneous” perspectives, arguing that to “bring together their testimonies would falsify the truth” (Morin, 2003, p251). Rouch felt the value of the film lay in the “evolution” of the subjects over the summer. So he proposed a chronological edit — “editing as a function of the filming rather than editing as a function of the subject” (*ibid.*, p251). This contrasted with Morin’s desire to impose a “collective halo” (*ibid.*, p252) around the subjects, by resisting individual stories, privileging the collective before returning to the particular. In my editing practice I encountered the dilemma highlighted by Rouch.³⁹

In making *Inside Stories* (2005, Belfast), Cahal McLaughlin recorded three personal perspectives of former occupants of Long Kesh Prison (the Maze), Belfast, in 2003, three years after the prison had closed down. Each individual occupied a different position in the prison during the political conflict in Northern Ireland: one was a loyalist, one a republican, and one a prison officer. The work was a visual investigation into the effect of location on memory, narrative, and performance, produced collaboratively with the film’s subjects.

McLaughlin described the frustrating process of trying to cut his research material into the form that he was most familiar with — a single screen, intercut linear narrative. He found that this form resulted in “fragmenting their contributions and forcing them together”. In part he attributed this to his open methodology and lack of a clear “line of enquiry”. Nevertheless, whether the narrative was constructed “chronologically, thematically, or aesthetically, it proved unconvincing” (McLaughlin, 2010, p96). McLaughlin abandoned intercutting and edited each contribution separately, allowing for contrasting,

³⁹ I watched a number of single screen documentaries that contained multiple perspectives to analyse how editors had intercut the material. For example, Peter Adair’s *Absolutely Positive* (USA, 1991), Bogнар and Reichert’s *Lion in the House*, (USA, 2006) and Morgan Matthews *Scenes from a Teenage Killing* (BBC2, 2011). Adair used highly reductive techniques, Bogнар and Reichert produced a film of 225’ duration, and Morgan privileged one narrative. None of which seemed to satisfy my aims.

rather than competing or contesting, versions of the prison experiences (*ibid.*, p99). Minimal editing intervention was used, and the participants were given the opportunity to change and comment on the final edit.

I also experimented with multiscreen edits, initially in order to address (and preserve for the participants) the sheer volume of footage. I felt that a large number of cademes lent themselves to a split screen format, where routines of daily life could run uninterrupted whilst other narratives played out alongside. One example was DE's durational observational filming of her baking a cake for her son's birthday, which had profound significance because of the uncertainty of how many more birthdays she would be able to do this for. Being able to run the whole cademe (30 minutes) whilst other aspects of her daily life continued on another screen had symbolic appeal. Another participant, WA, was snowed in her house for days and days — during which she filmed continuously — and she felt both physically and emotionally trapped. Being able to privilege these hours of containment simultaneously across screens had a certain logic. Similarly, WA mowing her lawn not had only a poetic rhythm but also provided a (unspoken) contrast to her personal dialogue, showing the ordinariness of life.

However, in a provisional feedback screening with other filmmakers, the predominant view was that splitting screens starkly imposed a standardised form over the participants' narratives, leading to a homogenisation of experience. Furthermore, additional meaning was created between screens that moved the film away from the conditions of production. I wanted — as much as possible — to lessen a retrospective external imposition of narrative by me.

In addition, when intercut, the different styles of filmmaking occasionally jarred; in seeking satisfactory transitions, decisions were often made for aesthetic reasons rather than due to content or participant priority. In initial screenings at the university, comparisons were frequently drawn between footage quality, rather than style or content. I concluded that, despite their

unifying diagnosis, the individuality of the participants' experiences and styles of filming resisted a single documentary form. The multiple lived experiences and forms of representation had to be prioritised.

So I abandoned my original aim for a single documentary containing all nine perspectives. Like McLaughlin, I edited individual films for each participant. I chose to follow the chronology of filming (like Rouch in *Chronicle*), preserving the fluctuations in feelings and attitudes over time, which were sometimes contradictory and iterative. Each film contains multiple self-contained narratives, whose reasoning relate to *a given* moment; these were not forced in the editing suite to yield to additional external narrative pressures, beyond the chronology of filming. Feedback from the screening of McLaughlin's films at London South Bank University attested to the important affect of avoiding intercutting and privileging individual narratives with their "own internal logic" (McLaughlin, 2010, p99).

Just like filmmakers, institutions, or experts, collaborative subjects may have motivations for "domesticating" images or centring meaning (MacDougall, 1999, pp296–8) and restricting the knowledge made available to audiences. However, in the feedback screening and collaborative edit, participants requested very little removal of footage. One participant felt her body was too exposed in one sequence; another asked to rerecord a piece where she also felt physically too exposed; and one participant disclosed something that she later decided to keep confidential. The feedback screenings and collaborative editing revealed how the nature of illness, feelings, and memory fluctuated; when watching their footage, a number of participants commented that they no longer felt the same and they were sometimes surprised by how much their feelings had changed.

As Rouch observed, the process of collaborative editing must be fluid and individual, rather than fixed. Two participants declined to take part in the feedback screenings and editing —TO simply did not want to watch herself, and

EA withdrew from further participation while encouraging me to use all of her footage for the installation. Of the seven women who participated in collaborative editing, one (BR) did not want to get involved beyond viewing the rushes, five participants watched and prioritised their rushes, and one (EN) became more deeply involved. EN and I often sat in the editing suite together, collaboratively making individual cuts and decisions.

For most of the participants there was still considerable 'loss' in relation to the amount of footage recorded over the course of the research, with some meaningful information regrettably lost to the 'cutting room floor'.⁴⁰ For example, BE had been advised by her surgeon never to have blood specimens taken from her arms. However, at hospital appointments, either other medical and healthcare personnel disregarded these instructions, or there were no staff present who were qualified to take blood specimens from her feet. This was a cause of concern for her. Another example involved EN, who had been unable to obtain her preferred brand of tamoxifen during filming. For several months she recorded both the problems she encountered and the help she received in trying to obtain the drug. In both instances, refilming and significant editing would have been required and we collectively decided to exclude these cademes from the film.

I do not claim that collaborative edits eliminate power imbalances, nor that intact cademes add greater truth-value. Dai Vaughan was right to point out that in film "the antithesis of the structured is not the truthful" (1999, p57). My decision-making has not been driven by a denial of the constructedness of the research. I have tried not to subordinate the participants' films to narrative conventions of resolution or closure, and again, I acknowledge the impossibility of maintaining complete equality in research relationships at all times.

⁴⁰ I have revisited and utilised all of the original footage in writing my thesis, unless I was asked to keep information confidential.

I have edited collaboratively because to do otherwise would be unethical (Pryluck, 2005, p205). Macdonald noted that the camera can act as a stimulant to talk and for subjects to reveal things “that they might not have said ever before - even to their family and friends... things they hadn’t ever properly formulated before” (2006, p392). This, he argued, can result in them being “surprised, and sometimes upset, how much they have betrayed themselves when you show them the finished film” (*ibid.*). The collaborative edit and feedback screenings provided an important safeguard to address this possible impact.

I have followed the chronology of filming and have tried to argue strongly for the irreducibility of experiences of breast cancer in these representations, agreeing that the “traditional method of composing the life history as a flowing narrative is not only morally dishonest but also intellectually inadequate because it conveys the false impression of a chronologically timeless and uninterrupted soliloquy” (Pack, 2011, p58).

McLaughlin engaged in collaborative filmmaking across a number of investigations with survivors of political violence in both Northern Ireland and South Africa. His work utilised a number of representational platforms, from ‘conventional’ linear, intercut, single-screen films, to interactive ‘multi-narratives on one screen’ and gallery installations. He argued that the gallery installation offers possibilities for ‘contradictions’ and ‘ambiguities’ of experience to inhabit the spaces between the screens, increasing “the spaces for interpretation” (McLaughlin, 2010, p149). Reasoning further for the imperative that audience members draw the interconnectedness between versions, experiences, and events (*ibid.*). The installation permitted an exploration of the segregation experienced by the individuals in *Inside Stories* in the prison, as each film was “shown in separate spaces within one overall space” (McLaughlin, 2006, p131).

McLaughlin cited Barbash and Taylor's polemic for preserving the principles and processes of collaborative polyphonic investigations as further justification for a multiscreen presentation of his material:

The answer surely is to reconceive the process of collaboration, not as a project by some imaginary univocal cooperative, but as a hybrid effort at polyvocal authorship, in which distinctions between participants may be visibly (or aurally) retained in the finished film (Barbash & Taylor, quoted in McLaughlin, 2010, p152).

THE INSTALLATION PLATFORM

Basu (2009) through the work of Kutluğ Ataman and Ann-Sofi Sidén argued for alternative ways of presenting visual ethnography. In revisiting these works, I will theorise how Kutluğ Ataman and Ann-Sofi Sidén's encounters with their participants in *Kuba* (2002, London) and *Warte Mal!* (2002, London) coalesce and negotiate with the gallery space to generate new meaning without exoticising, victimising, or making a spectacle of those in the film, while maintaining the intimate nature of the testimonies. I will focus on how the artists/filmmakers represented their role in co-constructing knowledge and how the architecture of the space played an integral role in meaning. I will also detail how they positively overcame the traditional viewing systems in exhibition spaces that may distract from empathetic readings — transience, lack of intimacy, altered connections to the outside world, narrative convention — and used the space to question our binary assumptions about prostitution and those excluded from mainstream society.

In her analysis of Ataman's praxis, Alisa Lebow alerted us to an anxiety that emerges when practices and practitioners blur disciplinary boundaries, posing the question, 'is it art or is it documentary?' (Lebow, 2007/8, p71). I agree with Minh-ha's assertion that it does not advance knowledge to simply "reproduce a discourse that states little more than the site it comes from, as it tends to gloss over the field of struggle, the mesh of established relations within which positions and postures are defined" (1991, p226). There has been an appeal to

working in the margins of ‘categories’ (*ibid.*, p53).

A key argument for our ⁴¹ collective decision to show the work in a gallery setting was the belief that the film’s intrinsic properties could symbiotically negotiate with the exhibition environment, in a way that will not render their ‘social/realist’ status obsolete. That is not to say that I claim a gallery or any exhibition space is a “neutral container” (O’Doherty, 1986). Context itself is content, (to continue O’Doherty’s polemic) and as films are assimilated by any environment, they are altered. Theorising this mediation process, and understanding how the films would be changed by the value systems of the exhibition space, formed an important part of my work.

However, I contend that O’Doherty’s argument originated in a specific time and context, referencing the white cube and post-minimalist conceptual art from the 1970s; in the twenty-first century, it is no longer valid to claim that the ideology of commodity fetishism defines all gallery spaces. The gallery, institutionally, has become increasingly “permeable and malleable” (Balsom, 2013, p51) and there are calls for a rethinking of “the boundaries between moving and still images, cinematic apparatus and gallery space” (Fowler, 2004, p 326). Whilst examples of the white cube as a commodity broker, for example, clearly still exist, practitioners from a variety of disciplinary backgrounds have demonstrated the flexibility of exhibition spaces by presenting social, cultural and ‘realist’ projects as installations in a variety of locations without facing accusations of commodifying human experience, and offer a significant departure from this paradigm.

Kuba, Kutluğ Ataman, 2005, The Sorting Office, London

Kutluğ Ataman’s *Kuba* (2005, London) was a 40-screen installation exemplifying

⁴¹ The participants and my collective decision.

a practice that challenged boundaries and ingrained value systems.⁴² Kuba, named after the Republic of Cuba, is a ghetto in Istanbul, isolated from the rest of Turkish society. Its inhabitants comprise “murderers, thieves, transvestite prostitutes, drug addicts, smugglers, extortionists, pill poppers, teenage delinquents and former left wing militants” (Ataman, 2003a) living in shacks without deeds to their land. It is resistant to penetration by outsiders. In making *Kuba*, Ataman stated:

I want to map an area, which to me first and foremost is a state of mind rather than a geographic zone, through the reported reality of the individuals that form it. I do not expect this film to be shown on television or cinemas due to the fact that I will not be employing the formulas of conventional documentary filmmaking. I realise that ultimately I will have access to audiences through museums and public spaces. The formula I found for this concept is to make an installation consisting of 40 taking heads, each one a Kuban, from the matriarchs to the children (2003a).

Ataman spent two years with the denizens of Kuba. Whilst it is a ‘geographical address’, it is a shocking space that lies beyond conventional forms of social documentation (Ataman, 2006, p28). Ataman is Turkish but has not lived in Turkey for 30 years; he was certainly an Outsider to this community, and had to work to gain their trust in order to film them.

Stories were accessed through filming and conversations initiated by Ataman. The result was a series of forty portraits each offering experiential knowledge: each described Kuba differently, sometimes revealing shocking personal secrets and intimate details, yet all were profoundly connected by place. It was actually this “single common identity” that ignited Ataman’s interest in this project, rather than the paternalistic notion of *giving a voice to the voiceless* (2006, p 28).

⁴² *Kuba* has been shown in multiple spaces in a number of Western cities. Venues range from traditional galleries to public spaces including an old postal and sorting office, charity office, prison, school, hotel, self-storage, a 68m barge and a disused railway carriage. In my writing I reference the installation at the Sorting Office, New Oxford Street, 2005.

Horrific acts permeated the narratives; but then, so did hope, resistance, and courage. Multiple perspectives on what it means to be Kuban emerged.

In examining *Kuba*, I wanted to analyse the strategies that Ataman used when taking such personal voices and intimate social knowledge from a community into a public space, without dehumanising, victimising, or idealising the denizens.

Ataman showed respect for the denizens' words and gestures, and to the diversity of their experiences — both in-frame and out-of-frame — in the context of the exhibition space. He advocated the talking head; these are durational pieces and “he accords them respect by submitting to the time it takes to listen to them speak” (Horrigan, 2005). He did not sanction their words with a voice-over or assertive interview technique, nor did he provide a State version that contested their experiences.

The installation prioritised the individuality of each contribution by creating an intimate encounter with the work:

Each one will have a monitor allocated to him or her, and each monitor will have one chair in front of it, allowing only one viewer per monitor. Each monitor will show one talking head and his/her videotaped story from his/her own mouth. Only by visiting the monitors one by one will the viewer start accessing and understanding Kuba, which is otherwise virtually inaccessible (Ataman, 2003a).

The chairs and the ‘one-on-one’ encounter worked against transient viewing, enabling an embodied, engaged, intimate spectatorship. However, this individuality was not at the expense of the collective. The cacophony of noise that engulfed the visitor, the visibility of multiple screens all sharing the same space, left no doubt that these polyphonic voices form part of same community. Whilst the installation presented all of the testimonies, they could not be viewed in their entirety. Their looped durational arrangement inevitably — and

deliberately — led to incomplete readings, subverting conventional narrative pleasure (Horrigan, 2005). The audience was denied the security and satisfaction of ‘knowing’, which may have been achieved from a fixed viewing of the material. This mitigated against tendencies to generalise and treat the Kubans “as fully accessible or consumable subjects” (Bayraktar, 2012, p91) and stands in contrast to the “vivid, framed portraits of identity” served up by intimate first-person television (Dovey, 2000, p104).

Within the gallery’s sculptural relationships, the frame undermined verisimilitude resisting generalisations and assumptions, in contrast to the screen in the cinema or television. Minh-ha argued that the “more the representation leans on verisimilitude the more it is subject to normative verification” (1991, p76). Ataman stated his aims clearly in this respect, saying: “I’m forcing you to expose yourself to someone’s life or reality and you can never totally attain it” (2003b). Horrigan argued that it is ethical to offer the antithesis to fixed, complete comprehension:

Ataman’s portrait installations sustain the inherent dignity of those depicted by placing those portraits in sculptural, spatial and temporal constructs strongly frustrating any viewer disposed to making judgments based on the doleful modern communication trope of the sound bite (Horrigan, 2005).

Warte Mal! Prostitution after the Velvet Revolution, Ann-Sofi Sidén, 2002, Hayward Gallery London

This resistance to an easily accessed, generalisable ‘knowing’, could also be applied to Ann-Sofi Sidén’s installation *Warte Mal!* (2002, London). *Warte Mal!* is an investigation of prostitution in the Czech Republic, which was presented at the Hayward Gallery, London, January–April 2002. Sidén spent nine months living with the prostitutes at the Motel Hubert, Dubi, where the prostitutes rented rooms. In an interview accompanying the installation, Sidén explained how she identified with the prostitutes, but ultimately was an Outsider:

I understood the danger of standing there. That isn't because I've been a prostitute but because I hitchhiked a lot when I was young. I'm of the generation that comes on the tail of the hippie movement and a sort of free, expansive, open experience of sex and men. I could do whatever I wanted, I could pick and choose. Sometimes I did bad things and I learned from that. Sometimes I was humiliated. But I was also discovering my sexuality on my own terms, I was choosing it (Sidén, 2007, p157).

Robert Fleck described how Sidén seems, superficially, to portray normal life in Dubi — until it is revealed that the town is home to prostitution on a massive scale (2002, p130). Fleck had visited Dubi himself in 1997, and commented that: “Having been an eyewitness, I could never imagine that an artist would manage to enter into and speak about this situation straightforwardly and persuasively... which has an open fluent touch... and never moralizes” (*ibid.*, p132).

The complex design of *Warte Mal!* facilitated a managed, staged movement through the installation:

The artist spun the interview portraits into complex sculptural relationships that surround the visitor and to some extent choreograph their movement and agency. This labyrinthine manifestation of the artwork at times suggested the town plan of Dubi. At other times it recalled sex tourist arcades in other cities around the world. To watch the video portraits, gallery visitors sat inside cubicles that suggested peep-show booths, with the exception that here viewers were exposed to each other through transparent walls (Carolin and Haynes, 2007, p155).

However, Fleck, argued that the “rigorous aesthetic of Sidén’s installation concentrates on the many and varied components of human existence in an urban rural context”, echoing Horrigan’s analysis of *Kuba*. By focusing on these diverse, complex individual human lives where all were exposed, all were implicated, whatever their status, any voyeuristic viewing was undermined (Fleck, 2002, p130). As in *Kuba*, we were denied certainty.

Another parallel with Ataman's work is the sense that Sidén had a trusting relationship with her subjects. Anthropologist Laura Bear concurred, arguing that by making visible her relationship with the women, Sidén undermined the objectification often witnessed in television treatments of similar subject matter (Bear, 2007, p159). The work employed the "mutual responsibility" that Minh-ha described as essential for reducing objectification (Minh-ha, 1999, p72). Below I will discuss this point further, by theorising Sidén's and Ataman's emplacement in the films and installation space in relation to my own decision-making, and by focusing on audience positioning and accountability in enabling sustained, empathetic viewing.

Reflexivity in the Installation Space

I am interested in Sidén and Ataman's presence in their work. For both artist/filmmakers, there was a deep reflexivity that was "inscribed in the nuances of detail" (Taylor, 1998, p18), both within their films and in the design of the space. The respectful, collaborative nature of the longstanding relationships was embodied within the text of the films and design of the installation. This was evidenced by: the duration; the use of intact cademes, spaces, and pauses; the practice of allowing participants to talk uncontested — and pursue their own trains of thought uninterrupted; the positioning of the audience; and the choice to display on individual screens.

Whilst there was ambiguity about the extent of their interventions 'in the frame', both Sidén and Ataman revealed their collaborative role as filmmaker/interviewer (and, in Sidén's case, social actor and more active interviewer). However, I wish to focus on Sidén's presence through extracts from her diaries, made available both in the installation space and in the accompanying book.

Her diary was a written account of time spent with the prostitutes, their customers, pimps, and other "community" members. While it took the 'form' of a

diary, it was clearly a carefully constructed, highly selective literary work. Like Ataman, she lived with the community that she was researching: "I am sitting in the bar of the Motel Hubert. My translator and I sleep in rooms upstairs. This is not a regular motel" (Sidén, 2002, p10); "A West German client thought I was a Czech prostitute. He started talking to me. He said he understood only a little Czech" (*ibid.*, p27). Largely descriptive, the diary offered historical insight, showing how she intimately situates herself in the research and revealing her physical and emotional closeness to the women: "I went to bed at six o'clock this morning. We partied all night at the Falk bar" (*ibid.*, p19); "Marcela hasn't said a word to me, which has made me really depressed" (*ibid.*, p27).

She appeared to have an ambivalent emotional relationship with the prostitutes; her position in the research and her rapport with them was not fixed, but fluctuated and evolved during the filming process and in response to circumstances. At times she was detached: "This afternoon, Eva went to the bar where the Russian woman works. The girls there told her that she had been beaten up really badly... Liba allows herself to be intimidated again and again." (Sidén, 2002, pp20-21); at times disdainful: "They were like flies on a piece of meat" (p25); complimentary: "Marcella looks great in the new hair" (p 29); or emotionally invested: "I get a big, teddy bear welcome from Eva! Over the summer she has started calling me mamma" (p28); "I was taken by surprise today hanging out with the girls on the street. Marcela opened up to me for the first time. I like Marcela very much... She seems so communicative tonight" (p25).

Aull-Davies warned of a reflexivity that only reveals the "outside of ourselves" (2008, p10). Sidén did not fall into that trap, but rather presented enough insight for us to learn of the layered nuances in her relationship with the women in her research. Though her diary was an externally constructed and highly selective work, it acted as a bridge linking the women to the wider world, rather than confining them to an insular world of prostitution (Bear, 2007,

p159). It is this link, her relationship, that undermined an objectified viewing and aided empathetic engagement with the women.

However, in making her role so overtly visible, did Sidén in fact impose a new “frame of reference” through which the *authenticity* of the participants films were brought into question? MacDougall warned that, “in the guise of insisting on the mediated nature of film, it actually maintains the ideology and mechanisms of nineteenth century positivism intact” (1998, p 88). Was making a diary available analogous to adding a retrospective voice-over in a film? Rouch argued that with imposed voice-overs, “instead of clarifying the images, the track simply obscures them, masking them until it finally substitutes itself completely for them. And so the film ceases to be a film and becomes a lecture” (2003a, p40) — could the same be true of Sidén’s diary?

Perhaps, then, Ataman’s less visible role in the co-construction of knowledge was actually more ethical. We could (should?) more readily question the exact composition of the Kuban’s voices and ask whether these are really “indigenous statements” (MacDougall, 1998, p154). Equally, however, “openly acknowledging the authorial role of the curator does not necessarily challenge the curator’s authority” (Basu & Macdonald, 2007, p8). Ataman’s less visible role did not mean that he “intends the work to be read as unmediated, objective reality” (MacDougall, 1998, p90).

Ataman’s ambiguous ‘in frame’ presence did not represent an abdication of his voice, nor a submission to “the treacherous simplicities of an unquestioned empiricism” (Nichols, 1983, p18). Rather than offering a denial of “the complexities of voice” (*ibid.*), Ataman reinforced the complexities of voices and of a society in flux and constantly under revision: there were no “treacherous simplicities”, but rather a competing multitude of truths. What was presented are “forty participant-witnesses, each the axis of her or his own world” (Horrigan, 2005), countering Nichols’ claim that Ataman’s praxis would

represent a loss of voice. Ataman's voice *was* that he made no claim to a framed, empirical truth, his voice *was* that he cedes control and lets people speak. The hand of the puppeteer (Ataman, 2004, p55) may have appeared light in the construction of the films, but it was operated by a respectful ethic.

In relation to my own work, I found myself caught between the two praxes. However, whilst I think that revisiting MacDougall, Rouch and Nichols has been helpful, and while there are legitimate links between gallery films and cinema (Fowler, 2004), I do not want to rely on documentary theory alone to analyse my decision-making. Thus, in the installation setting, I did not think that projecting my role in the research would be mistaken for a lecture, as it is not being placed 'over' the films. Rather, it was respectfully and discretely projected alongside them, shedding light on the co-construction of the work while ultimately acknowledging the ambivalent status of the knowledge produced.⁴³

Audience

Both Sidén and Ataman sought to orchestrate a rich audience engagement by privileging contact with the subjects of their films. Ataman avoided the "extravagant visuals, high production values, and a maximalist aesthetic of visual hypersaturation and bombast that unsettlingly mirrors the spurious production of affect and sensation by the image commodities" (Balsom, 2013, p55), which are associated with transient, detached viewing. Sidén did use some larger film projections, but not through sensationalised image commodification, but rather to "question the nature of our relationship with the people we watch" (Bear, 2007, p160).

Furthermore, Fleck argued that instead of relying on a theatrical architecture:

⁴³ See Appendix 4ii.

The rigorous aesthetic of Sidén's installation concentrates on the many varied components of human existence in an urban and rural context: individual stories with intense heights, depths, hopes, expectations and disintegration — all at once, *Warte Mal!* draws its strength from the fact that feelings and passions that go to make up a town and its life are its main focus (Fleck, 2002, p130).

Both Sidén and Ataman offered the possibility of an empathetic, productive, sustained engagement by privileging the individuals in the films, rather than offering a competition between narrative and architecture. That is not to deny that it was hard work for visitors to the exhibitions, with some describing *Warte Mal!* as an “endurance test” (Carolin, 2007, p163).

In both *Kuba* and *Warte Mal!*, the audience were also themselves put on show. This was particularly true in Sidén's work, where the audience sat in Perspex boxes, subverting the anonymity of a voyeuristic peep show-style encounter — turning the gaze back on the spectator. In *Kuba*, there were no darkened rooms for safe, unaccountable viewing, which also forced the audience to be critically self-aware of the way they viewed the films. This demand placed upon the spectator undermined a viewing based on entertainment — we were left questioning “the nature of our relationship with the people that we watch” (Bear, 2007, p160).

The spaces designed for each installation bore an indexical relationship to the communities that the practitioners were representing. Ataman used old armchairs, old TV sets, and disused and reused ‘social’ spaces for *Kuba*, with the aim to “create a neighbourhood that can travel as a whole” (Ataman, 2006, p21). Sidén created an installation evocative of the town of Dubi in which each visitor navigated their own route, to create individual narratives. Both exhibitions had associated seminars that provoked wider social and cultural debate about representation and the interventions of social documentary and art, in relation to respective issues of migration and prostitution.

McLaughlin used both neutral and comparative environments for his installation *Inside Stories*. His choice of a neutral gallery in Belfast offered the possibility of exploring and listening to stories from all sides and was cited as a “model for conflict resolution” (McLaughlin, 2010, pp99-100). Equally, though, placing the films in an apartheid prison in South Africa successfully promoted a productive comparative debate about the political situations in the two countries.

In considering venues for my practice, some colleagues suggested screening the films in a medical or hospital space/context. However, two important considerations mitigated against this. A unifying concern expressed by those who are diagnosed with breast cancer — both in the literature (i.e., Waldrop, 2011; Mahler, 1982; McKinley, 2000; Fallowfield, 1991, pp72-3) and by most of the participants in my research — was fear or concerns of cancer recurrence. I felt that to show the completed films in a hospital setting might carry powerful connotations of recurrence for the participants. In addition, having specifically located and conducted the research away from the clinic, it would have seemed self-defeating to return the films to the hospital setting and the codification described in Chapter Two. These films have value and meaning beyond the confines of medicine and the clinical environment, and I proposed that important new insights would be generated through discourse in an alternative space.

I researched galleries that have a history of displaying socially engaged work. One space of particular interest was Studio Voltaire, the gallery used for Jo Spence’s recent retrospective (*Jo Spence Work (II)*, 2006, London). However, cost and availability were ultimately prohibitive and ultimately I felt justified in using the University Gallery to show the material. The room design contained

individual domestic television sets and armchairs — evocative⁴⁴ of a home — inviting people to sit, to engage with the participants one-on-one, to stay and watch. Headphones were provided for a focused, intimate, prolonged, contemplative viewing. In this way, I aimed to encourage a new relationship with individuals diagnosed with breast cancer, in terms of responsibility and knowledge.

CONCLUSION

Evaluation of the research methodology as a respectful, effective way of producing knowledge about illness experiences extended into the process of editing and displaying the research material. This chapter has detailed the problems encountered in editing and presenting ‘thick’ ethnographic descriptions and has justified deviating from the original aim of a single documentary containing all nine perspectives. Participants’ wishes for preservation of material and the nature of the ‘rushes’ themselves were key issues that guided this decision-making.

What role was played by the collaborative edit and feedback screenings? In this chapter I have addressed the role played by the collaborative edit and feedback screenings. Acknowledging Rouch’s antecedence, I have explored the process of and significance attached to editing collaboratively when participants have been responsible for authoring and filming the material. My praxis involved showing rushes to participants and inviting them to prioritise the material, vetoing anything that they wished to. There was an ambivalent response to this invitation — involvement ranged from declining any participation to sitting with me in the edit suite for several days — but I argue strongly that it is an

⁴⁴ Evoking a home, but importantly *not* a home. Whilst I do not want to closely align the films with Video Diaries, the “closed circuit” of watching the diaries that have originated in a domestic space being consumed in a domestic space that Dinsmore described (1996, p54) is problematic for me. Rather than serving up the participants’ films for passive “consumption” I wanted to encourage both an ethical relationship with the material and to highlight the process and conditions of production.

essential continuation of collaborative knowledge production to offer participants a veto and other input into editing. Feedback screenings had added significance given I had asked participants not to delete any footage during filming.

I have described how, in line with McLaughlin (2010), editing the participants' rushes into a single, intercut documentary format was problematic. My objectives were to respect the participants' wishes and aims; the individuality of their interpretations of the research; as well as their discrete experiences of breast cancer. In addition, my intention was to preserve intact cademes; privilege the speaking voice; accept narrative gaps; resist imposing themes and a 'culturally validated' narrative.

In trying to cut a single documentary, I encountered many of the problems McLaughlin described when editing *Inside Stories*: false imposition of themes; fabricated chronology; loss of the individuality of experience; and centring of meaning. The theorising of MacDougall (1999) in relation to 'loss' in the editing process and the experiences of Rouch and Morin in bringing together the many perspectives in *Chronicle of a Summer* were particularly helpful in my decision-making. I also experimented with split screens in an attempt to privilege certain events and to satisfy the participants' desire for retained footage; however, these experiments also failed. Following McLaughlin, I edited nine separate films.

This failure of a single documentary to contain all nine (and my) perspectives produced by the work led me to analyse the potential benefits of a gallery installation. In the light of my aims to allow the many perspectives and 'truths' of breast cancer to sit alongside each other uncontested, I returned once more to McLaughlin's research in order to address my research question: *How to display and engage with durational polyphonic ethnographic / visual material?*

I have reflected upon the use of an installation for visual ethnographic research material through analysis of two polyphonic exhibitions brought to my attention by Basu (2009) that investigated issues of prostitution, migration and marginalised communities. Both successfully created an empathetic, engaged, accountable and sustained viewing of the subject matter without exoticising, victimising or commodifying participants. I have examined the position of the *author* in these installations and in the frame of the film in order to situate my own position.

I have maintained that the potential of the gallery to offer a counter-politics to established single screen documentaries and/or medical representations of breast cancer is compelling. I wanted to use the gallery setting to resist assumptions that the single diagnostic label of breast cancer encompasses *all* experiences, by privileging the multiplicity of individual experiences and prohibiting a fixed, reductive, generalised “knowing”.

In relation to Sidén’s *Warte Mal!*, Pollark asked: “is it a bad thing to break down the boundaries between documentary, art, ethnography and social knowledge?” (2007, p166) I have reasoned that, far from being a bad thing, this process positively opens up a space to consider and contemplate a disease that, despite its unified prominent visibility at the level of the population, contains discrete, complex and brutal individual experiences. It offered a way by which “viewers could be put into a new relation — of knowledge and responsibility — to the world” (*ibid.*, p169).

In the following chapter I will theorise how the participants used the cameras as tools of audiovisual inscription and will continue to analyse the impact the research had on their lives.

4. MAKING VISIBLE: AUDIOVISUAL INSCRIPTION & PARTICIPANT BENEFIT

INTRODUCTION

I have developed and applied a collaborative ethnographic methodology to facilitate nine women diagnosed with breast cancer to explore their lives through filmmaking. Problematising the interview and prior identification of themes, participants were given camcorders with the request: “You know you have been invited to take part because you have had a diagnosis of breast cancer. You are being given a camera for three to six months to film whatever is important to you.” Each participant filmed for an average of nine months and three weeks.

My rejection of a single-screen intercut documentary format was predicated on a desire to privilege the individuality of experience and the discrete ways the participants interpreted the project, while respecting the durational nature of their contributions. I had also not wanted to lose sight of the interconnectedness of their experiences. Furthermore, I have wanted to make visible my own emplacement in the co-construction of knowledge. To fulfil these aims, nine individual films were collaboratively edited; together with a projection of my role in the research, a ten-minute single screen compilation, and notes from the participants, the films formed a gallery installation, *What if?* The installation was accompanied by seminars on topics suggested by the participants.

The following chapter is divided into two sections. In the first — in order to answer my research question: *How were the cameras used as tools of audiovisual inscription?* — I discuss how the camera was integrated into participants’ lives and how they engaged in the process of making their lives and experiences visible. In the second section, I analyse how the process of making visible

experiences became beneficial for most of the participants, which continues to answer the research question: *What impact did the research have on the participants' lives?*

Whilst my aims in writing have been to emphasise the distinctiveness of the process for each participant, when I began to write separately about each woman's relationship to the research it became evident that I was losing any sense of what connected the women. This method of writing enforced a separation. However, writing in a more generalised way seemed reductive; at times, it stigmatised difference. The chapter therefore adopts a hybrid approach; focusing on specific individual examples whilst also highlighting shared experiences without seeking to generalise or reify.

In addition, in order to demonstrate one cross-disciplinary application of my research I have built on the work accepted for the NCRI 2014 Conference (Douglass *et al.*, 2014) and theorised the valuable experiences the participants chose to share in relation to their use of the drug tamoxifen. This section, contained in Appendix 5, deviates from the *process* of knowledge production which is the focus of the body of the thesis.

THE CAMERA AS A TOOL OF AUDIOVISUAL INSCRIPTION

In this section, I want to discuss how the participants have used their cameras as tools of audiovisual inscription. I will analyse the process of integrating the camera into their lives, and the reality that came into being as a consequence, in the context of their understanding of the research. I will continue to highlight the key influences of the overall methodology and my individual interventions as a facilitator, as an (most often) absent onscreen presence.

I have resisted categorising the films into genres, preferring to focus on how each individual has engaged with the camera in producing knowledge. Whilst the films arguably share features with video diaries, confessionals, home

movies, pathographies, documentaries, ‘framed’ first person filmmaking and essay films, I agree with Dovey that the “bewildering multiplicity of types of self speaking” that have emerged from this research is a “multiplicity that cannot be contained within the single discourse of the confessional” (Dovey, 2000, p. 113), or indeed any other specific genre.

Anne Jerslev provided a critique of Stella Bruzzi’s (2006) earlier work on performativity and performance in documentary studies.⁴⁵ Jerslev located most of her — predominantly oppositional — arguments in the analysis of *Family* (2000, Denmark), an intimate documentary by Sami Saif and Phie Ambo. For Jerslev, performativity emphasised process and encapsulated how reality is simultaneously “*represented* and *presented* through mediation” (2005, p106). She understood becoming a subject as:

a question of doing rather than being. Or, it seems there is little being without doing. Indeed, there may be nothing but doing ... Becoming a subject depends not only on being recognized and acknowledged but every bit as much on being seen doing (Gade & Jerslev, 2005, p7).

Where Bruzzi and Jerslev’s arguments agree in relation to my research is “the very notion of a complete, finite documentary is continually challenged and reassessed” (Bruzzi, 2006, p218). It is not my intention to unravel the complex ongoing arguments about performativity and performance.⁴⁶ I concur that,

⁴⁵Jerslev was particularly critical of Bruzzi’s definition of the performative documentary in opposition to the “invisibility” of the *classical* observational documentary and the inescapable falsification of mediated realities (Jerslev, 2005, pp98–99). Jerslev linked Bruzzi’s arguments to Nichols (1995), adding that classifying performative documentaries as an ontology or sub-genre is imprecise, as “performativity cannot simultaneously be used to propose a documentary ontology and to describe the specificity of certain filmic elements, certain acts...” (*ibid.*, p105).

⁴⁶Jerslev argued that Bal (2002) and Butler (1993) proposed conceptual differences between the terms. For Butler, performance was a “bounded act” and performativity refuted the possibility of “will” or “choice” (quoted in Jerslev, 2005, p105). Jerslev added however that performance was never a “unique” occurrence, and that Butler in her later theorising “provides the performing subject with a sense of agency” (*ibid.*, p105). I believe the two terms are inherently intertwined in my work and in trying to reconcile this to the theory I have found Peggy Phelan’s 1997 work on performative writing helpful. She described

whilst performativity is a messy concept (Gade & Jerslev, 2005, p7), it “proves useful in discussing different visual and narrative strategies and different ways of displaying subjectivity” (Jerslev, 2005, p111).

Jerslev proposed that intimate performative documentaries are about “the filming of a personal reality that is coming into being through the very act of filming ... and that reality is on both sides of the camera” (2005, p111). If this is so, then rarely can considerations of performativity and the acute nature of the dialogue between these two ‘realities’ be more exposed and challenging than in the recent aftermath of breast cancer diagnosis and treatment, where very existence is challenged and residual *lives* are unstable, in flux, uncertain and lack closure.

I want to highlight a key issue that most of the participants encountered when first engaging with the research, before considering how reality was mediated, and how the cameras became a part of the reality they were recording under Jerslev’s lens. Rouch has described the presence of camera and filmmaker as a catalyst for producing knowledge; “it was not a break, but let’s say, to use an automobile term, an accelerator. You push these people to confess themselves and it seemed to us without any limit” (Rouch, quoted in Eaton 1979b, p51). However, for many of the participants, in making visible the complexities of their lives post-breast cancer diagnosis, the camera initially acted as a break to expression rather than a stimulant.

I never contemplated pushing participants to film if they did not want to — rather, I chose to support their decision-making processes. The participants nearly always wanted to talk to the camera and to express themselves, but had to negotiate a way to do so; they often needed space and time, rather than

performative as “[a]lternatively bold and coy, manipulative and unconscious, this writing points to both itself and the scenes that motivate it” (1997, pp1-2).

proximity, probing, or persistence.

McLaughlin found that one of his participants in *Inside Stories* was uneasy engaging with an 'open' methodology. He had to deviate from his original stance of not interviewing participants with Desi, a prison guard, who struggled to engage with the research without a more direct intervention (McLaughlin, 2010, p92). Gibson noted in her research with young men diagnosed with Duchenne muscular dystrophy, that of the ten participants invited to 'independently' make 'video diaries' of their lives over a week, only three chose to film alone.⁴⁷ Two asked to make co-productions with the researcher, two asked the researcher to provide supplementary visual material and three filmed with family and/or friends (Gibson, 2005, pp36 – 38).

A variety of processes were invoked by the participants to create a stable, safe space for integrating the camera into their lives. However, rather than being calculated, inauthentic 'mechanisms' that they wanted to draw attention to (Jerslev, 2005, p110), how each process was negotiated, shaped and individualised was a reaction to a variety of issues that fluctuated over time: feeling uncomfortable with the camera and being visible on screen; imagining the audience and negotiating public/private boundaries; the emotional difficulties of recalling past events;⁴⁸ the ambivalence of memory, of wanting to move on but not wanting to forget;⁴⁹ medical crises in the present;⁵⁰ and imagining the future. And of course there were silences.⁵¹

⁴⁷ They were "given a week to create a video diary that reflected "who he is" and "what life is like" (Gibson, 2005, p35). This seems an extraordinarily short period of time to contemplate let alone enact the instructions.

⁴⁸ See WA recalling her biopsy (14:40) or BE's explanation that "I sort of put it all in little boxes and put it away". (19:30)

⁴⁹ "Although I don't want constant reminders... sometimes you sort of think to yourself well how did I feel during that time?" (BE 19:01)

⁵⁰ BI had a period where she could not film, when she faced the possibility of a secondary diagnosis.

⁵¹ There were undoubtedly silences in the films that the process of filming did not reveal, things that the participants could not, or chose not to, articulate. It is possible that a more interventional methodology would have 'revealed more' — but this project has never been about probing.

My findings are distinct from Ruth Holliday's research into the performative nature of queer identities. Also handing cameras over to subjects, she identified only two distinct styles of 'diary', making a binary division between filming where another known person was present, and filming alone (2009, pp51–52).

I will give brief examples of how participants engaged with the research methodology, before focusing more closely on one participant. PA felt uncomfortable and vulnerable, both about being alone with the camera and about the autonomy offered by the project. The methodology and camera inhibited expression, this was magnified by some physical difficulties operating the camera. It was only when we discussed inviting friends to engage with her that the camera became a catalyst to talk. The camera's direct gaze upon her shifted and scattered, creating a less intense, polarised space in which she could explore her experiences by connecting with friends, family, and others — including me — about her cancer experience. Thus the burden of producing knowledge was shared, and each dialogue had specific qualities unique to the encounter.

Another participant, EA, anthropomorphised the camera, saying, "Right ok, let's do the introduction. You're Princess, you're going to be called Princess, and I'm EA. Nice to meet you, finally" (00:17). TO and WA filmed observationally until they felt confident enough to turn the camera round and talk; and BE reported, both on and off camera, that she felt "uncomfortable" (1:20), describing the need for premeditated composure before she filmed. In this process of composing herself and switching on the camera she told me that she often forgot what she was going to say. On camera, she acknowledges that forgetfulness was typical of her post-treatment state (00:20). In our meetings she described the camera as initially "impersonal" and "mind-blanking",

imposing a 'writer's block' and evoking a silence.⁵² Many of the participants found anniversaries of key events a stimulus to use the camera. All the participants became noticeably more at ease with the camera as the research progressed.

It seems almost too self-evident to point out that all of the films foregrounded the camera as an artefact in the participants' lives. However, my research confirmed Jerslev's argument that

[c]onscious self-display is not necessarily a failed effort to act naturally. Rather it may express the social actors playful [for my research: requisite] interaction with the camera placed in front of them ... As such it is crucial to the theorising of contemporary (performative) documentary works to be able to sensitively conceptualise an unpretentious immanent reflexivity that may serve the projection of a sense of immediacy and proximity and thus involve the viewer emotionally (2005, p103).

To analyse this further, I will focus more closely on one of the participants. BR wanted to preclude closeness during the process of filming, to create a distance between herself and the wider audience. She achieved this through distinct styles that involved an absence or partial absence from the frame, and also by passing the camera to her instructor to record her performances on the ropes. She chose to use a mirror to enable her to dialogue with herself: literally fulfilling Spence's aim "to represent myself to myself, through my own visual point of view" (1986, p155). BR also saw the mirror as mediating and dispersing the camera's gaze, distancing her further from the audience. These strategies which were emotionally motivated by an uncomfortable imagining of an outsider's gaze and by the difficulties of expressing how she feels, were accompanied by an assured, familiar, and instinctive framing: the redolent,

⁵² This soon passed and BE often filmed cademes which are spontaneous, unguarded, and immediate — usually, though not always, in response to problems encountered or feelings emerging in the present, when she said she was extremely grateful to have the camera. (Diary, 16/1/13)

static mise-en-scène originated from her background as an artist. Whilst clearly containing strong elements of performance, they were not a representative fabrication.

In the context of this framing, BR's representation was a layered act of repetition that showed a deflected, and reflected performative body whose identity was in flux. Her recollections were often fluid and fragmented, and she sometimes used her diary or anniversaries of significant 'days' to revisit, guide, and stimulate her thoughts. These thoughts were often unresolved: she said of finding her lump: "that day changed my whole life. Did it change my life?... it changed me anyway..." (18:27). She revisited key events: her biopsy, operation, coming home, radiotherapy, the start of adjuvant treatment and the eighteen-month anniversary of diagnosis. The bright lights, the strange equipment, the noises of the machines, the relief, were selected memories retrieved and performed for the camera — invested with new meaning and prioritised in the here and now of filming: "And I said to them, this was the most frightening moment of my life, but it wasn't. It was just, it was a bit scary, but it was just peculiar. Just the strangest experience" (28:40).

These passages were set against the ambivalence of memories and experiences of cancer: not wanting to forget, being unable to forget, but also needing to move on (Diary, 6/4/12). Iterative fears of recurrence and concerns about her scarred post-surgery body were prioritised in her film and revealed in different contexts: dressing for a party (9:14); performing on the ropes (12:17); wearing a different bra (18:52); attending doctors' appointments (23:17); with her partner (44:25, 1:00:53); before her holiday (51:19); on New Year's Eve (52:47). The self of filming was in flux.

This style contrasted dramatically to that of the observational filmmaking when she handed the camera over to her instructor. This filming of her 'whole performing body' showed a confident, strong, coordinated body that

exemplified progress, coherence, stability, and a reconnection with her pre-diagnostic state. The ropes' significance in her life was demonstrated by her statement recalled from the moment of diagnosis: "my first fear was — am I going to die? And my second one was — am I going to be able to carry on and do rope?" (6:40).

Rather than theorise the process of filmmaking by BR as distancing or alienating, as Bruzzi and Nichols might propose in their ontological classification of the performative mode it could "be *understood* in the opposite way and intended for the opposite effect" (Jerslev, 2005, p100; my emphasis). Analysing the films through Jerslev's lens permits interrogation of the intricacies and intimacies of this "opposite effect".

While I have not attempted to predict how the films will be read in the installation, I relay two examples of where "proximity to the filmic space and the characters instead of distance, confirmation and communication instead of disavowal" (Jerslev, 2005, p100) occurred during readings in the research period.

I felt BR's use of the mirror, rather than distancing me from her, had the opposite effect: when viewing her footage her predicament became magnified and implicated me. As a viewer, I sensed I was being invited to see her as she saw herself and, by extension, to see ourselves in her position. When watching, editing, or analysing her film, I looked into the mirror and saw her reflection instead of my own, providing a stark reminder that this *could* be me.

I will now discuss an affective incident that took place in the collaborative edit with DE. DE was one of two participants who engaged confidently with the camera from the start. She had very clear aims in participating: her film was a legacy for her husband and son, and in making it she was imagining their future without her. DE had frequently told and retold audiences about her breast

cancer experiences in various contexts, as she reveals in her film: as an awareness educator in a school (56:38); to publicise a charity on a radio show (45:47); to an artist creating a plaster mould (1:14); to a counsellor (25:34); and specifically to the camera (15:47; 1:08:16). As she told me in an email: “I have told my story thousands of times, I say it almost clinically” (email correspondence). Whilst I certainly never felt this during the project, at the start I had wondered if she might appear distanced from the events and her feelings, given the number of times she had articulated her ‘story’.

However, DE noted experiencing an unexpected heightened response when alone with the camera: “but sitting saying it alone in my bedroom I found very emotional” (email correspondence). Her husband GE also noted that the *realities* produced by the research resulted in an unfamiliar proximity to his wife’s dilemma, despite the fact that he had heard her story numerous times. During the collaborative edit, GE sat behind DE and myself, feeding their son whilst watching us edit. As DE and I were making decisions, I heard a profound silence behind us, followed by deep sobbing. GE quickly left the room. When he returned several minutes later, he said: “I have never heard D speak like that before.” His response to watching her on camera challenged the distancing that Bruzzi and Nichols, and Sayad claim the ‘frame’ imposes:

What the frame actually does is multiply the degrees of separation between portrayed and biographical authors; *the frame stretches the distance between authors and audience*, widening the gap between the performing authors and their innermost selves (Sayad, 2013, p37; my emphasis).

For GE, the frame collapsed the separation between him (as audience) and his wife (as filmmaker). The performative mode — far from making the reality of their situation seem “deferred, dispersed, interrupted and postponed” (Nichols, 1994, p97) — projected into the present the abjectly tragic and inevitable outcome of DE’s diagnosis. It is possible that being alone with the camera permitted the “nakedness of expression”, a *rawness* of communication that had

not previously been witnessed by her husband *because* of his presence where “the imagined other effectuated by the technology turns out to be a more powerful facilitator of emotion than flesh and blood interlocutors” (Renov, 2004b, p204). Her purpose in making the film (to create a legacy) and his understanding of this movingly conflated.

To interpret GE’s response to his wife’s film, we can also look beyond the performative lens at the material qualities of film itself. MacDougall argued for an “excess” in film that exceeds our understanding where “the by-products of mechanical vision defy the containment of the work and are more capable of touching the exposed sensibilities of the viewer” (2006c, p18). DE’s film made her husband think further ahead than he had dared to before: she had become a ghost on the screen, invisible within the room. A ‘new’ kind of expression, a process of articulating previously unexpressed ‘knowing’ came into being: “a reality beyond [his] knowledge” (*ibid.*, p17).

I have found Jerslev’s proposal of the performative documentary helpful in exploring the participants’ “different visual and narrative strategies and different ways of displaying subjectivity” (Jerslev, 2005, p111) in their thoughtful — at times hesitant — and on-going negotiations between a pro-filmic and filmic reality. Jerslev’s rethinking of Bruzzi and Nichols’ proposal of performativity *not* as a ‘disavowing’ dialogue between ‘authenticity and construction’, but rather as process of making feelings and information visible has been helpful. It has provided a broader, more intimate framework for exploring the process of the participants’ engagement with the research and their use of the cameras as tools of audiovisual inscription.

THE PROCESS OF BREAKING SILENCES

In Chapter Two I outlined the participants’ interpretations of the research, their motivations for taking part, and the audiences for whom they were making the films. As highlighted, most of the participants (eight out of nine) found that the

process of producing and sharing knowledge, whether for themselves, others, or both, became a beneficial or fulfilling experience. Whilst there is a vast amount of literature on visual arts therapy and illness within a clinical framework, which has been comprehensively reviewed by Heather Stuckey (2010), I have found the reductive frameworks and analysis unhelpful in interpreting my research. However, while my research was not designed as an art therapy project, I have found feminist art therapy's theories and practices useful in analysing its benefit to participants who have recently completed active treatment for breast cancer.

Sarah Pink and Susan Hogan (Hogan & Pink, 2012) have drawn links between feminist art practices and visual ethnography, with reference to Andrew Irving's cross-disciplinary investigation of living with HIV/AIDS (2007) and Amanda Ravetz's challenge to the certainties of knowing/knowledge in anthropology (2007). Pink and Hogan undertook a "methodological exploration of how feminist art therapy might be understood as a route to ethnographic knowing, and to communicating about shifting interior states" (2012, p230). As Hogan argued, concentrating:

on the individual (as the site of suffering and distress) liberates art therapy from developing an over-reliance on, and rigid adherence to, set theories and a-priori categories of meaning inherent in theoretical orthodoxy, which can obscure as much as illuminate human suffering (Hogan, 2012, quoted in Hogan & Pink, 2012, p238).

Hogan and Pink argued that the nexus of feminist art therapy and anthropology conflate around the uncertainty of 'knowing'; of the recognition that knowing is subject to revisions; and of knowledge and selves being 'in process' (*ibid.*, p233).

The act of making visible, of breaking silences through visual practices, is at the heart of feminist art therapy. I will also draw upon the practices of Jo Spence (1986, 2005) and Rosy Martin (2001, 2012), and the theories of Audre Lorde (1988, 1997, 2000). My analysis will focus on the process and possibilities

offered by collaborative filmmaking in terms of negotiating and “reconfiguring” (Lammer, 2009a, p272) identity, contemplating and repositioning changed bodies, circumstances and relationships. Whilst much of Spence’s work on her breast cancer experiences was a reaction to the politics of the clinical gaze in hospital, this was not something that the participants in my PhD articulated. However, Spence gained empowerment from photo-therapeutic practices and from externalising repressed thoughts and experiences. This is at the heart of my proposal of benefit to participants in my work where after treatment finishes “the invisibility of body and self” (Thomas-MacLean, 2004, p639) is particularly acute. As BI described in her film:

To anyone who thinks that you finish your cancer treatment and you click your fingers and you are back to normal it really doesn’t work like that... the aftermath of it all is harder than dealing with the actual disease (53:00).

Lorde also argued passionately for the personal benefits of breaking silences about breast cancer: “the speaking profits me, beyond any other effect ... [F]or it is not difference which immobilizes us, but silence” (Lorde, 1997, p86).

There are some important methodological differences between feminist art practices and my research methodology. Most notably the knowledge produced in Spence and Martin’s work *started from* a “position ... of privacy” (2005, p166) and originated from within a specific therapeutic client/therapist relationship. The focus was on creatively addressing the limits of language, and Spence and Martin’s phototherapy work was located in an analytical psychodrama framework. Nevertheless, there is a highly relevant overlap, as both offer new and active ways of looking at experiences, empower through agency, and support “clients’ themselves to make visible what is to be subjected to and subject of the discourses within society” (Martin, 2001). Both have in common that there is never a “fixed story” to be followed, or a quest for narrative closure (Spence & Martin, 2005, p176), but rather an exploration of “different modes of

being” (Irving, 2007, p193).

In discussing the participants’ responses to taking part in the research, I will first describe some of the many ways in which silence continued to be present in their lives and within the broader culture of breast cancer. I will then argue that the filmmaking process offered participants a new and active way of looking at their experiences, providing a distance (Martin, 2012, p123) from which to contemplate and engage in dialogue(s), thus breaking these silences. I will then focus on the proposed benefits of making the *physical* effects of breast cancer visible in the process of filmmaking, whilst concurrently producing valuable insights.

The prevalence and imposition of silences in the participants’ lives was evidenced in a number of ways. Carol Ross explained that silences can be enforced through consideration of others’ feelings and through adherence to cultural norms that:

place women in the position of being defined in relation to the support of others. The selfless, caring, or nurturing behaviours that are usually part of these roles can be contradictory to expressions of anger, disagreement, or self-interest. Where then does that leave women when their own needs conflict with others, or when the various roles in their lives come into conflict? (Ross, 2012, p151)

EN confirmed this point in her film (4:16) through referencing Audre Lorde: “[c]ancer survivors are expected to be silent out of misguided concerns for other’s feelings of guilt or despair, or out of a belief in the myth that there can be self-protection through secrecy” (1988).

BE initially withheld feelings because of consideration for her family (13:42). BI, too, was concerned about emotionally imposing upon others: “You also don’t want to burden people with your concerns/worries” (Diary, 18/8/14). Sometimes her reluctance was due to the fact that even though she wanted to externalise feelings, “you know very well with any subject, that people don’t

want to talk about it or they get bored; you see the look on their face ...” (1:19:19). She acknowledged that it is hard to speak to people who have not experienced breast cancer — “unless you have been through it... you don’t know ...” (1:39:36) — and she noted that, despite “all the amazing people that you will meet and that will help you when you have cancer, it is quite a lonely place” (1:31:58). Christine Lammer observed similar silences and isolation in her work with a mother and a daughter with breast cancer – where the daughter “did not want to worry her [mother]. She felt alone with her anxieties” (Lammer, 2009a, p273).

BI also felt anxious about how to overcome the silence that cancer had imposed on her career:

I am dreading having interviews and things. I haven’t had an interview for years. I don’t know what to say... I dread it. Coz I mean ... what have you been doing over the last few years? ... Well .. my husband got sick and died, and then I got sick and so, not a lot... you kind of hope for the best, the way people react to things like that ... I don’t want to see that look of pity (1:34:40).

Both BE and PA spoke about the silences in their relationships with medical professionals. BE noted, movingly, that when facing the possibility of secondary breast cancer, she “couldn’t get out of the [doctor’s] room quick enough” (12:19), while PA initially avoided mentioning changes in her breast, which she had not initially attributed to breast cancer, to her general practitioner (08:45). BE also recognised the ambiguity of signs and symptoms of breast cancer: “I really appreciate why cancer was known as the silent killer for so long” (Diary, 18/9/12).

WA noted the silence surrounding breast cancer within society, concurring with Lorde’s view that “[b]y and large, outside the radiation lab or the doctor’s office, we are invisible to each other” (1988). When first diagnosed, WA would find herself in the supermarket wondering who else may have undergone a

mastectomy:

But when I first found out you know, I'd kind of be walking around, especially if it was like in a town or something and there were loads of other women walking around and I'd be thinking, has she had a mastectomy? or she might have had a mastectomy, she might have just been told she has breast cancer. You know there just always seemed to be, it was just in my head you know. Because I was just kind of walking around kind of looking normal and thinking there was all these other women walking around looking normal but you know not all of them... well not that we're, well that's it, we are all normal but you know we've just been told this news or we've just had this operation or whatever (1:13:02).

Lorde argued that the impact of this invisibility extends to self, as “we begin to be invisible to ourselves” (1988).

BE, DE and TO identified the lack of awareness about the heterogeneity of breast cancer within society: of bilateral, secondary, and genetic breast cancer respectively. EN recognised silences surrounding Black lesbian experiences of breast cancer. I will now focus on the ways in which she found the project beneficial, whilst at the same time producing experiential knowledge to help illuminate this gap.

By sharing her experiences and including her partner in the film, she “challenges dominant discourses” (Hogan & Pink, 2012, p238) though any “assumptions of heteronormativity” (email correspondence). Simultaneously, the project also facilitated personal contemplation and externalisation of the generational impact of cancer in her family, her family origins, her own cancer experience and the continued impact cancer still has on her life and family.

For EN profound silences in her life existed through an absence of knowledge about her mother's diagnosis of breast cancer earlier in her life (09:16) and the silence imposed by her death: “The loss of my mother also means the loss of knowledge of my ancestry and any links back to my mother's family of origin in

India. An absence, a void, a silencing” (46:40). EN described to me how “this film provided an opportunity to articulate (through images and narrative) my loss and my grief, pertaining to both my mother and my sister” (email correspondence). It also provided the opportunity to record her presence within her wider family — as the eldest daughter and the eldest sister — something that she had been denied because of her adoption. EN explored and made visible her mother’s origins and childhood, as well as publicly acknowledging her sister and brothers: the film thus enabled “making visible the multiple strands that have contributed to the construction of the self of making concrete, making visible a fragment, a moment in [her] own history...” (Martin, 2012, p135). In doing so served as a “tool for personal empowerment and catharsis” (Hogan & Pink, 2012, p238).

Making Physical Changes Visible

David Jay argued that making visible the physical effects of breast cancer offers the opportunity for individuals to:

reclaim their femininity, their sexuality, identity and power after having being robbed of such an important part of it ... they seem to gain some acceptance of what has happened to them and the strength to move forward with pride (2012b, p39).

In this section I will focus on four women who underwent mastectomy (BE, EN, TO & WA).⁵³ Within the context of their lives, and in relation to broader cultural and social factors, my analysis proposes that “the process as a whole enabl[ed] each woman to find ways to transform aspects of her lived experience” (Hogan & Warren 2012, p341) whilst simultaneously imparting “a route to knowing” (Hogan & Pink, 2012, p237). For each woman, the detail, priorities, and process of the “transformation of silence” (Lorde,

⁵³ I chose to focus on the impact of the physical effects of breast cancer because of the diverse experiences and choices of the participants in the research, and the lack of literature on the lived experience of women in this regard (Bredin, 1999, and Thomas-MacLean, 2005).

1997, p16) were different.

All the women explicitly conveyed the on-going, complex physical impact of breast cancer, of adjustment, of bodies in flux, and of lack of certainty within the continuity of their lives. Most existing discussion of breast cancer's physical effects focuses on body image and breast surgery. Whilst I will draw from these theories to further analyse the beneficial process of producing knowledge, within my research the performative, embodied experiences of mastectomy represented are multiple, changing and extend beyond surgery to the breast. I will also consider breast surgery choices in relation to wider cultural expectations.

BE had bilateral breast disease and underwent a left mastectomy; she was advised not to have reconstruction by her medical team. EN and TO both had risk-reducing bilateral mastectomies after previous diagnoses of breast cancer. TO underwent her mastectomy during the research period, and did not have reconstruction. EN had breast reconstruction prior to the start of filming. WA had a mastectomy and had her breast reconstructed, but did not have nipple reconstruction.

BE chose not to talk directly about her breast surgery, other than to joke (movingly) about the dispensability of her breasts along with other non-essential organs, in order to prevent the disease spreading (31:00). She wanted to make visible the physical effects of cancer which often remain silent and which, she felt, sat outside of biomedical interest. In doing so she sought to reduce the sense of loneliness for others through highlighting some common effects of breast cancer (00:00). The benefits of helping others, of being an advocate, can be significant. For BI, for example, it was so acute that:

the only times I feel... really positive and that I am doing something is when I am trying to help somebody get through any of this... when I am

trying to do something positive... and hoping that is going to make a difference ... writing my blog and doing this project (1:38:33).

Juhasz also argued for the benefits “of making work that is important and useful for others” (1999, p213) in documentary film.

However, while BE chose not to focus on her mastectomy in her film, the day of her first surgery remained highly significant:

Well, it's the 23rd February, and it is exactly two years since I underwent my first lot of surgery... I've actually spent most of today down at the company's warehouse at London Heathrow.... It's kept me busy, it's given me a focus, and I haven't really had much chance to dwell on the fact that it's two years really since my life changed dramatically. I know a lot of people who've had cancer fixate on the date that they were actually given their diagnosis, and although I know that date, for me, today is the day when my life changed (1:29:02).

Whilst all healthcare and support networks focus on early detection of breast cancer,⁵⁴ for BE this once more emphasised the ambivalence of silence:

I quite often struggle with the fact that if I hadn't have mentioned it to the GP a couple of years ago, would it really have taken hold? Would I have been able to have carried on life as normal? I think what I struggle with is, they can't tell me whether it was fast growing, slow growing... over a year, five years, ten years? I don't know. And that's what I struggle with now. The fact that if I hadn't have mentioned anything, could I perhaps had got 10 or 15 years of so-called 'normal life', without undergoing what I've undergone (1:23:22).

She chose to make visible the many other physical effects of breast cancer she continued to experience: tiredness of unknown origin (i.e., 26:30); overwhelming persistent sleeplessness (31:52) so much so that she no longer feels she “moves naturally” in her sleep (34:50); unnatural sensations when she drinks (52:30); unfamiliar hair texture and colour (1:04:34, 1:30:42); and hot

⁵⁴ Exemplified by <http://www.england.nhs.uk/2015/01/11/beat-cancer/> [Accessed 15 January 2015]

flushes from the tamoxifen (50:50). She revisited the sickness and constipation of chemotherapy, and pain from radiotherapy (32:52). A further significant physical change for BE was the fact that, because of her bilateral breast cancer and node involvement, she could not have blood taken from her arms when she needed a blood test.⁵⁵ This was repeatedly a problem for her on hospital visits and caused significant anxiety.

The process of filming enabled a renegotiation, an exploration of the impossibility of escaping the wider effects of breast cancer and society's ignorance of them. This was highlighted through the incident on the train when, after a trip to the theatre, BE was caught unawares by a group of young girls who ridiculed the condition of her toe nails, which still showed the effects of chemotherapy: "I know that they look horrible because of chemotherapy, but for people that don't know, they can think it's just general nasty looking toenails with infections maybe" (51:39).

There were two key moments where BE experiences positive transformation of some of these physical effects and a reinstated, welcome familiarity with her pre-surgery body. When her 'chemo-hair' was transformed, she said:

But it's really natural looking and I'm really pleased with it. And it's looking like normal hair, not chemotherapy hair. So yeah, I'm really pleased with the results. Now all I need to do is continue to grow it down and it'll start to resemble my hair before I was diagnosed with the cancer (1:31:53).

And being able to fit into her boots was a personal triumph (59:46).

Her film was set against the shifting anxieties of on-going medical investigations into the physical effects of tamoxifen on her body (which were initially feared to

⁵⁵ As noted in Chapter Two, this was not included in the final edit.

be further cancer) and the long wait for the results (and the wider impact for her family). This was a time when she described the camera as particularly beneficial: it enabled her to reflect, deconstruct, and articulate decision-making processes, without burdening others (Diary, 16/1/13).

Through her filmmaking, TO represented and negotiated the process of declining breast reconstruction surgery and rejecting prostheses following her bilateral mastectomy. She chose to live her life without hiding the direct physical effects of her surgery. Whilst the disjuncture between private/public bodies in breast cancer is still highly evident in society, there has been a marked shift in public/private boundaries in relation to making bodies visible after breast surgery since Audre Lorde's *Cancer Journals*, Jo Spence's experiences, and Matuschka's first appearance on the cover of *The New York Times Magazine* in 1993. David Jay's scar project was a central influence in this shift (2012a).

Jay's intimate, ethical photographic work makes visible women's surgical scars in a way that privileges individual choice,

demanding that we recognise the embodied materiality of breast cancer (rather than the symbol of the disease), and that this becomes a part of social consciousness and discussion because, as Jay argues, 'breast cancer is not a pink ribbon' (Ehlers & Krupar, 2012, p6).

TO had inherited a faulty gene that significantly increased the chance of her developing breast cancer, and of it recurring.⁵⁶ Her decision to have a bilateral mastectomy followed an earlier diagnosis of breast cancer and was undertaken to reduce the risk of recurrence. At the start of filming, FH's representation was located in the here and now, where she anticipated and then underwent her surgery. The preoperative fear — the profound, intense, palpable uncertainty of how she will feel once her "toxic tits" (03:58) have been removed — was

⁵⁶ There is a 45–90% lifetime risk of breast cancer recurrence for BRCA positive women.

represented free from any a priori knowledge of outcome.

The immediate aftermath of surgery, including drains and persistent fluid accumulation, was set against an increasing confidence in rejecting reconstruction that emerged during the process of filming: a public revealing of her scars in the context of her life outside her filming; the immediate relief and a celebration of being alive — “I feel like I’ve been given a second chance at life, I feel like now they’ve been taken away that I’m here and I’m living and I’m breathing and everything” (7:13). TO told me in a meeting that she wanted to help others, by saying in her film: “Look at me. I have no breasts. I am doing OK” (Diary, 12/6/12).

During a meeting in June 2014, TO said that when she occasionally wears her breast prosthesis, under dresses for example, they make her feel like Danny Le Rue. Her “new sense of self” (Lorde) was closely aligned with her post-surgery body. It was making visible her scars, rather than reconstruction or the use of temporary prostheses, that helped her regain a sense of femininity and acceptance. I propose that this process permitted “an enjoyment of self and becoming” (Spence & Martin, 1995, p176) and of positive collective identification with others who had made the same decision. Within her film, she did not record or explore her body alone with the camera — in contrast to her lived experience — and her decision to reveal her breastless body only came right at the end of filming.

There are a number of issues that the last cademe of TO’s film raises. I find it both profoundly intimate and inspiring, yet at the same time problematic. I hesitated about whether or not to include it. Although TO chose not to take part in the edit, I consulted her on this question; she was adamant that it should go in. However, my reaction remains ambivalent. I am concerned about audience reading of it in light of TO’s jocular reference to Page 3, and the framing of the filming of her breastless body under a “for consumption” critique associated

with an objectifying, masculine gaze. Does she feel objectified in any way? (She said she didn't and doesn't). I am also troubled by the domestic intimacy of the scene: it was shot in the home (rather than a studio), the family clothes were drying by the radiator just out of shot, she was not wearing makeup — the raw intensity of the composition troubles me. Mainly, however, I am concerned because it was the only shot that I filmed. TO asked me to do it. She was so gung-ho at the time — she just whipped her top off one day just as I was leaving and said, "Come on, Chrissie, switch it on ..." Her children, who were on the sofa, did not flinch (or only momentarily, because we obstructed their view of the TV).

The inclusion of this cademe still sits uneasily with me. The ethics of my research have been to avoid using the participants as signifiers for my arguments. Is it an intrusive intervention? Even though I was invited to set the camera up and turn it on, it still worries me that it infringes. But it does embody the TO I have come to know: honest, confident in her body (although not necessarily about the future), bold, spontaneous, jocular, and proudly and publicly breastless.

Subsequently we have had conversations about it. These conversations and the earlier discussion in the coffee shop raise interesting questions about the subjectivity of intimacy, and reiterate the ambiguities of sites for intimate discourse. FH said that showing her scars or talking about her medical history are not particularly intimate acts — her body was now frequently and willingly (actively) exposed in the public sphere. Her (on-going) reassurances did not alleviate my ambivalence. Even as I now proofread my thesis, I am uncertain about whether the cademe should be included.

Two participants (WA and EN) had been keeping a photographic record of their bodies throughout their treatment. They both used the film as an opportunity to continue documenting — as well as revisiting — the processes of physical change and their perceptions of their bodies: "There is no peeling away of layers

to reveal a real self, just a constant reworking process” (Spence, 1986, p97).

WA chose to have partial reconstruction surgery following her mastectomy, but resisted the invitation from the medical profession for further surgery to provide ‘younger’ breasts:

When the surgeon ... we were talking about the new boob and he said we could give you a really good boob and he was saying you could come back and we could do the other one too. Give me an uplift, that’s right, and I just thought, actually, I don’t want the boob that’s fine to be operated on when it would be purely for vanity so I actually said to him just make my new one saggy like my old one And again talking to a friend about the whole nipple thing, I don’t know if I really do want a nipple; I like my boobs. I like scars; I’ve always liked scars. Various accidents and mishaps or whatever; so I quite like my scar. You know it’s like a total circle. The sun or the moon or the earth; so I like it (49:50).

Like BE and TO, WA wanted to connect with others and make them feel that they were not alone. She specifically wanted to remove the anonymity and impersonal message conveyed in medical literature about surgical procedures (1:14:37). As Ehlers & Krupar argued, “the medical arena depersonalizes representations of the body with breast cancer; from medical pamphlets to medical studies, the body generally appears passive, injured, damaged, and divorced from subjectivity” (2012, p5). By making visible her body and experiences, WA felt empowered to overcome this.⁵⁷

WA used the heightened sense of agency afforded by the camera to explore her body for *herself*, both for creative fulfilment and therapeutic benefit; to contemplate and negotiate her changed body, and to explore past and present emotions. She created a ‘ducket’” (the white board) which she used to revisit,

⁵⁷ Whilst Chalfen argued that participants benefit from being experts and teaching physicians, the participants in my research never said that they felt like experts nor that there was a hierarchy of knowledge. The empowerment they felt through sharing experiences was grounded in empathetic exchange rather than pedagogic ‘teaching’ (Chalfen *et al.*, 2010, p206).

reflect upon, and re-order archive photographs, reinvesting meaning in the here and now of filming (7:45 onwards). She painted a moss breast that celebrated the function of her breast (56:49) and stones that explored past feelings (30:15). She recorded scars in nature that reminded her of her scars (51:21), and revealed her post surgery body with the camera (34:15). The process of filming "...offer(ed) a form of active looking in which new meanings can be made, new stories told and new narrative fragments constructed" (Martin, 2012, p135).

WA explained that the filmmaking process had been beneficial for her, and that taking part had been empowering. In particular, making her post-surgery body visible had benefits which, as for TO, started to extend beyond the making of the film:

This film has been like, definitely part of my healing, you know because it's as I said, you know, it's just made me push myself to do things that I wouldn't have done before. And I've really enjoyed doing them. And especially like the life modelling side of things; has just kind of opened me up to the, just the thing of well, I don't know if other people really want to see kind of women who have scars and everything, but I suppose I just kind of want to normalise it (1:12:03).

I have already outlined some of the benefits EN experienced from participating. Whilst exploring the physical effects of breast cancer was not the most important aim of her filmmaking, by making them visible she draws attention to the wider politics of breast reconstruction and to the lack of Black lesbian feminist literature. This absence of literature was problematic for her own decision-making prior to her surgery; her film was thus used "as a space in which to rehearse and explore strategies of resistance, as well as to explore and reconcile contradictory discourses" (Hogan & Pink, 2012, p166).

EN revisited and selected photographs from her own archive that document each stage of her surgery, and introduced images from her nipple

reconstruction in the here and now of the film. The chronology of the still photographs (36:45-41:05; 43:28-45:18) showed a body in flux, under revision, that may seem out of order to anyone expecting outward physical linear progress. However, despite nearing the end of the long surgical process, she viewed her breast reconstruction in line with Nadine Ehlers's polemic which offered a compelling critique of the tendency to describe breast reconstruction as normalising. "Everything is not 'back to normal' because I now have two new 'breasts' (or mounds of flesh that resemble breasts even if they don't exactly function like breasts) now, perhaps, with 'nipples'" (email correspondence).

I want to provide a brief contextualisation of the individual responses to and representations of undergoing mastectomies in the research. Audre Lorde's arguments were grounded in a rejection of reconstruction. Nadine Ehlers (2012) challenged Lorde's view with a contemporary theoretical perspective that is relevant to the wide range of surgical and medical choices made by the participants in my research. Ehlers acknowledged the historical importance of Lorde's work and did not dismiss her theorising; however, she saw Lorde's rejection of reconstruction as an oversimplification. Ehlers argued that viewing the prosthesis as "a dangerous fantasy" that denied experience (Lorde, 1980, p16, quoted in Ehlers, 2012, p125) inhibits acceptance of a post-surgery body. It is thus at odds with post-structuralist theorising on both the docility of bodies and the understanding of the body "as never "natural," but as *co-emerging with technology*: the body and technology are never separate" (Ehlers 2012, p135). It is not the decision to have or refuse reconstruction that offers an "unencumbered liberatory potential: both techniques engage the norm in some way and both can be practiced in ways that reify femininity or particular configurations of identity as either located in the breast or as transgressing the breast" (*ibid.*, p136). What is important is to "learn ways to use the power of its disciplines to propel us in new directions" (McWhorter, 1999, p181, quoted in Ehlers, 2012b, p136), as the participants have done in their lives and through the filmmaking process. These new directions, though, will continue to be fluid

and in process; a salient example is Matuschka's recent decision to undergo breast reconstruction, after being one of the first public advocates for a breastless identity.

Whilst Mairs Dyer's research confirmed the beneficial potential of collaborative filmmaking in Northern Ireland, she asserted that it would be incorrect to assume that the process would be beneficial for all (2013, p250). The same was true in my research. For example, EA asked to stop filming (Diary, 10/10/12). She cited a number of factors that influenced her decision. She had been persuaded to take part by a friend (Diary, 10/7/12), but also had not placed a high priority on her breast cancer diagnosis and treatment. When first introducing herself to the camera, she said that she did not regard cancer as "a problem anymore" (1:43), and indeed she often felt that she couldn't think of anything to say to the camera. Significantly, she regarded her own illness experience in relation to her sister's recent diagnosis of motor neuron disease. She was also concerned that she did not want to take up a camera that someone else might use, who would "spend more time with you, as you should be talked to" (46:05).

For those who found the process beneficial, there was also an ambivalent relationship between breaking and retaining silences; between forgetting and remembering. For BI, the importance of remembering cancer was linked to her identity: "at the end of the day cancer is ... it becomes part of you" (27:07). However, at times she longed for days "where that looming shadow of cancer just doesn't affect me in any way shape or form" (1:04:32). This echoed BR's ambivalence about remembering and forgetting. For BE, the disappointments that came from unexpected reminders of her disease were exemplified by the comments made about her toe nails — still damaged by chemotherapy — on the train home from a concert (51:09).

BI asked "at what point do you let go?" (Diary, 24/10/12). This was reminiscent

of participant A in Mairs Dyer's research, who felt that retelling his story "can keep you in the past" (2013, p94), and of a question put to another participant by an audience member: "Do you not think it's time you just walked away and forgot about it?" (*ibid.*, p250).

BE stated that the camera occasionally functioned as a reminder of cancer. At times she said that she did not always feel like filming and sometimes she "just wanted to forget" (Diary, 3/12/12). This comment came in response to a question I posed, which I thought at the time was innocuous but which, in fact, turned out to be my single biggest influence on BE's film. I asked if she was taking the camera on holiday with her. She replied that she wasn't aware that she could. Subsequently we had a conversation where BE raised the possibility of the camera being a negative reminder. This triggered an anxiety in me about the methodology hindering participants' progress by rooting them in the past. However, BE seemed unconcerned about this, saying that the camera was hugely beneficial, that the feeling was only fleeting, and that she would make her own decisions about when and where to film.

The risks of silence for someone who has had breast cancer, of forgetting or being complacent, were set against being alert to signs of recurrence. As EN describes:

I need to ensure that I don't become so complacent that I forget to be vigilant. Complacent in that I can think that breast cancer isn't going to come back, but I need to remember that while I have had surgery — a bilateral mastectomy — this doesn't mean that it won't come back. It just means that my risk of having a local recurrence or a new primary tumour is massively reduced. At the same time I don't want to worry that it is going to come back, spend my time worrying and being overanxious and over-vigilant. There's a balance to be found really between being able to relax and getting on with my life and at the same time being vigilant, so that should I have any recurrence, I will spot it earlier on and the earlier I spot it then the sooner I can get treatment. And obviously early detection is vital in terms of good outcomes. So

yeah, there is definitely a balance to be sought between the two positions (32:55).

In my ongoing conversations with EN, it is interesting to note how these feelings are in flux and become heightened at certain times, for example close to the anniversary of her sister's death.

CONCLUSION

As discussed in Chapter One, each participant interpreted the project in distinct ways. In the first part of this chapter I questioned how the participants used their cameras as tools of audiovisual inscription and integrated them into their lives. Most participants had some initial hesitations about the open-ended nature of the project and/or the act of filming. Each carefully considered a variety of issues that included, but weren't restricted to, negotiating public/private boundaries, the ambivalence of memory, and medical crises in the present.

Whilst hesitations were transient, and all the women engaged positively with the project some participants took several weeks to feel comfortable with the camera, and for one to commence filming, so a protracted study period is strongly recommended. Time and space, allowing each to engage with the research in a way of their choosing, rather than probing or direct researcher-led interventions, was found to be effective. However, one participant did not feel benefit from participating and stopped filming after four months.

In exploring the different ways of expressing subjectivity, I found Jerslev's theorising of the performative documentary useful. Jerslev's rethinking of Bruzzi and Nichols' understanding of performativity as "disavowing", as a process of making intimate feelings and information visible, has provided a framework to explore the participants' engagement with the research. I offered a more detailed empathetic reading of two participants' engagement processes,

as key examples.

In continuing to address the question, *what impact did the research have on the participants' lives?* I explored and theorised the finding that most participants found taking part in the research beneficial. I proposed that the camera offered them agency and an active way of breaking silences, allowing the women to negotiate, explore and perform their experiences. As stated in Chapter Two, it is well documented that the end of active treatment often leads to a sense of abandonment, which can persist for several years. As BI explained, the end of treatment does not bring a sense of closure, but rather the question, "what do I do now?" (47:24). I have proposed that this project offered participants "a blank screen and the necessary distance to see from a different point of view" (Martin, 2012, p123) in order to break some silences surrounding breast cancer.

I have identified how silences continue to be present in the participants' lives and in the wider culture of breast cancer, and how they are created and/or imposed through a variety of mechanisms. In highlighting the participants' explorations of the physical effects of breast cancer, I drew attention to the multiple ways in which women experience, understand, prioritise and choose to represent experiences of mastectomy. I argued that this project allowed participants to negotiate a body in progress, with the possibility of recovery and/or acceptance.

I have found the theories of Sarah Pink and Susan Hogan, Jo Spence, Rosy Martin, and Audre Lorde helpful in my analysis. Examining feminist practices enabled me to consider benefit beyond the "short hand labels" of clinical models that "are crude at best and run the risk that people's needs and concerns become seen, by both professionals and patients alike, as a form of pathology or illness rather than being understood within the unique and complicated context of people's lives" (Brennan, 2004, pxxxiii).

It would be incorrect to assume that projects of this nature would be universally beneficial. One participant found that the process of filming did not fulfil her aims in taking part. The research also identified ambivalence around forgetting and remembering following cessation of treatment for breast cancer; the camera may, at times, be an unwanted reminder of cancer experiences. While such implications were transient and not expressed by all, they are important to note. Furthermore, the research's offer of a safe space to talk followed by public disclosure of information could be problematic if collaborative editing and feedback screening was not part of the methodology. However, nearly all participants found the process of articulating their experiences beneficial.

5. CONCLUSION

My aim in this research was to develop an ethical, collaborative visual ethnography to explore and make visible individual experiences of breast cancer. Through my thesis and practice I have questioned how we, as researchers and filmmakers, investigate and make visible the lives of others. Breast cancer is a highly conspicuous disease within the population, but much knowledge of individual experience is often either lost or generalised concealed by hegemonic research and filmmaking practices. A heavy reliance on predetermined themes, questionnaires and even scripts, and a tendency to submit to persuasive narratives to appeal to audiences and broadcasters, often characterises established production processes. Individual testimonies are frequently compressed to easily consumed sound bites, bolstered using 'expert' voices, and subjugated to director's views and/or broadcast agendas.

My thesis focussed on a critical analysis of the *process* of collaboratively producing knowledge. In answering each research question I have prioritised the research encounter. My study design, whilst grounded in collaborative visual ethnography, has drawn from a number of other disciplines in response to the both the research process and the emerging findings.

In this conclusion I summarise the answers to my research questions; state my original contribution to knowledge; propose secondary use of the research material; describe some limitations of the work and make recommendations for future research.

RESEARCH QUESTIONS

The following research questions were identified and answered through my thesis and practice: *Is the methodology an effective, respectful way of producing new knowledge, and new ways of knowing, about illness experiences? How were*

we, as co-participants emplaced in the research? What role did the collaborative edit and feedback screenings play? How best to display and engage with copious amounts of polyphonic ethnographic material? How were the cameras used as tools of audiovisual inscription? What impact did the research have on the lives of the participants? In response to my practice, an additional question was identified and addressed: *What ethical guidelines arose from this research?*

Is the methodology an effective, respectful way of producing new knowledge, and new ways of knowing, about illness experiences? I have proposed through my thesis that this collaborative visual methodology has been a novel, ethical, therapeutic and successful way to explore individual experiences of breast cancer. A key aim of my methodology was to reduce my interventions in the research and enable participants to “become authors of their own stories and not just the subjects of others’ stories” (McLaughlin, 2003, p177). I have argued that there is a compelling need to deconstruct and reconsider the interview as the most frequently adopted methodological tool in social research. I have proposed that it reduces, homogenises and regulates experiences. I was not present during filming unless invited into the frame. I guided the participants: “you know you have been invited to take part because you have had a diagnosis of breast cancer. You are being given a camera for three to six months to film whatever is important to you.” I acknowledged and exposed my role in the co-construction of knowledge, making no claims of being a neutral presence and urged consideration of research relationships and researcher positioning, which I describe in more detail below. I identified the possibility that research that originates from and is situated in a clinical setting can codify responses.

Two important factors emerged in the research process with regard to ethics and led to me ask a further research question: *What ethical guidelines arose from this research?* My work highlighted the difficulties in predicting outcomes from research. There was a need for consent and ethical considerations to be a process, and to consider a range of outcomes rather than be a binary fixed

agreement established before the research has started. Ownership of material should be clearly agreed and collaboration on future use of the material should continue after cessation of the research, with right of veto remaining with participants.

Ethical considerations and consent should feed participants' views back into the study design and research space. I had set parameters in consultation with the medical profession for the inclusion of individuals in the study. For example, we decided that for anyone still receiving chemotherapy participating in a project of this nature could possibly be unethical, due to the side effects of the drug treatment, and that the study should be restricted to primary breast cancer. However, two participants disagreed with these binary distinctions. BE strongly expressed that she wished she had been able to use the camera from the point of her diagnosis, and DE, who has secondary breast cancer felt passionately that a project of this nature should contain a perspective of secondary breast cancer. Arguably, whilst a safeguard against the (at the time) unknown effects of the research, the parameters were paternalistic.⁵⁸ I would still argue that most research interventions during active treatment for cancer should be carried out — if at all — with extreme caution, however therapeutic projects where control of time and energy invested lies with the participant, may be helpful.

How were we, as co-participants emplaced in the research? My background and outsider status did make me think carefully about my positioning in relation to the participants in this research, as well as the ethical positioning of researchers in general. I cautioned that intimate research relationships and working “nearby” are not unproblematic concepts. I questioned the possibility of becoming “similarly situated” (Pink, 2012b, p50) for outsider researchers, but

⁵⁸ Although, because I was seeking to look at specific time frame after treatment had finished, regrettably women with secondary breast cancer never ‘finish’ treatment in this regard I might have been justified in restricting the study to primary breast cancer.

argued too that having shared experience is not a guarantee of an equitable research relationship. In advising future researchers, I do *not* promote distant, observation but I do suggest that working at a respectful proximity to participants involves creating space; space that incorporates and values *their* experiential, expert knowledge; *their* views on the research; and *their* research aims — feeding them back into the research process. In addition, the trusting research relationship necessary to generate such rich, personal testimonies would be broken if cameras were routinely handed out for data production.

Whilst I have tried to make my role visible through the presentation of my diaries in the installation space and in the writing of this thesis, I still feel that there is ambiguity and I have failed to master the act of revelation. Maybe though as researchers it is impossible to *fully* reveal our role whilst still claiming to represent others: surely then the research process becomes an investigation of *us* and not the lives of others? In re-reading my thesis — I wonder if I have conveyed enough of the sense of the privileged I have felt, and have contemplated if it would have been better if the encounters I had with the participants had been filmed. But then, if the relationships had been subject to the camera's gaze and record, they unquestionably would have not been the same. It is possible that we had such strong mutually respectful relationships *because* we have had such long periods of 'off-camera' interactions.

The participants were free to interpret the project as they wished and to choose what they made visible. Importance was attributed to sharing knowledge with others diagnosed with breast cancer, but another imperative was breaking myths and assumptions that existed within the general population. Similarly some participants wished to fill gaps in biomedical knowledge and others to communicate that breast cancer was not a homogenous disease. In

disseminating the work I aim to fulfil their wish to reach these audiences.⁵⁹ The film as a process for self-fulfilment and/or benefit was also acknowledged by most. Sarah Pink (2001) is rightly critical of projects that fail to address how participants interpret what is being asked of them in research contexts.

What role did the collaborative edit and feedback screenings play? Participants were asked not to delete any footage during the research process, and whilst I proposed that feedback screenings may have greater significance in projects where participants had not been filming themselves or if there had been a decision to markedly reduce the amount of footage, feedback screenings form a necessary safeguard in ethical filmmaking. It was a helpful process for those who did take part in order to prioritise footage. Only one participant became closely involved. Lack of take up should not justify its exclusion from research practices.

How best to display and engage with copious amounts of polyphonic ethnographic material? The single screen intercut documentary originally planned could not adequately contain the nine perspectives and multiple ways of experiencing and representing breast cancer. There were several factors that led to the consideration of alternative ways of presenting visual ethnographic data: the resistance of the research material to a conventional intercut documentary format; the desire not to reify the evidence into a 'grand' illness narrative; to privilege the individuality of each narrative; the individual styles of filmmaking and relationship with the camera; as well as the quantity deemed important by the participants. This decision-making is in line with McLaughlin (2010) and Basu (2009).

⁵⁹ Excerpts of the films have already been presented to a number of clinical groups at Cancer Research UK and Imperial College, to *patient* support groups, at NCRI 2013 & 2014. The installation is being promoted through a number of cancer charities as well as the University data-base and wider audiences.

Nine individual films were edited, as Rouch in *Chronicle of a Summer*, as a chronology of filming. A priority was to maintain intact cademes. There was a deliberate archival feeling to the material and I was unconcerned about narrative gaps, contradictions and iterations.

Cahal McLaughlin, Kutluğ Ataman, and Ann-Sofi Sidén have all exhibited films that explore social issues in the gallery or installation spaces. My aims in presenting the research material were to promote an intimate sustained engagement with the films, respect the individuality of experience and preserve the dignity of participants. I wanted to use the installation as an opportunity to disrupt the 'taken for granted-ness' of experiences of breast cancer and resist binary readings. I have proposed that the installation space and viewing films on loops is well suited to the open-ended nature of the research material which is made of multiple self contained narratives and depicts illness experiences as chaotic with unstable boundaries.

How were the cameras used as tools of audiovisual inscription? The process of engaging with the research and the camera, for some, required overcoming inhibitions. Only two participants confidently and immediately started filming — seemingly — uninhibited. The others hesitated to varying degrees at the beginning of the research. Reasons for hesitations included the autonomous nature of the research; being a visible 'presence' on screen; imagining audiences; the ambivalence of remembering; the emotional difficulties of recalling events; and of medical crises in the present. However, I did not want to over exaggerate these negotiations in the process of theorising them — they were often productive periods that lessened over time. Active interventions by me (rather than time and space and/or listening to ideas) were only necessary with one participant, who also had to overcome physical difficulties operating the camera alone, which undoubtedly contributed to her initial hesitance in engaging with the research. A variety of processes were invoked by the participants — for example, inviting others into the frame; being alone with the

camera; anthropomorphising the camera as a therapist-listener or friend; being absent from the frame; and premeditated thought and planning.

Any initial pensive hesitations were soon overcome for eight out of nine participants. Despite the contemplative start for some, the control the open-ended methodology offered the participants was valued. Jerslev's performative lens was helpful for theorising the process of engaging with the camera in a way that acknowledged that any self-consciousness was not a "failed attempt to act naturally" (2005, p103) but rather requisite to engaging with the research.

What impact did the research have on the lives of the participants? My research confirmed the initial proposal of McLaughlin (2010) and findings of Mairs-Dyer's (2013) that participating in collaborative filmmaking is beneficial for most participants. Sarah Pink and Susan Hogan (i.e., 2012) have already drawn links between knowledge production and knowing in visual ethnography and feminist art therapy practices and my work expanded their theorising through consideration of filmmaking as a creative, therapeutic practice by women with breast cancer.

The participants all identified silences that continue to surround both their past, present and imagined future experiences of breast cancer, but also of breast cancer within society. I propose that the project provided a sense of agency, empowerment, a new and active way of 'looking' and a distance from which to view and externalise their lives, changed post-surgical bodies, experiences, fears and hopes. The films as a record, was important for some participants; it enabled them to resituate themselves within their family (EN); in their own personal album (BE); and as a legacy (DE). The films also exist as documents for wider dissemination to help others diagnosed with the disease.

In line with, Mairs Dyer (2013), benefit should not be taken for granted. Whilst still completing four months of filming, one participant in my research, EA,

asked not to continue with the research. There were no negative effects for her from participating, but she did not find the process helpful.

My findings show ambivalence about recalling past experiences and the *possibility* of the research as an unwanted reminder of cancer. This was rare and only at the start of filming.

ORIGINAL CONTRIBUTION TO KNOWLEDGE

My original contribution to knowledge has been the development of a methodology to explore, produce knowledge about, and represent experiences of breast cancer. This has been achieved through establishing a supportive research framework, in which my own interventions have been reduced and participants themselves have prioritised knowledge production. An alternative to the interview format and prior identification of themes was offered through 'handing cameras over' to participants for a protracted period of time, and my being absent from filmmaking unless invited into the frame by participants. My detailing of the discrete interpretations and understandings of the project by participants, as well as my own interventions and positioning in the research has countered reductive models of reflexive analysis. The need for consent to be a flexible process emerged in the field, and this model in conjunction with anticipatory planning is strongly proposed as best practice for future projects. My theorising on how the cameras were used adds to debates within film theory of performativity and displaying subjectivity. Whilst participants were ambivalent about feedback screenings, I have argued for their importance as ethical safeguards. I have demonstrated the inability of a single intercut documentary to adequately contain polyphonic durational research material. In presenting the research material I have subverted homogenous, culturally validated narrative tropes. Exhibiting the films in the gallery has built on existing proposals to explore alternative ways of displaying visual ethnographic material. I have proposed the beneficial effects for most participants of making their experiences of breast cancer visible.

SECONDARY USE OF THE RESEARCH MATERIAL

The choice of nine separate, durational films and the installation platform satisfied many ethical obligations in terms of privileging the knowledge produced by the participants, however, there is a further responsibility on me for the work to reach as wide an audience as possible.

i. Further Exhibitions.

The exhibition will tour to other cities in the UK. Plans are already underway in Manchester. Four other cities are tentatively proposed: Dundee, Birmingham, Cardiff, and Newcastle. However, audience numbers will still be lower than for a single screen film.

ii. Single Intercut Documentary

Although compromise on depth and individual experience was necessary, single intercut perspectives have already been made to show to clinical and support groups, and a single screen documentary will be edited collaboratively. It is hoped that this will increase audiences that the research material reaches. A key aim is to submit to BreastFest 2016. Participants will be individually consulted about each proposed outcome.

iii. Archive

The research material, subject to consent from all participants, will be kept as an archive for access by future researchers. Currently discussions are taking place with the Wellcome Collection, London.

LIMITATIONS

Process versus product

In order to contain my analysis, my thesis has focused on applying and testing the methodology of handing cameras over to explore experiences of breast cancer and the process of knowledge production. I have sought to give the readers of this thesis a thorough explanation of how the knowledge has been produced. I have wanted to allow the knowledge produced to (largely) 'speak

for itself' in the installation and to not be reduced through a written critical analysis and theoretical interpretation.

To have encouraged self-expression then subject *what* is said to the scrutiny of academic analysis felt uncomfortable. However, there is a vast body of knowledge produced that can make a valuable contribution to medical and health care literature, and the participants are encouraging of the dissemination of the findings. The NCRI 2014 tamoxifen paper, details of which are in Appendix 5, is an example of this wider dissemination.

Older women

One limitation of my work left unexplored is that no older participants took part in the research.⁶⁰ There are a number of factors why this may have happened. Firstly, one cannot ignore the logistical and financial limitations of a single researcher co-ordinating polyphonic research — moving beyond nine participants in various geographical locations would simply not have been feasible. Whilst I did target elderly groups, simultaneously I was responding positively to everyone who expressed an interest in taking part — not wishing to turn anyone down. I quickly reached capacity and left no 'space' to more actively pursue older age groups. I could have said 'no' to people who wanted to participate, but genuinely did not want to do so. In speculating why this research appealed less to older women: it could have been the visual methodology and technology; it could have been a greater acceptance/expectation of developing breast cancer; it would be interesting to explore this in greater depth. I can conclude though that when an open invitation to participate in visual research is issued, younger age groups respond. For future visual research that wants to focus on older women, invitations may need to be more targeted and issued in person.

⁶⁰ As already stated, 80% of breast cancers in women occur in the over 50s. The age range in this research was 26-51 years at diagnosis.

Silences

There were definitely silences in the films that originated from a number of sources, for example despite the durational nature of the films, there was still considerable loss in the edit. But there were silences surrounding what the participants chose to talk about, and whilst this was entirely their prerogative and indeed the point of the research, I contemplated whether more intervention by me could have permitted a productive, beneficial exploration of some issues. A notable example is in TO's film. She made a single statement to convey her greatest fear: passing the gene on to her children (40:05). Other than in this statement she did not explore the issue more in the film, even though she talked to me about it in more detail. Could there have been a better resolution for TO through a more interventional engagement or if the research had been conducted within a feminist art therapy paradigm of confidentiality?

FURTHER STUDY

There are proposals to increase the duration of prescribed tamoxifen from five to 10 years (ATLAS, 2013) and for tamoxifen to be used as prophylactic treatment for 'healthy' women who are at heightened risk for developing breast cancer (Cuzick, 2015). It has been identified by CRUK that more data is needed about the lived experience of women taking tamoxifen. This methodology clearly identifies important information not detected in clinical research and its use to explore this issue more widely may be justified.

I have been invited to apply a similar collaborative methodology to explore experiences of rare cancers. In presenting and discussing my PhD with a number of medical specialists and support groups it was felt that producing visual knowledge and knowing about experiences of uncommon cancers would be beneficial. My planning this time starts from Pink and Hogan's (2012) cross-disciplinary framework. I intend to focus on a smaller group of individuals and to also give cameras to family members to explore *their* experiences and perceptions. BE in the course of the research suggested that she would have

liked to use the camera to leave messages about her feelings for her son, in the hope that he would reciprocate; TO's daughter provided moving insight into an issue that her mother did not address during her filming (30:09); during the filming of my short film *Remember the Day* (2010, London) the camera served as a tool of communication between family members of previously unspoken feelings; and in the BBC's film *Kris Dying to Live* (2014, London) the power of the film to reveal unexpressed emotions between Kris and her twin sister was revealed.

Further explorations and experiments into how we exhibit and share 'thick' ethnographic descriptions to the wider public and interested parties are warranted. I remain keen to continue to investigate the gallery space and other social spaces to display and explore health and illness related material, and to challenge assumptions about how we view and consume representations of illness.

APPENDICES

Appendix 1. Charities and Community Groups Contacted.

Appendix 2. Collaboratively Written Diagnostic Details.

Appendix 3. Consent and Release Forms.

Appendix 4. Research Diary.

Appendix 5. Experiences of Tamoxifen.

Appendix 1. Charities and Community Groups Contacted.

Paul's Cancer Support Centre <http://www.paulscancersupportcentre.org.uk>
The Haven Breast Cancer Support Centres <http://thehaven.org.uk>
CoppaFeel <http://coppafeel.org>
National Hereditary Breast Cancer Help Line <http://breastcancergenetics.co.uk>
West London Asian Cancer Support Group <http://www.macmillan.org.uk/in-your-area/local-dashboard/detail/Support%20groups/6949/Asian-Cancer-Support-Group---West-London>
Asian Women's Breast Cancer Group <http://www.awbcg.co.uk>
Ponayi https://www.facebook.com/ponayicharity/info?tab=page_info
Trinjan Women's Social and Community Group <http://www.trinjan.co.uk/about.php>
BME Cancer Communities <http://www.bmecancer.com>
Cancer Black Care <http://www.cancerblackcare.org.uk>
Asian Cancer Support Group North London <http://canceractive.com/cancer-active-page-link.aspx?n=2467&Title=Asian%20Cancer%20Support%20Group%20-%20North%20London>
Ealing Community Network <http://www.ealingparkhealthcentre.nhs.uk/wp-content/uploads/2013/07/ealing-health-self-help-directory-printable-version.pdf>
Community Cancer Centre <http://communitycancercentre.ning.com>
Cancer Equality <http://www.cancerequality.co.uk>
The Macmillan Cancer Information Centres
<http://www.macmillan.org.uk/?gclid=CKfOyJiwr8UCFezHtAodaT8AkA>
Macmillan Chinese Information Project <http://www.cnhlc.org.uk/english/projects/cancer-awareness/>
The Mulberry Centre <http://www.themulberrycentre.co.uk>
Trojans <http://www.trojansupport.me.uk>
Age Concern <http://www.ageuk.org.uk>
Turkish Cypriot Women's Project <http://www.tcwp.org.uk>
BetterDays <http://www.betterdays.uk.com>
Against Breast Cancer <http://www.againstbreastcancer.org.uk>
Breast Cancer Care <http://www.breastcancercare.org.uk>
Older Lesbian Network <http://www.olderlesbiannetwork.btck.co.uk>
Chai Cancer Care <http://www.chaicancercare.org>

Appendix 2. Collaboratively Written Diagnostic Details.

WA discovered a lump in her left breast just after she stopped breast-feeding her two and a half year old son. She knew instinctively that something was wrong though she and the doctor hoped it was just hormone changes. She was diagnosed with breast cancer in September 2011 aged 41 and in November 2011 had a mastectomy with immediate reconstruction using her tummy fat and skin with which she is delighted. She did not need chemotherapy or radiotherapy, which she was so relieved about. WA took tamoxifen for about two and a half years at her own dosages until she realised she really did not want to take it anymore and has now stopped. Recently there have been concerns about the other breast and she is choosing to deal with it through diet, supplements, homeopathy, herbs, yoga, reiki, enemas and a healthy lifestyle. She now uses thermography instead of mammograms and has regular ultrasounds with her breast specialist doctor.

EN received a diagnosis of primary breast cancer in her left breast on 5 October 2009, aged 43. She had been receiving annual screening at the Royal Marsden Hospital Family History Clinic since 1999 when she had asked to be referred there following an ultrasound on her left breast. She had also had an ultrasound and core biopsy on her left breast in autumn 2006.

Her mother had been diagnosed with primary breast cancer in her left breast in 1976 aged 38, after being turned away by her GP on several occasions. She had a mastectomy in 1976. Two years later the cancer spread to her liver and she was diagnosed with metastatic breast cancer. She had died in 1980 aged 42 at the Royal Marsden Hospital.

EN's younger sister received a primary breast cancer diagnosis on the same date as her in October 2009, aged 36. In August 2009, her GP had failed to follow the NICE guidelines by not referring her to the hospital. She was subsequently

diagnosed with bi-lateral primary breast cancer and triple negative breast cancer, followed by metastatic breast cancer in 2010 as the cancer had spread to her bones. She died in July 2011 aged 38.

EN underwent breast-conserving surgery with a wide local excision and sentinel node biopsy in October 2009. The node biopsy was negative and her tumour was found to be oestrogen-positive. She received four rounds of Taxotere (Docetaxel) chemotherapy between December 2009 and February 2010, followed by radiotherapy throughout March 2010. EN began taking tamoxifen in April 2010. She commenced a phased return to work in late April 2010.

After completion of her treatment, in early summer 2010 EN decided that she would like to have a bilateral mastectomy. In order to remove her risk of ovarian cancer, EN underwent a Bilateral Salpingo Oophorectomy in May 2011. She began taking AdCal D3. To reduce her risk of a reoccurrence of primary breast cancer or a new primary breast cancer, she underwent a prophylactic bilateral mastectomy with DIEP reconstruction in October 2011. Revisions to the reconstruction and abdominal scar took place in July 2012, with nipple reconstruction in January 2013, followed by nipple tattooing.

In April 2015 EN will be five years post-treatment.

BR had found a lump in her breast but ignored it for several weeks. She visited the doctor's surgery for a routine smear and mentioned the lump in her breast in passing to the nurse. The lovely smear test nurse suggested that she made an appointment about the lump before she left the surgery that day. She was very persuasive. She was diagnosed with a stage 1, grade 3 cancer in her left breast in August 2011. In September that year, as well as a wide local excision she also had a sentinel node biopsy. Luckily the node biopsy was clear of cancer so was able to escape chemotherapy. She had radiotherapy and takes tamoxifen.

BI found a lump in her left breast in May 2011. She was 33. BI made an appointment to see the doctor as soon as she could. The biopsy showed DCIS with one lymph node affected. Prior to the biopsy she had felt sure that it was going to be found to be cancerous. She had a wide local excision and an auxiliary node clearance, followed by chemotherapy and radiotherapy. Her husband had recently died from lung cancer. BI takes tamoxifen.

PA noticed some weeping from her breast in 2009 but initially felt both uncomfortable mentioning it to the doctor and also didn't associate the symptoms with possibly being cancerous. However, her husband persuaded her to seek medical advice and she was diagnosed with cancer in her right breast in May 2009, aged 48. Following a mastectomy and removal of nodes, she had chemotherapy and radiotherapy, and now takes Letrozole. PA also has multiple sclerosis and diabetes.

DE was 26 years old when she was diagnosed with breast cancer in April 2009. Following a lumpectomy she had chemotherapy and radiotherapy. She was diagnosed with secondary breast cancer following the birth of her son the following year. The cancer has now spread to bones and is in her spine & pelvis. She had further chemotherapy. DE currently takes tamoxifen and has herceptin administered intravenously and her cancer is stable.

BE approached me to ask if she could take part in the project following a presentation I gave at Trojan's support group in North London. At that stage of the research there were six participants actively filming. She [rightly] felt strongly that her own diagnosis of bilateral breast disease would broaden the knowledge produced by the research. In January 2011 she noticed change in appearance & slight inward pulling of skin in her left breast. She hadn't gone to the GP for this, but for a routine "check up" and only mentioned it when the nurse asked if her cervical screens were up to date and if she had been shown how to self assess for breast cancer. Still not thinking it could be breast cancer

she underwent tests. “As soon as I saw the radiographers face [during a scan], I knew the diagnosis”. A subsequent MRI scan revealed cancerous tissue in her right breast, and further investigations revealed her nodes were affected on both sides. The doctor described her cancer as cribiform. She asked if her cancer had spread beyond her nodes, the doctors said they did not know. She still finds it hard to come to terms that a "off the cuff" comment suddenly turned into a life-changing event. It does however, she feels, prove awareness schemes and health clinics actually work and are saving lives.

TO found a lump in her breast when she was having a bath — completely by chance as she does not normally examine her breasts. The result of the biopsy was negative for cancer and she was given the option to have the lump removed or not. TO chose to have it removed. The lump was re-biopsied in April 2010 and she was diagnosed with Stage 3 grade 1 triple negative cancer. TO was 39 years old. She had both chemotherapy and radiotherapy. In 2011 TO was diagnosed with the BRCA 2 gene mutation and had a oophorectomy in December 2011.

EA no diagnostic details provided.

Appendix 3. Consent and Release Forms.

Identification Number for this trial:

Title of Project:

Name of Researcher:

Please initial box

I confirm that I have read and understand the information sheet dated March 2014 for the above study.

☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

I understand that sections of data collected during the study, will be used to make films which will be aired publicly.

☐

I agree to my name, first name or a pseudonym of my choice being used in the credits. Towards the completion of the doctoral research project I will inform the researcher, Christine Douglass, which name I agree to being included in the credits.

☐

I agree to take part in the above study.

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

Signature consent completed: 1 for participant; 1 for researcher site file.

Release Form

Identification Number for this trial:

Title of Project:

Name of Researcher:

I, _____ agree to the inclusion of my contribution in the VIVA installation, the nature of which has been explained to me. I understand that my contribution will be edited.

I give/do not give the researcher, Christine Douglass, use of my contribution (i.e. still, motion pictures, sound track recordings and records of me) to publicise the VIVA installation.

I give/do not give the researcher, Christine Douglass, use of all still, motion pictures and sound track recordings and records which are made of me, my voice and image for the purpose of writing her PhD thesis. Including information shared during our meetings.

I give/do not give the researcher Christine Douglass use of all/some still, motion pictures and sound track recordings and records which are made of me, my voice and image for educational purposes i.e. to be made available lay/professional/student audiences with specific interests in health care and/or visual research.

I give/do not give the researcher Christine Douglass use of all/some still, motion pictures and sound track recordings and records which are made of me, my voice and image for future installations and to made available to public audiences.

I give/do not give the researcher Christine Douglass use of my image (photograph or still picture) and information from the field-work in publication(s) or exhibition(s) (e.g. journal articles, book chapters or book, conferences).

I give/do not give the researcher, Christine Douglass, use of all/some still, motion picture and sound track recordings and records which are made of me, my voice and image for the purpose of making a combined documentary which will be aired publicly to general audiences. I agree/do not agree that my contribution may be used to publicise the documentary.

I agree/do not agree to my contribution being on the internet.

I do/do not consent to the University of Westminster and other third parties associated with the university having use of any still, motion pictures and sound track recordings and records which are made of me, my voice and image.

I understand that my participation in this research is voluntary and that I may at any time discontinue my involvement.

I confirm that I am at least 18 years of age

Name of /participant	Date	Signature
----------------------	------	-----------

Name of person taking consent	Date	Signature
-------------------------------	------	-----------

Signature consent completed: 1 for participant; 1 for researcher site file.
Please delete as appropriate.

Appendix 4. Research Diary.

I reveal more detailed aspects of my diary with great caution. I have not wanted to offer participants the opportunity to tell their stories in their own words, choosing what knowledge and experiences *they* want to make public, only to then place their possibly unguarded conversations with me in the public domain. I have permission to use excerpts for my thesis. I have not included email correspondence between us.

i. Diary Excerpts from Thesis (referenced to page number in thesis).

P70. March 1, 2014. BR.

Expressed how incredibly privileged I feel to have a part of this; of everyone's lives for three years. How grateful I was that the project was embraced by all with such diligence and enthusiasm, at such an extraordinarily difficult time. BR said how it had been a positive, enjoyable experience for her. She jokingly mentioned the research not harming any sheep. Forgot that we had talked about Worth and Adair previously. But pleased and relieved that there was positive benefit.

Discussed together abandoning our original plan to make a single documentary in favour of nine individual films for the gallery. I recalled the struggle to make a single film that satisfied all our aims; each attempt producing poor results that failed to accurately and respectfully reflect the nature of the participants' contributions. Remembered the panic I felt; all the hundreds of hours of footage and how my inability to bring them together felt overwhelming; that I was failing. The precise organisation of my storage of the footage (Aaron Kay's brilliant filing system; how thankful I was to him) — each minute (reassuringly) carefully logged and ordered — in stark contrast to the timelines I was assembling on FCP.

Having found a solution in the nine individual films — asked how would she feel about us revisiting a single film, making a more conventional intercut documentary but with all the compromising that would entail? She actively encouraged me to “impose” my thoughts and views, to pull out connections and parallels.

Feel a strong ethical imperative to do it; so that the work reaches as wide an audience as possible. Reconsidering a single screen format — acknowledging and accepting the huge concessions on content and the original principles of the research — would enable the work to be more extensively seen. Will discuss further with everyone.

P74. March 1, 2014. BR.

Talked about the aesthetic she had brought to her film as a result of her expertise as an artist. BR acknowledged it was instinctive: “All those things that I do unconsciously.”

In addition, she raised a couple of issues that she had thought about since we last met. Said in particular how helpful it had been that I hadn’t put pressure on her, and had given her time and space to allow her to reach her own decision about participating.

An iterative concern (there have been so many!) *during* the research was: was the project too open-ended? Remembered asking colleagues at the start of the project: what will I do if no one films anything? One was firm: ‘you must incite action in a Rouchian way’. Must I? I didn’t want to. I wanted to let things unfold (or not) without provocation, in their own time. My supervisor agreed. But I felt anxious. Whilst it turned out to be — not only a respectful way to work but also gave strong, discrete, personal results — I confessed to BR of fearing, at times, that there would be no ‘practice’ element of my PhD; no film.

P78,79. **May 8, 2014. BE.**

BE mentioned that she has said things to the camera that she felt she wouldn't have said to anyone else. Later, alone, I recalled reading Renov, who (unkindly I felt) asked why do people "eviscerate" themselves to a camera (2004, p206). He clearly hadn't witnessed the silences surrounding breast cancer. Of women — bound by supporting others, trying to reduce the impact of the disease on family and friends — barred from talking about the impact of the disease.

BE described the camera as her "invisible friend", *someone* that she could express her innermost thoughts to; acknowledging that feelings change over time and how good it had been to share thoughts in this way. It caused 'no offence' and didn't 'burden' anyone.

Described how she would like to leave messages for her son on the camera about her experiences, messages that he could reply to — the camera, she imagined, would provide a necessary distance to communicate sensitive issues. This idea reminded me of Grierson's recollections of Zavattini's 'dream' of filmic letters being exchanged between villages in Italy (Sussex, 1972).

The desire not to burden others is such a recurrent feeling expressed by many of the participants in our meetings. Am pleased, indeed relieved, that the camera is, in some small way, serving to address this. But, also feel incredibly sad that in many lives, the desire — actually the need — to suppress feelings is so widespread.

BI had said in her film how sometimes the only people who can understand are those who have been through it. I re-read Stoller. Grateful to Sarah Pink for alerting me to his imminent publication. Wonder at what stage do you stop looking for new references when writing your thesis? Possibly never.

BE described how having the camera had enabled her to have some tangible

evidence of what she had been through; of her life post-cancer diagnosis. So many of her experiences to date had not been subject to record. Keeping an archive was something that some of the participants have done since their diagnosis — recording their changing bodies. David Jay's work really marked an important paradigm shift — publicly legitimising, acknowledging, and privileging changed and changing bodies.

Reflect on the silences in my life. Periods of time where there are no records. Only memories. Would I have been brave enough to film and publicly share them? I am more of a burier.

P79. April 1, 2012. TO.

First meeting by phone. Long conversation, lasted over an hour, which, at times made us both laugh, but also upset me. Described her experiences in a very calm, matter of fact way; but the impact that carrying the gene for breast cancer on her family was made movingly evident. Sounded so strong and forthright. Expressed a passionate desire to raise awareness about hereditary breast cancer, which she feels is poorly understood in society.

Find myself hugely conflicted when first meeting or talking to potential participants: I feel so moved and absorbed by the tragic, brutal impact breast cancer has on them and their families, but also — I am ashamed to admit— feel relief when it is made evident how much their perspective will add to the research.

P79, 138. June 12, 2012. TO.

Expressed today how she would like to get more involved with Breast Cancer Care, become a mentor. Will mention it to them tomorrow. Described how helpful talking to people with a shared diagnosis and experiences is; support groups have been hugely important since her diagnosis. Finds though few people she meets in life know about genetic breast cancer and wants to use her

film to publicise this, and the fact that not all breast cancers are the same. Wants too to confidently share her experiences, her changed body and proudly state: “look at me. I have no breasts. I am doing OK.”

Again, I am reminded of my outsider status in this research. I wonder anxiously though, if that will remain the case; my first government-recommended breast screening appointment arrived in the post today. Turn my camera on. Talk. Watch it back; my thoughts seem so superficial, so superfluous. Try to think of how the participants must feel when they attend their annual screenings; the anticipatory dread. Cannot compare it. Never the less, feel a real unease.

P80. March 1, 2014. BR.

Talked more about the methodology. Said how pleased I was now that I hadn't interviewed (she agreed), but stated that at the beginning of the research I had perhaps under-estimated just how hard it would be to film alone. We collectively thought about if anything should have been done differently. She didn't think so.

Stated how therapeutic she had found taking part, described how the project came just at the right time for her. A time when she was considering doing something creative based on her cancer experience.

Feel such relief each time the benefits for the participants are confirmed.

P80, 143. July 10 2012. EA.

First meeting. Same age as me. A childhood, early adulthood spent on the athletics track. Also like me. She, significantly more successfully than me though. Conveyed that she was concerned that she will have little to say on camera, as she has not felt at all “traumatised” by her diagnosis. She was persuaded to take part by a friend. Wonders if it will hit her further down the line. But she doesn't think about it much and certainly hasn't felt depressed.

Contemplate how this will be reflected in her filming. Wonder if the process of filming will raise issues she isn't prepared for. Or possibly if her diagnosis will remain unproblematic.

Lively, charming, funny.

Feels lucky to have caught it early and to have not needed chemotherapy or radiotherapy. Wants to help others in any way she can. Became a mentor through a support group, but finds it deeply upsetting when she sees young women diagnosed with breast cancer.

Talks about her sister's recent diagnosis with MND. Wants to be as supportive as she can. Feels it puts her breast cancer diagnosis into 'perspective'.

P81. July 5, 2012. WA.

Met for the first time. Amazingly thoughtful and prepared. Emphasised how important exploring her experiences through art has already been to her. Aware that she has always looked so well during her treatment, sometimes people comment about this in a way that makes her feel a little defensive and apologetic. Also worries that the validity of her experiences may be called into question.

Later I reflect on the heterogeneity of the disease in terms of outcomes for those diagnosed, which surfaces on a number of occasions in the research. Many express gratitude and relief at not being diagnosed with advanced disease, but at the same time feel an element of — guilt almost — certainly deep empathy and respect — when they meet people with a much poorer outcome or secondary cancer.

Revisit these thoughts again when, in 2014, the awareness campaign about pancreatic cancer, based on a comparative statement: I wish I had breast cancer

[instead of pancreatic cancer] hits the headlines. Feel a marked ambivalence: aware of the appalling outcome for those diagnosed with pancreatic cancer, but simultaneously find the comparative wish of having breast cancer instead offensive.

P82. July 13, 2012. WA

WA expressed how the film might help her address a range of issues in her life related to her breast cancer experiences. She identified certain aims when first diagnosed and recognised that these could be achieved through making her film.

Again, feel so reassured when the participants identify the project as potentially helpful for them as individuals. In the planning stages of the research, I was primarily concerned with knowledge production; respecting and promoting the validity and value of experiential voices. Hadn't fully anticipated (or hoped to presume) the potential for personal benefit from participating.

P82. August 31, 2014. DE.

Met in a hotel in London, she had come to London to spend an evening with friends. Expressed again how she had made the film as a legacy. Her description in a public place, a place where lives and anniversaries were being celebrated, was very sobering. At no stage did she, (has she ever), indicate any sense of feeling sorry for herself.

Found myself close to tears.

P82. July 5, 2014. DE.

Described how exhausting and frustrating she finds it to constantly explain that much of the positive bravado that surrounds primary breast cancer simply isn't relevant to and indeed is very unhelpful for people with secondary breast cancer. Wants to promote understanding of the unique aspects of living with secondary breast cancer. Relayed how often when people hear she has breast

cancer say: “its OK – the prognosis is good. You’ll be OK” – but the reality is the complete opposite of that. Wants to state things clearly: she “has a life-limiting disease” but also that breast cancer does not define her.

We reflect back on how she ‘persuaded me’ to include her in the research. When we first spoke, I had set parameters to only explore experiences of primary cancer. How right she was to press me into including perspectives on secondary breast cancer. I feel dreadful that I even hesitated. Interesting to contemplate research parameters — the need to research defined groups, but how those who would like to take part but don’t *fit* these parameters are rarely considered.

P83. August 18, 2014. BI.

The iterative concerns expressed by participants of not burdening others resurfaced again. Really makes me more convinced about the therapeutic possibilities of filmmaking for individuals who have experiences of illness. But again, feel sadness that there is so much imposed silence between and within families and friends about feelings related to cancer.

P83. March 5, 2014. EN.

EN had well-defined aims for taking part in the project; from the start she clearly articulated her reasons for participating and what she wanted to achieve through making her film. Been consistently impressed by the detail of her considered and considerate approach; been consistently moved by the generational impact breast cancer has had on her family.

P84. September 6, 2014. PA.

PA recalled how: “When you gave me the camera I thought, ‘oh my god, what I am going to do with this.’” Described how nervous she felt in the beginning, and the difficulties, both physical and emotional of being alone with camera. It became easier when she engaged in conversation with others, when the camera became a catalyst to talk. So much so that it became helpful: “It released things

inside that you haven't talked about before or had the chance to talk about before."

Reflect on how finding a way to engage with the project had been the main barrier for PA. And how I wanted to carefully offer support and suggestions without unduly influencing. Think we got the balance right.

I never tire of watching her conversations. They are such privileged insights into her relationships. I worry about the light often not being quite right, not in terms of searching for an 'idealised image' but in the hope that audiences see past the varied technical qualities of the participants' images.

P123, 137. January 16 2013. BE.

BE thoughtfully and without intervention from me, negotiated her lack of ease with the camera. Then soon found the camera an effective tool for decision-making, without having to burden others. Particularly so, at this period of time during her on-going medical investigations. Wished she had had the camera from the start of treatment. Wondered why they weren't handed out earlier. I said it was an ethical issue: would asking people to take part in research/giving cameras to people during active treatment be unethical? She thought it would be an incredibly positive thing to do; it could be helpful, particularly in light of the lack of pressure to film to a fixed schedule.

At the start of the research I contemplated filming myself as part of the research process. Thought having a visual record of my thoughts and feelings, rather than a written 'diary', may have been appropriate. I tried and did three or four entries, but found it really difficult. Couldn't think of — not necessarily what to say — but how to say it and for it be meaningful in the context of everyone else's lives. Surprised (ashamed) by my vanity too. I felt too that with the vast amounts of footage already being produced — was more film logistically manageable? Wonder now though if this last reason was entirely honest.

My difficulties in filming myself certainly increased my respect for the participants.

P124. April 6, 2012. BR.

Incredibly sensitive thoughtful comments about the project and what becoming involved might really entail. Said that very much she did not want to forget the experience of having breast cancer. Described the conflict between moving on and acknowledging the person the experience has made her. But also the need to project forwards, to build a new life. In her discussions with the medical team — they talk about her breast cancer as being quite recent. But she thinks of it as being a long time ago.

I have worried about the project possibly keeping people in the past, but in talking to BR she made me realise the possibilities that the project can also be used to project forwards, to take on new challenges, to explore the past and invest it with new — conceivably more positive meaning.

I hope this is the case.

P131. August 18, 2014. BI.

BI expressed how she did not want to worry her parents by telling them how she *really* felt about her diagnosis and her fears for the future. I am consistently moved by how considerate everyone is about not being a burden on others at a time when ones very existence is being challenged.

Have a flash back to my daughter's illness. Think too about my mother-in-law when my sister-in-law was diagnosed with brain cancer. Of mother's fearing loosing children. Think well into the night of BI. And EN and TO; of their family histories and the generational impact.

P131. September 18, 2012. BE.

Reflect on the shifting paradigms of breast cancer detection and the signs we, as women, are advised to look for. The insidious onset of the disease is now widely acknowledged and the focus of only looking for a breast lump has now been replaced by looking for any slight change that deviates from normal.

I wonder if embarking on this research I will develop an anxiety about developing breast cancer. Will I obsessively check my breasts for example? I think, that having volunteered for a breast cancer charity for many years possibly I won't. But have noticed already — almost subconsciously — I have stopped saying, if asked, that I do not *have* breast cancer. Rather stating that I have never been diagnosed with breast cancer. Unsure of the significance of this.

P143. October 10, 2012. EA.

EA said she would like to stop filming. Expressed again that her diagnosis has been more of an issue for those around her, than for her. Doesn't know if she is in denial, or if she has come to terms with it: but really doesn't regard her diagnosis as problematic. Cannot find things to talk about, other than — she offered — to moan about her day. I never once felt she moaned. Her immersion in the detail of the *every day* was so thoughtful, thought-provoking and highly relevant.

Very importantly, her priority has to be supporting her sister.

Feel sorry that she wants to stop, but understand and respect her decision. Have found her energy, her engagement with and interpretation of the project wonderful. She wants her footage used in what ever way the collective decides, but doesn't want to take part in feedback screenings or dissemination projects.

Will miss our interactions. Re-watch her first cademe. Wonder if this will

introduce the documentary.

P144. October 24, 2012. BI.

Mentioned the problem of “getting on” with her life after treatment has finished; how difficult this is without the support of the doctors and nurses. She questioned: “At what point do you let it all go” — the support, the reliance, the memory.

Moved by the *actuality* of this. I have been reading extensively about it in the literature; the ‘theory’ — but the *reality* of it within BI’s life is clearly far more profound than anything I had conjured up in my minds-eye; anything written on the pages of academic papers.

P144. December 3, 2012. BE.

Met before her holiday. Without thinking I asked if she was taking the camera with her. She said she wasn’t sure that she could, or indeed if she wanted to. Sometimes she needed to forget her cancer experience, and that the camera was a reminder. She talked about the need to move on and forget, but equally at times she wanted, needed to remember, needed to revisit emotions and feelings. Discussed the fragmented nature of remembering — how for her at different times greater significance is attached to certain events. Looked back through my notes, recalling my meeting with BI and my conversations with BR about the ambivalence of remembering. I wonder if at some stage there will be an equilibrium for everyone.

Felt anxious about the camera keeping people in the past. BE said far from it, she was finding it very helpful. Said she would decide nearer the time whether she took it with her on holiday. She said my comment served as a reminder to film ‘normal’ moments’, I apologised and said I shouldn’t have influenced her. She didn’t understand why I felt the need to apologise.

ii. Diary Excerpts presented in the Exhibition

June 6, 2012. BR.

BR asked to meet in a coffee bar. I spent most of the meeting worried about eavesdroppers and their motives— didn't want to encourage her to reveal more about her experiences of cancer than she was comfortable with in a public place. BR was perplexed by my anxiety and playfully teased me about my shyness in openly discussing cancer and death.

June 25, 2012. BI.

Long phone conversation with BI. Great ideas but not filming. Camera still in the box. Contemplated making suggestions, but didn't. BI sees the natural starting point for her film as her trip to the USA. Fingers crossed.

July 2, 2012. BI.

Spoke on the phone. Has developed an acute pain in her spine. Health care team were reassuring. Understandably she is very anxious. Project seems totally irrelevant.

July 10, 2012. BI.

BI's voice barely recognisable on the phone. Was told there is a six-week wait for a scan and she cannot imagine how she will endure the wait. The fear in her voice was overwhelming. Cancelled her trip to the States. Said she would call when she has news.

July 23, 2012.

Was invited into the frame for the first time by one of the participants. Became so focused on trying not to influence what was said that I barely said anything. Felt awkward. Watched it back tonight. The lack of reciprocal engagement on my part looked as it had felt — disrespectful.

September 4, 2012. WA.

Ate and talked in the sun on a deserted platform. WA stated that she feels a bit lost with the open-ended nature of the project. Was surprised. She is filming really thoughtfully. Great breadth and variety. Said she doesn't feel she is talking enough, and that many of her ideas have been hard to bring to fruition. Reiterated that she doesn't have to talk — can just film, or take a break and step back from it. Revisited her ideas. Reassured her that her interpretation of the project and the work she is producing is outstanding. Contemplated if the project is too open ended. Should I have been more interventional and structured interviews? It is hard to talk to a camera alone.

January 15, 2013. BE.

Revisited this moment. The holiday ended up being a turning point. She was glad she took the camera with her. My question reminded her of recording 'normal' moments. Stated that it is really the only time I "led" her in the filming process. Anxiously raised the issue of the camera being a reminder of cancer. She said "far from it, it would have been helpful to have had the camera from the start, from my initial diagnosis, it became my invisible friend."

January 4, 2013. BE.

Didn't sleep well last night. Woke for long stretches and thought of BE's night time footage, her sleeplessness and the recording of the clock chalking up the hours and hours spent awake. Reminded me of my accident which triggered insomnia. Sought advice from a sleep clinic: "whatever you do don't look at the clock when you wake in the night" they said. BE's clock watching. Should I tell her? Recalled the all consuming tiredness of not sleeping, the physical sickness that stays with you all day, the blurring of thoughts, the fogginess, then the fear in the evening of going to bed and not sleeping.

May 6, 2013. DE.

Watched and prioritised the footage with DE at the University. DE's husband

and son came and were sitting behind us. The hum of their jovial interactions a backdrop to our dissection of the films on the screen. After about 30 minutes there was a profound silence. Her husband quickly left the room. Red eyed, he returned. Stated that even though he felt that they had discussed everything regarding her diagnosis and prognosis, he had never heard her speak like that before. Requested not to watch any more. It was as if he had been projected into the future, imagining a world without her. DE commented that she didn't entirely recognise herself in the film. She saw a strong person on the screen, but doesn't feel strong. I saw — both next to me and on the screen — the strongest person I think I have ever met. She felt positive about everything she has shot. She was surprised by this as she thought she would ask me to edit out significant chunks, but would be happy for it all to be included. I wish it all could be.

May 25, 2015.

Compressed final film today. Watched them all now hundreds of times. Each time seeing something new. Reflected on the past 3 years. I've changed during the research. Changed more than I imagined I could and in a way I cannot articulate.

Appendix 5. Experiences of Tamoxifen.

Shared Visual Anthropology & Breast Cancer: Experiences & Perceptions of Tamoxifen Therapy in the Social Context of Women's Lives. ⁶¹

I want to theorise the valuable experiences the participants chose to share in relation to their use of tamoxifen. In this section, rather than focusing on the processes of production, whilst acknowledging that the representations are situated, contingent and contextual, I will build on the work accepted for the NCRI 2014 Conference (Douglass *et al.*, 2014) and apply the knowledge produced about the lived experience of taking tamoxifen to existing medical debates.

Tamoxifen is the most widely prescribed hormonal therapy used as treatment for breast cancer. It is frequently prescribed for five years after active treatment finishes. Recent studies have indicated that increasing treatment to ten years may further decrease mortality (ATLAS, 2013). Within the medical and health care literature there is a lack of information on the impact of the drug in the day-to-day lives of those prescribed it. ⁶²

Tamoxifen significantly reduces the rate of breast cancer recurrence and mortality by a third, in women who have ER positive cancer and who take the drug for five years (EBCTCG, 2011). However, despite this clear evidence of

⁶¹ This Appendix builds on the work presented at the NCRI 2014 cancer conference (Douglass, *et al.*, 2014). Whilst the final films for the installation did not contain all the information on tamoxifen, for the purpose of this analysis, reference has been made to all visual material and discussions by participants in the research context (with their consent). A short film was cut for the NCRI conference containing some of the cademes that reference tamoxifen. This film has not been submitted with this thesis. Thus in the text time codes have been removed. Where knowledge originates through correspondence it is noted.

⁶² Many forms of breast cancer are stimulated to grow by the hormones oestrogen and progesterone. These cancers are called oestrogen or progesterone receptor (ER or PR) positive. Tamoxifen works by blocking the oestrogen receptor within cancer cells. Through stopping oestrogen binding with the breast cancer cell, cell growth is prohibited. Cancer Research UK <http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/cancer-drugs/tamoxifen> [Accessed 6 November 2014]

benefit, there is poor adherence to and persistence with prescribed protocols. McCowan *et al.*'s review of the medical literature cited that up to one third to a half of women do not take their tamoxifen as prescribed (McCowan *et al.*, 2013). The treatment, despite being described in the medical literature as a "well tolerated and easily administered treatment" (Lash *et al.*, 2006) does have side effects which are significant for many women. Side effects have been associated with cessation of treatment (Grunfeld *et al.*, 2005, Lash *et al.*, 2006, Pellegrini *et al.*, 2010). An underestimation of the severity of side effects by the medical profession has been proposed (Ray & Leonard, 1996). A strident example, provided by Luschin and Habersack (2014), cited physician reported side effects (hot flushes) of women taking endocrine therapy as 1.9%, whereas 68.3% of women themselves reported the same symptom (*ibid.*, p422). Alerting to the fact that social and cultural values and beliefs may too influence use of medication, Pellegrini (2010) asserted that the reasons why women do not take tamoxifen has not been widely investigated. This remains the case, with a call for more qualitative research that explores the complexities of non-adherence and non-persistence to oral anticancer drugs (Verbrugghe, *et al.* 2013).

Six women in this collaborative research were taking tamoxifen. In line with feminist art therapy paradigms, I proposed that by focusing "on the individual (as the site of suffering and distress)" [Hogan, 2012, p28] — on how it *feels* to take tamoxifen, how it impacts on lives — will give greater insight into the complex relationship that individuals have with tamoxifen therapy than can be obtained through biomedical models of investigation.

WA had been taking tamoxifen for about a year when she started filming. The ongoing physical and emotional impact tamoxifen had on her life was illustrated in her filming through (often) intense, moving talking head descriptions to the camera. She frequently relayed this impact in a number of locations: at home, on the beach on holiday, in Scotland, in the garden, and in the car.

Tamoxifen had caused changes in her menstrual cycle. Which as well as challenging her identity – her regular menstrual cycle was, she felt, part of who she ‘is’ — at times the symptoms associated with these changes were so overwhelming that she “just wanted to cut herself open and bleed”. She also had debilitating headaches, hair loss, and marked mood swings that affected her family relationship and left her with deep feelings of regret.

The side effects were so severe for her, that after a consultation with her doctor, she contemplated further major surgery rather than continue with the tamoxifen: “... and he was talking about [how] they used to just remove your ovaries and [I] wondered if that would just be easier than taking the tamoxifen” She tried to offset the effects of the tamoxifen by using homeopathic remedies, but ultimately wanted to stop taking the tamoxifen, and had started to self-dose:

so I have decided I am still taking my tamoxifen but I have kind of basically halved the dose and sometimes .. I am so bad at remembering things that anyway quite often I just end up taking one lot a day, because you are supposed to take some in the morning and some at night, so I end up taking probably 1/3 or 1/2 of a dose every day, even sometimes maybe a wee bit more than that.

Her decision making about whether to continue with tamoxifen was linked to a fear of recurrence that “just makes you keep taking the stuff” even though she had reduced the dose, she felt there was still some protection. There was a marked improvement in her physical symptoms in response to reducing the dose, but her iterative decision-making remained filled with anxiety “I really want to come off the tamoxifen but it is just that fear you know, if it came back then would I blame myself? .. oh don’t know “

After filming had finished, WA decided to completely stop her tamoxifen.

BE had been taking tamoxifen for six months longer than WA. Her

representation also contained detailed references to the side effects of tamoxifen: hot flushes, sleeplessness, fatigue, and rash. In addition, tamoxifen had caused physical changes to her endometrium. Initially it was feared that the changes were cancerous. Her life during filming was dominated by these medical investigations and the wait for results.

She made visible the invasive unrelenting sleeplessness and nocturnal hot flushes caused by the tamoxifen through filming at night. Their regularity was also made apparent through her statement: "But, no sooner have I got in, and my hot flushes are coming, which is normally right. They normally start later in the evening."

Despite the severity of the side effects, she did not discuss discontinuing and waited for advice from the medical profession:

The problems I am experiencing with the uterus they still believe are tamoxifen induced so they are going to leave it up to the gynaecology department, but they think it might mean that I either consider a hysterectomy or change the tamoxifen that I am on. (Correspondence)

She described further, like WA, a profound loss of identity. She specified finding the growth of facial hair particularly upsetting: "especially following the chemo when you have no body hair. It is the extremes between the two and the fact I sometimes feel I could be mistaken for someone undergoing a gender change." She also expressed that she found the idea of having to continue with tamoxifen for another 5 years "daunting. (Correspondence)

BI and DE were of child bearing age when diagnosed with breast cancer. Preserving fertility in relation to taking tamoxifen⁶³ was a key issue for both. DE

⁶³ It is strongly advised that whilst taking tamoxifen women must not become pregnant as there are concerns over birth defects occurring. It is also possible that taking tamoxifen will affect fertility, so for

declined medical advice to take tamoxifen when it was offered to her as an additional precaution to her surgery, chemotherapy and radiotherapy:

They wanted me to have herceptin and tamoxifen and things like that but I wanted to have a baby if I still could possibly have a baby. So I declined the treatment. They had always along the way said that my cancer wasn't aggressive and they were giving me all the treatment they could as a precaution. They had taken cancer out, it wasn't spreading .. it was fine. And I thought I can't keep having everything a precaution because I will be here forever. That was going to take another five years out of my life and I just thought, what if? what if I don't get pregnant in that time and I get my cancer back? And I thought I am going to decline it. I've done enough and I wanted my life back in order. So I declined and got pregnant the next month six days after he was born while they were scanning me they found that my cancer had come back and was now in my spine.

DE now takes tamoxifen (and herceptin intravenously). She described how “you are stripped of your identity and ... you look in the mirror and that person is not you anymore. I have put on three stone that I cannot shift. No matter how hard I try. It is a problem of the medication that I am on.”

Tamoxifen featured in BI's representation. As a younger women diagnosed with breast cancer she faced a similar predicament to DE — that she would like to have a child. In posing the question “do I want to be 40 when I am trying for a baby?” she contemplated the recommended prescribed protocols:

what is the difference between three years and five years ... I don't know. I mean. It is certainly not something I will be trying to do any time soon, but it is something that is sort of in the back of my mind. It is not as if I can say right, lets start trying for a baby because I can't. I have to come off the tamoxifen — we have to wait for six months to get it out of my system then you start trying, then if you don't conceive do you go back on it? Do you want to be messed about .. and try fertility

women taking the drug there will be uncertainty about whether they will be able to become pregnant after treatment finishes. Cancer Research UK <http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/cancer-drugs/tamoxifen> [Accessed 6 November 2014]

treatment. I don't know. I am kind of still of the opinion that if it is meant to happen, it will happen naturally but er... I don't know ... I am just at the wrong age I suppose. If I was younger it probably wouldn't be as much of an issue. But just because of the way things have panned out for me I haven't got any children.

She cited that due to the tamoxifen she feels like a “decrepit old thing” — the weight gain, a rash on her arm, fatigue, and hot flushes. Her identity, she expressed was far from a young woman in her 30s. Furthermore, someone recently asked if her weight gain was due to the fact that she was pregnant.

BI conveyed concerns of breast cancer recurrence in her film and indeed faced the possibility that the cancer had spread at the start of filming.

BR had been taking tamoxifen for a year. The side effects had lessened, so much so that she no longer noticed them. However the drug — both its ability to stop cancer recurring and possible negative long-term effects still featured in her representation. BR understood the preventive effects of tamoxifen: impending menstruation triggered memories of the feelings in her breast that occurred prior to her diagnosis. She noted that “these pains have now stopped” and attributed this to “the tamoxifen blocking the hormones that were responsible for the changes.”

But nevertheless iterative concerns of recurrence are represented, with any reassurances transient:

I wonder if the cancer is going to recur. And then I reassure myself. No it's fine. ... there is no reason why it should come back. The conditions that it grew in have changed, I have treated it both on a homeopathic way through acupuncture and also through the ionopathic way with the tamoxifen so I am kind of doing belt and braces ... and I ... and ... feel reasonably confident that it will be OK, but you still don't know, you still don't know. And I kind of think, every now and then I think: is this the period of remission before it comes back and before I then die or or is this the rest of my life?

She wondered about stopping taking the drug, but is conflicted:

I don't want the cancer to come back and that is the fear of course and I wonder if I stopped taking the tamoxifen whether — you know — how much of a difference that would make, but I am a bit scared .. because you know what if I am wrong and it comes back? Then I'd really kick myself.

And had started to miss days that she takes it, citing a need for control over her body as a motivating factor:

I know it is only a stupid little thing — but it kind of makes me feel like I have got a hand in it, I have got some control over what is happening and I am not just under the dose, you know and it does seem like .. the acupuncturist thinks it is a high dose and I am only a very small person, and so I think day off a week hopefully is not going to kill me but it makes me feel better...

BR also articulated concerns of the long term effects:

..but I am worried about the long term effects what it may be doing to me that I just don't know about. And I may be worrying needlessly as often happens. ... I am worried that it is going to make me — this is stupid — old before my time. I don't even know if this is an effect of the medication. I am sticking with it for now though... it has been just over a year since I started taking it. Another four to go, if I do the whole five years.

Equally though, there was an ambivalence to stopping the prescribed course, “of course I can only take it for five years anyway, and after that I'm on my own”

EN experienced only negligible side effects on tamoxifen and attributed this to the specific brand that she was taking. Over a six month period of her filming she documented the difficulties she experienced and the lengths she had to go to in contacting manufacturers and negotiating with GPs to obtain her preferred brand. A process that was stressful and anxiety inducing:

When the surgery will not give a prescription for 10mg tamoxifen tablets I don't think they realise how much distress and upset it causes, how much worry and anxiety, and how it feels that suddenly everything is out of control. That the very thing I feel that I need to sustain my health and well being is being taken from me by the possibility of having to take another brand that will induce a range of unpleasant side effects.

Discussion

The experiences the participants chose to represent in their filmmaking show highly individual, complex and fluctuating relationships with tamoxifen. In the context of the research tamoxifen plays a significant ongoing role in the lives of those taking it.

The side effects reported by the participants do overlap with the findings of biomedical studies (Pellegrini 2010, Thomas Mclean 2005, Lash *et al.*, 2006, Fink 2004). However, what this research reveals is the extent to which tamoxifen impacted on the lives of those taking it, and the variation in decision making in response to side effects and other factors between individuals.

In terms of autonomous decision making processes in relation to cessation of recommended treatment participants did not necessarily share their concerns or plans with the medical profession before altering doses. Choosing to change prescribed doses was not related to severity of side effects for all. The profound way tamoxifen impacted on and modified WA and BE's life was made clear in their representations and communications. However, only WA chose to modify her drug dose (and has subsequently stopped taking it) in response to these side effects. BE was persisting (with dread) with the prescribed dosage. However, she faced the possibility of the drug being discontinued by the medical profession because of the changes it was causing to her endometrium. Whilst not reporting side effects in her representations, one participant, BR, was modifying her dose, citing a need for control over her body and fear of possible

long-term side effects as motivating factors. Thomas Mclean (2005) highlighted the loss of control over lives that illness can cause as being problematic (*ibid.*, p206).

As already described, fear of recurrence is a consistent finding within the wider literature, with Koch *et al.* (2014) citing a wide range of 25 - 97% in the medical literature. In my research 8/9 of all participants expressed concerns or fear of recurrence. However, in the individual reporting of those taking tamoxifen, knowledge of the benefits did not always impact directly on autonomous decision making to discontinue or modify dosages. Both WA and BR expressed clear knowledge of the benefits. This paradox was also found in Pellegrini's (2010) research, however, these participants seemed ultimately to accept the changes to their bodies caused by tamoxifen: the "changes and problems caused by the treatment were found to be neither uniformly or permanently distressing" (*ibid.*, p 478). It should be noted that the period of time of taking tamoxifen in this study was much longer (1 - 60 months) and they were an older cohort (35 - 64 years).

Issues surrounding fertility were described by the two participants of child-bearing age. DE declined the treatment, became pregnant and had her baby only to find she had developed secondary breast cancer, and BI was contemplating the effectiveness of persisting with the prescribed dose because, already in her mid 30s, she did not want to begin trying to get pregnant in her 40s.

Grunfeld *et al.*'s (2005) large cohort questionnaire led-study concluded that a relationship existed between the severity of side effects and adherence to prescribed protocols. In addition they concluded that knowledge of the preventive effects of tamoxifen was linked to adherence to prescribed dosages. Research focused at the level of the individual has demonstrated that the relationship between side effects and fear/concerns of recurrence was *far* more complex and discrete than any generalised conclusion implies.

Conclusion

Physicians do underestimate the extent of the impact that taking tamoxifen has on women's lives, as well as the individuality of responses to taking it. Educating women about the benefits of taking the drug may not improve adherence, or importantly quality of life for women. Similarly, addressing issues surrounding side effects may not impact on adherence to prescribed protocols. This is important data that may not be detected in questionnaires or clinic-based research.

There is a need for better communication between women prescribed tamoxifen and health care professionals. Early community-based, rather than clinic-based interventions at annual follow up, may help identify and support women who are struggling to adhere to and persist with dosing schedules.

BIBLIOGRAPHY

Abu-Lughod, L. (1991). Writing Against Culture. In: Fox, R. (ed.) *Recapturing Anthropology: Working in the Present*. Santa Fe: Santa Fe School of American Research Press, 466 – 497.

Agar, M. (1996). *The Professional Stranger: An Informal Introduction to Ethnography*. New York, NY: Academic Press.

Anderson, C. & Benson, T. W. (1988). Direct Cinema & the Myth of Informed Consent. In: Gross, L. et al. (eds.) *Image Ethics. The Moral Rights of Subjects in Photographs, Film & Television*. Oxford: Oxford University Press, 58 – 90.

Anton, S. (2003). A Thousand Words: Kutluğ Ataman Talks about 1+1=1. *Artform*. February.

Arman, M. & Rehnsfeldt, A. (2003). The Hidden Suffering Among Breast Cancer Patients: A Qualitative Metasynthesis. *Qualitative Health Research*. **13**(4), 510 – 527.

Armstrong-Coster, A. (2005). In Morte Media Jubilate [2]: A Study of Cancer-related Pathographies. *Mortality*. **10**(2), 97 – 112.

Armstrong-Coster, A. (2001). In Morte Media Jubilate [1]: An Empirical Study of Cancer-related Documentary Film. *Mortality*. **6**(3), 288 – 305.

Arnold, E. M. (1999). The Cessation of Cancer Treatment as a Crisis. *Social Work in Health Care*. **29**(2), 21 – 38.

Aronowitz, R. A. (2009). The Converged Experience of Risk & Disease. *Milbank Quarterly*. **87**(2), 417 – 442.

Aronowitz, R. A. (2001). Do Not Delay: Breast Cancer & Time, 1900 - 1970. *Milbank Quarterly*. **79**(3), 355 – 386.

Asch, T. (2000). The Ethics of Ethnographic Film-making. In: Crawford, P. & Turton, D. (eds.) *Film as Ethnography*. Manchester & New York: Manchester University Press, 196 – 204.

Asch, T. et al. (1991). The Story We Now Want to Hear is Not Ours to Tell: Relinquishing Control Over Representation: Toward Sharing Visual Communication Skills with the Yanomami. *Visual Anthropology Review*. **7**(2), 102 – 106.

Ataman, K. (2006). What is Kuba? In: Poljak, R. (ed) *Journey Against the Current*. Vienna, Thyssen-Bornemisza Art Contemporary. New York: Springer Wien, 21

Ataman, K. (2004). Interviewed with Sarah Greenberg. The Story Teller. *The Royal Academy of Arts Magazine*. Winter (85), 54 – 55.

Ataman, K. (2003a). *Kuba transcript*. Artangel Archives. [Accessed 7/6/13].

Ataman, K. (2003b). Interview with Martin Herbert. *Screentherapy, Art Review*. February, 71.

http://www.kutlugataman.com/uploads/KA_ArtReviewFeb2008_web.pdf
[Accessed 2/6/13]

Ataman, K. & Zyman D. (2006). Life as a Metaphor. In: Poljak, R. (ed) *Journey Against the Current*. Vienna, Thyssen-Bornemisza Art Contemporary. New York: Springer Wien, 26 – 31.

ATLAS, (2013). Long-term Effects of Continuing Adjuvant Tamoxifen to 10 years versus Stopping at 5 Years after Diagnosis of Oestrogen Receptor-positive Breast Cancer: ATLAS, A Randomised Trial. *The Lancet*. **381** (9869), 805 – 816.

Atkinson, P. & Silverman, D. (1997). Kundera's Immortality: The Interview Society & the Invention of the Self. *Qualitative Inquiry*. **3**(3), 304 – 325.

Aufderheide, P. (2008). "You See the World of the Other & You Look at Your Own": The Evolution of the Video in the Villages Project. *Journal of Film & Video*. **60**(2), 26 – 34.

Aufderheide, P. (1995). The Video in the Villages Project. Videomaking with & by Brazilian Indians. *Visual Anthropology Review*. **11**(2), 83 – 93.

Aull Davies, C. (2008). *Reflexive Ethnography. A Guide to Researching Self & Others*. 2nd ed. Oxford & New York: Routledge.

BABS Project, (2009).

http://www.breastcancercare.org.uk/sites/default/files/files/pdf/microsoft_word_-_older_women_executive_summary.pdf0 [Accessed 1 July 2013]

Badger, M. B. & Balikci, A. (1993). Towards a Native Visual Ethnography in Siberia. *The Polar Record*. **29**(169), 145 – 148.

Bal, M. (2002). *Travelling Concepts in the Humanities. A Rough Guide*. Toronto, Buffalo, London: University of Toronto Press.

Balsom, E. (2013). *Exhibiting Cinema in Contemporary Art*. [online] Amsterdam: University of Amsterdam Press. OAPEN <http://library-collections-search.westminster.ac.uk>. [Accessed 2 January 2014]

Banks, M. (2001). *Visual Methods in Social Research*. London, Thousand Oaks & New Delhi: Sage Publications.

Banks, M. (1992). Which Films are the Ethnographic Films? In: Crawford P. & Turton, D. (eds.) *Film as Ethnography*. Manchester & New York: Manchester University Press, 116 – 130.

Barbash, L. & Taylor, L. (1997). *Cross-Cultural Filmmaking: A Handbook for Making Documentary and Ethnographic Films and Videos*. Berkeley & Los Angeles: University of California Press.

Barnes, D. B. *et al.* (1997). “I Didn’t Leave Y’all on Purpose”: HIV-infected Mothers’ Videotaped Legacies for their Children. *Qualitative Sociology*. **20**(1), 7 - 32

Barron, T. I. *et al.* (2007). Early Discontinuation of Tamoxifen. A Lesson for Oncologists. *Cancer*. **109**(5), 832 - 839

Basu, P. (2009). Reframing Ethnographic Film. In: Austin, T. & de Jong, W. (eds.) *Rethinking Documentary. New Perspectives, New Practices*. Berkshire & New York: Open University Press, 95 – 107.

Basu, P. & Macdonald, S. (2007). Introduction: Experiments in Exhibition, Ethnography, Art, and Science. In: Macdonald, S. & Basu, P. (eds.) *Exhibition Experiments*. Oxford: Blackwell, 1 – 24.

Bayraktar, N. (2012). Location & Mobility in Kutluğ Ataman’s Site Specific Video Installation, Kuba. In: Hake, S. & Mennel, B. (eds.) *Turkish Cinema in the New Millennium: Sites, Sounds & Scenes*. New York: Berghahn Books, 84 – 95.

Bear, L. (2007). The Politics of Display: Ann-Sofi Sidén’s *Warte Mal!* Art History & Social Documentary. In: MacDonald, S. & Basu, P. (eds.) *Exhibition Experiments*. Oxford: Blackwell, 158 - 161, 171.

Becker, G. (1997). Mediating Disruption. In: Becker, G. (ed.) *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkley, Los Angeles & London: University of California Press, 1 – 24.

Behar, R. (1996). *The Vulnerable Observer*. Boston: Beacon Press.

Bell, K. (2013). Biomarkers, the Molecular Gaze & the Transformation of Cancer Survivorship. *Biosocieties*. **8**(2), 124 – 143.

Bell, R. J. *et al.* (2010). Psychological Well-being in a Cohort of Women with Invasive Breast Cancer Nearly 2 Years after Diagnosis. *Support Care Cancer*. **18** (8), 921– 929.

Bell, S. E. (2002). Photo Images: Jo Spence's Narratives of Living with Illness. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine*. **6**(1), 5 – 30.

Bellman, B. L. & Benetta, J. R. (1977). *A Paradigm for Looking: Cross Cultural Research with Visual Media*. Norwood, New Jersey: Ablex Publishing Corporation.

Bennett, C. (2012). What Is It, Participatory? UK Visual Anthropology. <http://ukvisualanthropology.com/2012/07/17/what-is-it-participatory/> [Accessed 15 May 2013].

Berland. G. (2007). The View from the Other Side - Patients, Doctors, & the Power of the Camera. *New England Journal of Medicine*. **357**(25), 2533 – 2536.

Biella, P. (2009). Visual Anthropology in a Time of War: Intimacy and Interactivity in Ethnographic Media. In: Strong, M. & Wilder, L. (eds.) *Viewpoints: Visual Anthropologists at Work*. Austin: University of Texas Press, 141 – 179.

Blumenthal, D. (1999). Representing the Divided Self. *Qualitative Inquiry*. **5**(3), 377 – 392.

Boon, T. (2008). *Films of Fact. A History of Science in Documentary Film & Television*. London & New York: Wallflower Press.

Boon, T. (2005). Health Education Films in Britain, 1919 - 39: Production, Genres, Audiences. In: Harper, G. & Moor, A. (eds.) *Signs of Life. Medicine & Cinema*. London: Wallflower Press, 45 – 57.

Bredin, M. (1999). Mastectomy, Body Image & Therapeutic Massage: A Qualitative Study of Women's Experience. *Journal of Advanced Nursing*. **29**(5), 1113 – 1120.

Brennan, J. & Moynihan, C. (2004). *Cancer in Context: A Practical Guide to Supportive Care*. Oxford & New York: Oxford University Press.

Bruzzi, S. (2006). *New Documentary*. Second Edition. London & New York: Routledge.

Butler, J. (1993). *Bodies That Matter. On the Discursive Limits of "Sex"*. London & New York: Routledge.

Buchbinder, M. H. *et al.* (2005). Assessing Adolescents with Insulin-dependent Diabetes Mellitus: A Multiple Perspective Pilot Study Using Visual Illness Narratives & Interviews. *Journal of Adolescent Health*. **36**(1), 71.e, 9 -13

Cancer Research UK, <http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/cancer-drugs/tamoxifen>. [Accessed 10 January 2015]

Cantor, D. (2009). Choosing to Live: Cancer Education, Movies, and the Conversion Narrative. *Literature & Medicine*. **28**(2), 278 – 332.

Cantor, D. (2007). Uncertain Enthusiasm: The American Cancer Society, Public Education, & the Problems of the Movie, 1921-1960. *Bulletin of the History of Medicine*. **81**(1), 39 – 69.

Carelli, V. (1988). Video in the Villages: Utilization of Videotapes as an Instrument of Ethic Affirmation among Brazilian Indian Groups: Un instrument de Reaffirmation Ethnique. *CVA Newsletter*. May, 10 – 15.

Carolyn, C. (2007). The Politics of Display: Ann-Sofi Sidén's *Warte Mal!* Art History & Social Documentary. In: MacDonald, S. & Basu, P. (eds) *Exhibition Experiments*. Oxford: Blackwell, 161 – 164, 171 – 174.

Carolyn, C. & Haynes, C. (2007). The Politics of Display: Ann-Sofi Sidén's *Warte Mal!* Art History & Social Documentary. In: MacDonald, S. & Basu, P. (eds) *Exhibition Experiments*. Oxford: Blackwell, 154 – 156.

Chalfen, R. (1997). Afterward. In: Worth, S. & Adair, J. (eds.) *Through Navajo Eyes. An Exploration in Film Communication & Anthropology*. Revised edition. Albuquerque: University of New Mexico Press, 275 – 341.

Chalfen, R. (1989). Native Participation in Visual Studies: From Pine Springs to Philadelphia. In: Boonzaier Flaes, R. M. (ed.) *Eyes Across the Water: The Amsterdam Conference on Visual Anthropology & Sociology*. Amsterdam: Het Spinhuis, 71 – 79.

Chalfen, R. (1981). A Sociovidistic Approach to Children's Filmmaking: The Philadelphia Project Report. *Studies in Visual Communication*. **7** (1), 2 – 33.

Chalfen, R. *et al.* (2010). VIA's Visual Voices: The Awareness of a Dedicated Audience for Voices in Patient Video Narratives. *Visual Studies*. **25**(3), 201 – 209.

Chalfen, R. & Hayley, J. (1971). Reaction to Socio-documentary Film Research in a Mental Health Clinic. *American Journal of Orthopsychiatry*. **41**(1), 91 – 100.

Chalfen, R. & Rich, M. (2009). Combining the Applied, the Visual & the Medical.

Patients Teaching Physicians with Visual Narratives. In: Pink, S. (ed.) *Visual Interventions. Applied Anthropology*. New York & Oxford: Berghahn Books, 53 – 70.

Clarke, A. (2012). Visual Ethics in a Contemporary Landscape. In: Pink, S. (ed.) *Advances in Visual Methodology*. London: Sage, 17 – 35.

Clark, J. *et al.* (2010). Ethical Issues in Image-based Research. *Arts & Health: An International Journal for Research, Policy and Practice*. **2**(1), 81 – 93.

Cleary, E. H. & Stanton, A. L. (2014). Mediators of an Internet-Based Psychosocial Intervention for Women with Breast Cancer. *Health Psychology*. E-publication ahead of print. <http://www.ncbi.nlm.nih.gov/pubmed/25401686> [Accessed 2 January 2014]

Clifford, J. (1992). Traveling Cultures. In: Grossberg, L. *et al.* (eds.) *Cultural Studies*. New York & Oxford: Routledge, 96 – 116.

Conrad, P. (2007). *The Medicalization of Society. On The Transformation of Human Conditions into Treatable Disorders*. Baltimore: The John Hopkins University Press.

Couser, G. T. (1997). *Rediscovering Bodies. Illness, Disability & Life Writing*. Wisconsin & London: The University of Wisconsin Press.

Cowie, E. (2009). On Documentary Sounds & Images in the Gallery. *Screen*. **50**(1), 124 – 134.

Crawford, P. (1995). Nature & Advocacy in Ethnographic Film: The Case of Kayapo Imagery. In: Philipsen, H. H. & Markussen, B. (eds.) *Advocacy & Indigenous Filmmaking*. Denmark: Intervention Press, 7 – 22.

Cuzick, J. *et al.* (2015). Tamoxifen for Prevention of Breast Cancer: Extended Long-term Follow-up of the IBIS-I Breast Cancer Prevention Trial. *The Lancet*. **16**(1), 67 – 75.

Davis, E. (2008). Risky Business: Medical Discourse, Breast Cancer & Narrative. *Qualitative Health Research* **18**(1), 65 – 76.

de Brigard, E. (2003). The History of Ethnographic Film. In: Hockings, P. (ed.) *Principles of Visual Anthropology*. 3rd Ed. Berlin: Mouton de Gruyter, 13 – 43.

Department of Health. (2011). http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4124294 [Accessed November 2011]

DiGiacomo, S. M. (1992). Metaphor as Illness: Postmodern Dilemmas in the Representation of Body, Mind & Disorder. *Medical Anthropology*. **14**(1), 109 – 137.

Dinsmore, S. (1996). Strategies for Self Scrutiny. Video Diaries 1990 – 1993. In: MacCabe, C. & Petrie, D. (eds.) *New Scholarship from BFI Research*. London: British Film Institute, 41 – 57.

Douglass, C. *et al.* (2013). Patients as Authors. NCRI Cancer Conference; 3-6 November 2013; Liverpool.

http://abstracts.ncri.org.uk/?s=authors&sess_type=poster-sessions&year_published=2013

Douglass, C. *et al.* (2014). Shared Visual Anthropology & Breast Cancer: Experiences & Perceptions of Tamoxifen Therapy in the Social Context of Women's Lives. NCRI Cancer Conference; 2-5 November 2014; Liverpool.
http://abstracts.ncri.org.uk/?s=tamoxifen&sess_type=poster-sessions&year_published=2014

Dovey, J. (2000). *Freakshow: First Person Media & Factual Television*. London: Pluto Press.

Dow, K. H. & Lafferty, P. (2000). Quality of Life, Survivorship & Psychosocial Adjustment of Young Women with Breast Cancer after Breast Conserving Surgery & Radiation therapy. *Oncology Nursing Forum*. **27**(10), 1555 – 1564.

Duncombe, J. & Jessop, J. (2012). 'Doing Rapport' and the Ethics of Faking Friendship. In: Miller, T. *et al.* (eds.) *Ethics in Qualitative Research*. 2nd edition. Los Angeles, London, New Delhi, Singapore, Washington DC: Sage, 108 – 121.

Early Breast Cancer Trialists' Collaborative Group (EBCTCG). (2011). Relevance of Breast Cancer Hormone Receptors & Other Factors to the Efficacy of Adjuvant Tamoxifen: Patient-level Meta-analysis of Randomised Trials. *Lancet*. **378**(9793), 771 – 784.

Eaton, M. (1979a). Chronicle. In: Eaton, M. (ed.) *Anthropology. Reality, Cinema: The Films of Jean Rouch*. London: British Film Institute, 1 – 34.

Eaton, M. (1979b). The Production of Cinematic Reality. In: Eaton, M. (ed.) *Anthropology. Reality, Cinema: The Films of Jean Rouch*. London: British Film Institute, 40 – 53.

EBCTCG. (2011). Relevance of Breast Cancer Hormone Receptors and Other Factors to the Efficacy of Adjuvant Tamoxifen: Patient-level Meta-analysis of Randomised Trials. *The Lancet*. **378**(9793), 771 – 84.

Ehlers, N. (2012). *Tekhne of Reconstruction: Breast Cancer, Norms, and Fleshy Rearrangements. Social Semiotics. 22*(1), 121 – 141.

Ehlers, N. & Krupar, S. (2012). The Body in Breast Cancer. *Social Semiotics. 22*(1), 1 – 11.

Elder, S. (1995). Collaborative Filmmaking: An Open Space for Making Meaning, A Moral Ground for Ethnographic Film. *Visual Anthropology Review. 11*(2), 94 – 101.

Elwood, S. E. & Martin D. G. (2000). Placing Interviews: Location & Scales of Power in Qualitative Research. *The Professional Geographer. 52*(4), 649 – 657

Essex-Lopresti, M. (1997). Centenary of the Medical Film. *The Lancet. 349*(9055), 819 – 820.

Fallowfield, L. & Clark, A. (1991). *Breast Cancer*. London: Routledge.

Farris, J. C. (2000). Anthropological Transparency: Film, Representation & Politics. In: Crawford, P. & Turton, D. (eds.) *Film as Ethnography*. Manchester: Manchester University Press, 171 – 182.

Feld, S. (2003). Editor's Introduction. In: Feld, S. (ed.) *Cine-Ethnography. Jean Rouch*. Minneapolis & London: University of Minnesota Press, 1 – 25.

Fink, A. K. *et al.* (2004). Patient Beliefs & Tamoxifen Discontinuance in Older Women with Oestrogen Receptor-positive Breast Cancer. *Journal of Clinical Oncology. 22*(16), 3309 – 3315.

Fleck, R. (2002). *Wart Mal! (Hey Wait!)*. In: Sidén, A. S. (ed.) *Warte Mal! Prostitution After the Velvet Revolution*. London: Hayward Gallery, 128 – 139.

Fosket, J. (2000). Problematising Breast Cancer: Women's Constructions of Breast Cancer Knowledge. In: Potts, L.K. (ed.) *Ideologies of Breast Cancer*. Basingstoke: Macmillan Press Ltd.

Fontana, A. & Frey, J. H. (2005). The Interview: From Neutral Stance to Political Involvement. In: Denzin, N. K. & Lincoln, Y. S. (eds.) *The SAGE Handbook of Qualitative Research*. 3rd ed. London: Sage Publications, 695 – 727.

Foucault, M. (2003). *The Birth of the Clinic. An Archaeology of Medical Perception*. Oxford: Routledge Classics.

Foucault, M. (1998). *The Will to Knowledge. The History of Sexuality: 1*. New York: Pantheon Books.

Foucault, M. (1994a). The Politics of Health in the Eighteenth Century. In: Faubion, J. D. (ed.) *Michel Foucault. Power. Essential Works of Foucault 1954 - 1983*. London: Penguin Books, 90 – 105.

Foucault, M. (1994b). Questions of Method. In: Faubion, J. D. (ed.) *Michel Foucault. Power. Essential Works of Foucault 1954 - 1983*. London: Penguin Books, 223 – 238.

Foucault, M. (1991). *Discipline & Punish. The Birth of the Prison*. London: Penguin Books.

Fowler, C. (2004). Room for Experiment: Gallery Films & Vertical Time from Maya Deren to Eija Liisa Ahtila. *Screen*. **45**(4), 324 - 334.

Frank, A. W. (1995). *The Wounded Storyteller. Body, Illness & Ethics*. Chicago: University of Chicago Press.

Fuchs, P. (1988). Ethnographic Film in Germany: An Introduction. *Visual Anthropology*. **I**(3), 217 – 233.

Ganz, P. A. *et al.* (2008). Ensuring Quality Care for Cancer Survivors: Implementing the Survivorship Care Plan. *Seminars in Oncology Nursing*. **24**(3), 208 – 217.

Garofalo, J. P. *et al.* (2009). Uncertainty During the Transition from Cancer Patient to Survivor. *Cancer Nursing*. **32**(4), E8 - E14.

Greene, L. (2013). Placing the Three Bernadettes: Audio-visual Representations of Bernadette Devlin McAliskey. In: Daniels, J. *et al.* (ed.) *Truth, Dare or Promise. Art & Documentary Revisited*. Newcastle: Cambridge Scholars Publishing, 112 – 134.

Gade, R. & Jerslev, A. (2005). Introduction. In: Gade, R. & Jerslev, A. (eds.) *Performative Realism: Interdisciplinary Studies in Art & Media*. Copenhagen: Museum Tusculanum Press, 7 – 17.

Gardner, K. E. (2006). *Early Detection: Women, Cancer & Awareness Campaigns in the Twentieth Century United States*. Chapel Hill: The University of North Carolina Press.

Geertz, C. (2000). Thick Description: Toward an Interpretive Theory of Culture. *The Interpretation of Cultures*. New York: Basic Books, 3 – 30.

Gibson, B.E. (2005). Co-producing Video Diaries: The Presence of the Absent Researcher. *International Journal of Qualitative Methods*. **4**(4), 34 – 43.

Gillies, V. & Alldred, P. (2002). The Ethics of Intention: Research as a Political Tool. In: Mauthner, M. *et al.* (eds.) *Ethics in Qualitative Research*. London: Sage, 32 – 52.

Ginsburg, F. D. (2002). Screen Memories. Resignifying the Traditional in Indigenous Media. In: Ginsburg, F. *et al.* (eds.) *Media Worlds. Anthropology on New Terrain*. Berkeley, Los Angeles & London: University of California Press, 39 – 57.

Ginsburg, F. D. (1998). Institutionalizing the Unruly: Charting a Future for Visual Anthropology. *Ethnos: Journal of Anthropology*. **63**(2), 173 – 201.

Ginsburg, F. D. (1995). The Parallax Effect: The Impact of Aboriginal Media on Ethnographic Film. *Visual Anthropology Review*. **11**(2), 64 – 76.

Ginsburg, F. D. (1993). Aboriginal Media & the Australian Imaginary. *Public Culture*. **5**(3), 557 – 578.

Ginsburg, F. D. (1991). Indigenous Media: Faustian Contract or Global Village. *Cultural Anthropology*. **6**(1), 92 – 112.

Griffiths, F. D. *et al.* (2010). Screening for Breast Cancer: Medicalization, Visualization & the Embodied Experience. *Health (London)*. **14**(6), 653 – 668.

Grimshaw, A. & Ravetz, A. (2005). *Visualizing Anthropology*. Bristol & Portland: Intellect.

Grunfeld, E.A. *et al.* (2005). Adherence Beliefs Among Breast Cancer Patients Taking Tamoxifen. *Patient Education & Counseling*. **59**(1), 97–102.

Hammersley, M. & Atkinson, P. (2007). Oral Accounts & the Role of Interviewing. In: Hammersley, M. & Atkinson, P. (eds.) *Ethnography Principles in Practice*. London: Routledge, 97 – 120.

Heider, K. G. (2006). Introduction. In: Heider, K. G. (ed.) *Ethnographic Film*. Austin: University of Texas Press, 1- 14.

Herzog, H. (2005). On Home Turf: Interview Location & Its Social Meaning. *Qualitative Sociology*. **28**(1), 25 – 47.

Henley, P. (2009). *The Adventure of the Real. Jean Rouch & the Craft of Ethnographic Cinema*. Chicago & London: The University of Chicago Press.

Henley, P. (2000). Ethnographic Film: Technology, Practice & Anthropological Theory. *Visual Anthropology*. **13**(2), 207 – 226.

Hockings, P. (2003). *Principles of Visual Anthropology*. 3rd ed. Berlin & New York: Mouton de Gruyter.

Hogan, S. (2012). *Revisiting Feminist Approaches to Art Therapy*. New York and Oxford: Berghahn Books, 13 – 38.

Hogan, S. (2003). A Discussion of the Use of Art Therapy with Women who are Pregnant or who have Recently Given Birth. In: Hogan, S. (ed.) *Gender Issues in Art Therapy*. London & Philadelphia: Jessica Kingsley Press, 148 – 172.

Hogan, S. & Pink, S. (2012). Visualising Interior Worlds: Interdisciplinary Routes to Knowing. In Pink, S. (ed.) *Advances in Visual Methodology*. Los Angeles, London, New Delhi, Singapore, Washington DC: Sage, 230 – 247.

Hogan, S. & Warren, L. (2012). Dealing with Complexity in Research Processes & Findings: How Do Older Women Negotiate & Challenge Images of Aging? *Journal of Women & Aging*. **24**(4), 329 – 350.

Holaday, D.A. (1991). Self-presentation to Majority Others - Toward Media Anthropology. *CVA Review* (Spring), 4 – 6.

Holliday, R. (2009). Reflecting the Self. In: Knowles, C. & Sweetman, P. (eds.) *Picturing the Social Landscape: Visual Methods & the Sociological Imagination*. London & New York: Routledge, 49 – 64.

Holliday, R. (2004). Filming “The Closet”: The Role of Video Diaries in Researching Sexualities. *American Behavioural Scientist*. **47**(12), 1597 – 1616.

Holliday, R. (2000). We've Been Framed: Visualising Methodology. *The Sociological Review*. **48**(4), 503 – 521.

Horrigan, B. (2005). Kuba. Si!
http://www.artangel.org.uk/projects/2005/kuba/bill_horrigan_kueba_si/bill_horrigan_kueba_si [Accessed 17/4/13]

Hunsaker-Hawkins, A. (1999). Introduction. In: Hunsaker-Hawkins, A. (ed.) *Reconstructing illness: Studies in Pathography*. 2nd ed. West Lafayette, Indiana: Purdue Research Foundation, 1 – 30.

Hunsaker-Hawkins, A. (1992). Restoring the Patient's Voice: The Case of Gilda Radner. *The Yale Journal of Biology & Medicine*. **65**(3), 173 – 181.

Hubbard, P. (2003). In the Border-zone: Warte Mal! – A Video Installation by Ann-Sofi Sidén. *Cultural Geographer*. **10**(1), 112 – 119.

Hyden, L. C. (1997). Illness & Narrative. *Sociology of Health & Illness*. **19**(1), 48 – 69.

Illich, I. (1976). *Medical Nemesis. The Exploration of Health*. London: Marion Boyars.

Independent UK Panel on Breast Screening, (2012). The Benefits & Harms of Breast Cancer Screening: An independent Review. *The Lancet*. **380**(9855), 1778 – 1786.

Irving, A. (2010). Dangerous Substances & Visible Evidence: Tears, Blood, Alcohol, Pills. *Visual Studies*. **25**(1), 24 – 35.

Irving, A. (2007). Ethnography, Art & Death. *Journal of the Royal Anthropological Institute*. **13**(1), 185 – 208.

Jack, R. H. *et al.* (2009). Breast Cancer Incidence, Stage, Treatment & Survival in Ethnic Groups in South East England. *British Journal of Cancer*. **100**(3), 545 – 560.

Jay, D. (2012a). The Scar Project. <http://www.thescarproject.org/> [Accessed 10 October 2014]

Jay, D. (2012b). The Scar Project. *Social Semiotics*. **22**(1), 39 – 46.

Jerslev, A. (2005). Performativity & Documentary. Sami Saif's and Phie Ambo's *Family* and Performativity. In: Gade, R. & Jerslev, A. (eds.) *Performative Realism: Interdisciplinary Studies in Art & Media*. Copenhagen: Museum Tusculanum Press, University of Copenhagen, 85 – 116.

Jhala, J. (1998). The Shaping of Gujarati Cinema: Recognizing the New in Traditional Cultures. *Visual Anthropology*. **11**(4), 373 – 385.

Juhasz, A. (2003). No Woman Is an Object: Realising the Feminist Collaborative Video. *Camera Obscura*. **18**(3), 70 – 97.

Juhasz, A. (1999). They Said We Were Trying to Show Reality - All I Want to Show is My Video. In: Gaines, J. M. & Renov, M. (eds.) *Collecting Visible Evidence*. Minneapolis: University of Minnesota Press, 190 – 216.

Juhasz, A. (1995). *AIDS TV: Identity, Community & Alternative Video*. Durham & London: Duke University Press.

Kaminsky, M. (1992). Myerhoff's "Third Voice": Ideology & Genre in Ethnographic Narrative. *Social Text*. **33**, 124 – 144.

Keighron, P. (1993). Video Diaries: What's Up Doc? *Sight & Sound*. **3**(10), 24 – 25.

Kennedy, T. (1989). Community Animation - An Open-ended Process. *Media Development*. **3**, 5 – 7.

Kilborn, R. W. (1998). Shaping the Real. Democratization & Commodification in UK Factual Broadcasting. *European Journal of Communication*. **13**(2), 201 – 218.

Klawiter, M. (2008). *The Biopolitics of Breast Cancer*. Minneapolis & London: University of Minnesota Press.

Kleinman, A. (1988). *The Illness Narratives. Suffering, Healing & the Human Condition*. New York: Basic Books.

Kleinman, A. *et al.* (1978). Culture, Illness, & Care: Clinical Lessons from Anthropological & Cross-cultural Research. *Annals of Internal Medicine*. **88**(2), 251 – 258.

Koch, L. *et al.* (2014). Fear of Recurrence in Long-term Breast Cancer Survivors - Still an Issue. Results on Prevalence, Determinants, & the Association with Quality of Life & Depression from the Cancer Survivorship - A Multi-regional Population-based Study. *Psycho-oncology*. **23** (5), 547 – 554.

Kuhn, A. (1988). A Moral Subject. In: Kuhn, A. (ed.) *Cinema, Censorship & Sexuality 1909 - 1925*. London & New York: Routledge, 49 – 74.

Kuhn, T. (1962 [1996]). *The Structure of Scientific Revolutions*. Third Edition. Chicago & London: Chicago Press.

Kuipers, J. C. (1989). Medical Discourse in Anthropological Context: Views of Language & Power. *Medical Anthropology Quarterly*. **3**(2), 99 – 123.

Lammer, C. (2009a). Empathographies: Using Body Art Related Video Approaches in the Environment of an Austrian Teaching Hospital. *International Journal of Multiple Research Approaches*. **3**(3), 264 – 275.

Lammer, C. (2009b). Bodywork: Social Somatic Interventions in the Operating Theatres of Invasive Radiology. In: Pink, S. (ed.) *Visual Interventions. Applied Visual Anthropology*. New York & Oxford: Berghahn Books, 91 – 116.

Lansing, S. (1990). The Decolonization of Ethnographic Film. In: Boonzajer Flaes, R.M. (ed.) *Eyes across the Water. The Amsterdam Conference on Visual Anthropology & Sociology*. Amsterdam: Het Spinhuis, 10 – 17.

- Lash, T. L. *et al.* (2006). Adherence to Tamoxifen over the Five-year Course. *Breast Cancer Research & Treatment*. **99**(2), 215 - 220
- Lebow, A. (2007). Worldwide Wigs: Kutluğ Ataman & the Global Art Documentary. *Arab Studies Journal*. **Fall 2007/Spring 2008**, 57 – 82.
- Light, R. & Henio, B. (1977). The Role of Media in Ramah Navajo Society. *Audio Visual Instruction*. **27**(10), 10 - 12, 45.
- Lorde, A. (2000). *The Collected Poems of Audre Lorde*. New York & London: Norton.
- Lorde, A. (1997). *The Cancer Journals*. Special Edition. San Francisco: Aunt Lute Books.
- Lorde, A. (1988). *A Burst Of Light: Essays by Audre Lorde*. London: Sheba.
- Low, C. (2010). Grierson & Challenge for Change. In: Waugh, T. *et al.* (eds.) *Activist Documentary at the National Film Board of Canada*. Montreal-Kingston: McGill-Queen's University Press, 16 – 23.
- Luschin, G. & Habersack, M. (2014). Oral Information About Side Effects of Endocrine Therapy for Early Breast Cancer Patients at Initial Consultation & First Follow-Up Visit: An Online Survey. *Health Communication*. **29**(4), 421 – 426.
- Macauley, D. (2010). The SCAR Project: Surviving Cancer. Absolute Reality. *British Medical Journal*. <http://blogs.bmj.com/bmj/2010/11/05/domhnall-macauley-the-scar-project-surviving-cancer-absolute-reality/> [Accessed 10 October 2013]
- MacClancey, J. (1995). Brief Encounter: The Meeting, in Mass-Observation, of British Surrealism & Popular Anthropology. *Journal of the Royal Anthropological Institute*. **1**(3), 495 – 512.
- Macdonald, K. (2006). By No Half-measure. In: Macdonald, K. & Cousins, M. (eds.) *Imagining Reality*. London: Faber & Faber, 390 – 393.
- MacDougall, D. (2006a). The Visual in Anthropology. In: MacDougall, D. (ed.) *The Corporeal Image*. Princeton & Oxford: Princeton University Press, 213 – 226.
- MacDougall, D. (2006b). New Principles of Visual Anthropology. In: MacDougall, D. (ed.) *The Corporeal Image*. Princeton & Oxford: Princeton University Press, 264 – 274.
- MacDougall, D. (2006c). The Body in Cinema. In: MacDougall, D. (ed.) *The*

Corporeal Image. Princeton & Oxford: Princeton University Press, 13 – 31.

MacDougall, D. (2003). Beyond Observational Cinema. In: Hockings, P. (ed.) *Principles of Visual Anthropology*. 3rd edition. Berlin & New York: Mouton de Gruyter, 115 – 130.

MacDougall, D. (1999). When less is less: The Long Take in Documentary. In: Henderson, B. & Martin, A. (eds.) *Film Quarterly: Forty Years - A Selection*. Berkeley: University of California Press, 291 – 305.

MacDougall, D. (1998). *Transcultural Cinema*. New Jersey: Princeton University Press.

MacDougall, D. (1978). Ethnographic Film: Failure & Promise. *Annual Review of Anthropology*. 7, 405-425.

Mahler, E. L. (1982). Anomic Aspects of Recovery from Cancer. *Social Science & Medicine*. 16(8), 907 – 912.

Mairs-Dyer, J. (2013). *Audiovisual Storytelling in Post-conflict Northern Ireland – Participant and Audience Responses to Filming, Editing and Exhibiting Memories of the Troubles via Two Practice-led Collaborative Documentary Film Productions*. Ulster: Faculty of Arts, University of Ulster.

Mak, M. (2012). Visual Postproduction in Participatory Video Making. In: Milne, E. J. et al. (eds.) *Handbook of Participatory Video*. New York: Alta Mira Press, 194 – 207.

Makubate, B. et al. (2013). Cohort Study of Adherence to Adjuvant Endocrine Therapy, Breast Cancer Recurrence & Mortality. *British Journal of Cancer*. **108**(7), 1515 – 1524.

Marcus, G. E. & Fischer, M. M. J. (1986). A Crisis of Representation in the Human Sciences. In: Marcus, G. E. & Fischer, M. M. J. (eds.) *Anthropology as Cultural Critique*. Chicago & London: The University of Chicago Press, 7 – 17.

Martin, R. (2012). Looking & Reflecting: Returning the Gaze, Re-enacting Memories & Imagining the Future through Re-enactment Phototherapy. In: Hogan, S. (ed.) *Revisiting Feminist Approaches to Art Therapy*. New York & Oxford: Berghahn Books, 112 – 139.

Martin, R. (2001). The Performative Body: Phototherapy & Re-enactment. *Afterimage*. Nov - Dec. http://www.rosymartin.info/performative_body.html [Accessed: August 4 2014]

McCowan, C. et al. (2013). The Value of High Adherence to Tamoxifen in

Women with Breast Cancer: A Community-based Cohort Study. *British Journal of Cancer*. **109**(5), 1172 – 1180.

McKinley, E. D. (2000). Under Toad Days: Surviving the Uncertainty of Cancer Recurrence. *Annals of Internal Medicine*. **133**(6), 479 – 480.

McLaughlin, C. (2010). *Recording Memories from Political Violence: A Film-makers Journey*. Bristol & Chicago: Intellect.

McLaughlin, C. (2006). Inside Stories, Memories from the Maze & Long Kesh Prison. *Journal of Media Practice*. **7**(2), 123 – 133.

McLaughlin, C. (2003). Collaboration as Research: Testimonies from the Apartheid Era. *Journal of Media Practice*. **3**(3), 171 – 177.

Mead, M. (2003). Visual Anthropology in a Discipline of Words. In: Hockings, P. (ed.) *Principles of Visual Anthropology*. 3rd edition. Berlin & New York: Mouton de Gruyter, 3 – 10.

Michaels, E. (1985). How Video has Helped a Group of Aborigines in Australia. *Media Development*. **1**, 16 – 18.

Michaels, E. & Kelly, F. J. (1984). The Social Organisation of an Aboriginal Video Workplace. *Australian Aboriginal Studies*. **1**, 26 – 34.

Miller, L. J. *et al.* (2002). Through Medical Eyes: The Medicalization of Women's Bodies & Women's Lives. In: Bolaria B.S, & Dickenson H.D.(eds.) *Health, Illness & Health Care in Canada*. 3rd edition. Toronto: Harcourt Brace, 185 – 210.

Minh-ha, Trinh, T. (1999). *Cinema Interval*. London: Routledge.

Minh-ha, Trinh, T. (1991). *When The Moon Waxes Red: Representation, Gender & Cultural Practices*. New York: Routledge.

Mishler, E. G. (1984). Introduction: The Medical Interview and Clinical Practice. In: Mishler, E. G. (ed.) *The Discourse of Medicine: Dialectics of Medical Interviews*. Norwood NJ: Ablex, 1 – 16.

Mishler, E. G. (1981). Critical Perspectives on the Biomedical Model & the Social Construction of Illness. In: Mishler, E. G. *et al.* (eds.) *Social Contexts of Health & Illness & Patient Care*. Cambridge: Cambridge University Press, 141 – 168.

Moore, R. (1994). Marketing Alterity. In: Taylor, L. (ed.) *Visualising Theory. Selected Essays from Visual Anthropological Review, 1990 - 1994*. New York & Abingdon: Routledge, 126 – 139.

Morin, E. (2003). Chronicle of a Film. In: Feld, S (ed. & trans). *Cine-Ethnography Jean Rouch*. Minneapolis & London: University of Minnesota Press, 229 – 265.

Moyer, A. *et al.* (2012). Mediators of Change in Psycho-social Interventions for Cancer Patients: A Systematic Review. *Behavioral Medicine*. **38**(3), 90 – 114.

Murphy, E. & Dingwall, R. (2007) Informed Consent, Anticipatory Regulation and Ethnographic Practice. *Social Science & Medicine*. **65**(11), 2223 – 2234.

Myerhoff, B. (1992). Surviving Stories: Reflections on Number Our Days. In: Myerhoff, B. (ed.) *Remembered Lives. The Work of Ritual Storytelling & Growing Older*. Ann Arbor: University of Michigan Press, 277 – 304.

Myerhoff, B. & Ruby, J. (1982). Introduction. In Ruby, J. (ed.) *A Crack in the Mirror: Reflexive Perspectives in Anthropology*. Philadelphia: University of Pennsylvania Press, 1- 37.

Myers, F. (1988). From Ethnography to Metaphor: Recent Films from David & Judith MacDougall. *Cultural Anthropology*. **3**(2), 205 – 220.

Naficy, H. (2007). Ethnography & African Culture: Jean Rouch on La Chasse au Lion à L'arc & Les Maitre Fous. In: ten Brink, J. (ed.) *Building Bridges. The Cinema of Jean Rouch*. London: Wallflower Press, 97 – 108.

Nash, M. (2005). Kutluğ Ataman's Experiments with Truth. In: Kent, R. (ed.) *Kutluğ Ataman*. Sydney: Museum of Contemporary Art, 42 – 47.

National Research Ethics Service.(2011). <http://www.nres.nhs.uk/> [Accessed November 2011]

National Cancer Intelligence Network (NCIN) (2009). Cancer Incidence & Survival by Major Ethnic Group in Engl & 2002-2006. NCIN. <http://www.ncin.org.uk/search/breast+cancer> [Accessed: 20 April 2013].

National Cancer Intelligence Network (NCIN) (2006). West Midlands Cancer Intelligence Unit. A UK Analysis of all Symptomatic & Screen-detected Breast Cancers Diagnosed in 2006. NHS Cancer Screening Programmes. <http://www.ncin.org.uk/search/breast+cancer> [Accessed: 20 April 2013].

Nichols, B. (1994). Performing Documentaries. In: Nichols, B. (ed.) *Blurred Boundaries. Questions of Meaning in Contemporary Culture*. Bloomington and Indianapolis: Indiana University Press, 92 – 168.

Nichols, B. (1993). "Getting to Know You" Knowledge, Power, and the Body. In: Renov, M. (ed.) *Theorizing Documentary*. London & New York: Routledge.

- Nichols, B. (1991a). Axiographics: Ethical Space in Documentary Film. In: Nichols, B. (ed.) *Representing Reality. Issues & Concepts in Documentary*. Bloomington & Indianapolis: Indiana University Press, 76 – 103.
- Nichols, B. (1991b). Telling Stories with Evidence & Arguments. In: Nichols, B. (ed.) *Representing Reality. Issues & Concepts in Documentary*. Bloomington & Indianapolis: Indiana University Press, 107 – 133.
- Nichols, B. (1991c). Sticking to Reality. In: Nichols, B. (ed.) *Representing Reality. Issues & Concepts in Documentary*. Bloomington & Indianapolis: Indiana University Press, 134 – 164.
- Nichols, B. (1983). The Voice of Documentary. *Film Quarterly*. **36**(3), 17 – 30.
- O'Doherty, B. (1986). *Inside The White Cube. The Ideology of the Gallery Space. Expanded Edition*. Berkeley & Los Angeles, California: University of California Press.
- Pack, S. (2012). Towards a Reflexive Ethnography: (Re-)inserting the Producer & Process Into the Research Equation. *International Review of Social Research*. **2**(3), 43 – 58.
- Pack, S. (2011). Give & Take: Reconceptualizing the Life History as Dialogue. *International Journal of Humanities & Social Science*. **1**(5), 58 – 65.
- Pellegrini, I. A. *et al.* (2009). Women's Perceptions & Experiences of Adjuvant Tamoxifen Therapy Account for their Adherence: Breast Cancer Patients' Point of View. *Psycho-Oncology*. **19**(5), 472 – 479.
- Pelusi, J. (1997). The Lived Experience of Surviving Breast Cancer. *Oncology Nursing Forum*. **24**(8), 1343 – 1353.
- Phelan, P. (1997). Introduction: This Book's Body. In: Phelan, P. (ed.) *Mourning Sex: Performing Public Memories*. London & New York: Routledge, 1 – 22.
- Picton, O. (2011). Anthropologists Working "at Home": On the Range of Subjects & Forms of Representation in Film, & What Makes These Ethnographic. *Visual Anthropology*. **24**(5), 421-436.
- Pink, S. (2012a). Advances in Visual Methodology. An Introduction. In: Pink, S. (ed.) *Advances in Visual Methodology*. Los Angeles, London, New Delhi, Singapore, Washington DC: Sage, 3 – 16.
- Pink, S. (2012b). *Doing Sensory Ethnography*. Los Angeles, London, New Delhi, Singapore, Washington: Sage.

- Pink, S. (2009). *Visual Interventions. Applied Visual Anthropology*. New York & Oxford: Berghahn Books.
- Pink, S. (2007). *Doing Visual Anthropology*. Second Edition. Los Angeles, London, New Delhi, Singapore, Washington: Sage.
- Pink, S. (2006). *The Future of Visual Anthropology*. London & New York: Routledge.
- Pink, S. (2003). Interdisciplinary Agendas in Visual Research: Re-situating Visual Anthropology. *Visual Studies*. **18**(2), 179 – 192.
- Pink, S. (2001). More Visualising, More Methodologies: on Video, Reflexivity & Qualitative Research. *The Sociological Review*. **49**(4), 586 – 599.
- Pink, S. & Mackley, K.L. (2014). Re-enactment Methodologies for Everyday Life Research: Art Therapy Insights for Video Ethnography. *Visual Studies*. **92**(2), 146 – 154.
- Pink, S. *et al.* (2011). Intersections & Inroads: Art Therapy's Contribution to Visual Methods. *International Journal of Art Therapy (Inscape)*. **16**(1), 14 – 19.
- Piper, H. & Frankham, J. (2007). Seeing Voices & Hearing Pictures: Image as discourse & the framing of image-based research. *Discourse Studies in the Cultural Politics of Education*. **28**(3), 373 – 387.
- Pollark, G. (2007). The Politics of Display: Ann-Sofi Sidén's *Warte Mal!* Art History & Social Documentary. In: MacDonald, S. & Basu, P. (eds.) *Exhibition Experiments*. Oxford: Blackwell, 164 – 171.
- Predal, R. (1982). Jean Rouch, Un griot gaulois. *CinemAction*. **17**, 77-78. Berthe, T. (Trans, 2010). Paris: Harmattan. <http://www.maitres-fous.net/Sembene.html> [Accessed 12 December 2012]
- Propp, V. (2009). *Morphology of the Folktale*. Texas: University of Texas Press.
- Pryluck, C. (2005). Ultimately We Are All Outsiders: The Ethics of Documentary Filming. In: Rosenthal, A. & Corner, J. (eds.) *New Challenges for Documentary*. Manchester: Manchester University Press, 194 – 208.
- Radley, A. (2010). What People Do With Pictures. *Visual Studies*. **25**(3), 268 – 279.
- Ray, A. & Leonard, R.C. (1996). Side Effects of Tamoxifen are Distressing and Common. *British Medical Journal*. **313**(7070), 1484.

Ravetz, A. (2007). "A Weight of Meaningless About Which there is Nothing Insignificant": Abjection and Knowing in an Art School and on a Housing Estate. In: Harris, M. (ed.) *Ways of Knowing: New Approaches in the Anthropology of Experience and Learning*. Oxford: Berghahn, 266 – 287.

Reagan, L. J. (2007). Projecting Breast Cancer: Self Examination Films & The Making of a New Cultural Practice. In: Reagan, L. J. *et al.* (eds.) *Medicine's Moving Pictures. Medicine, Health & Bodies in American Film & Television*. New York: University of Rochester Press, 163 – 199.

Remennick, L. (2006). The Challenge of Early Breast Cancer Detection among Immigrant & Minority Women in Multicultural Society. *The Breast Journal*. **12**(S1), S103 - S110.

Renov, M. (2004a). New Subjectivities: Documentary & Self Representation in the Post-verite Age. In: Renov, M. (ed.) *The Subject of Documentary*. Minneapolis: University of Minnesota Press, 171 – 181.

Renov, M. (2004b). Video Confessions. In: Renov, M. (ed.) *The Subject of Documentary*. Minneapolis: University of Minnesota Press, 191 – 215.

Renov, M. (1993). Introduction. The Truth About Non-fiction. In: Renov, M. (ed.) *Theorising Documentary*. New York & London: Routledge, 1 – 11.

Rich, M. *et al.* (2002). Visual Illness Narratives of Asthma: Explanatory Models & Health Related Behavior. *American Journal of Health Behavior*. **26**(6), 442 – 453.

Rich, M. *et al.* (2000). Video Intervention/Prevention Assessment: A Patient-centered Methodology for Understanding the Adolescent Illness Experience. *Journal of Adolescent Health*. **27**(3), 155 – 165.

Rich, M. & Chalfen, R. (1999). Showing & Telling Asthma. Children Teaching Physicians with Visual Narrative. *Visual Sociology*. **14**(1), 51 – 71.

Richards, M. A. *et al.* (1999). Influence of Delay on Survival in Patients with Breast Cancer: A Systematic Review. *The Lancet*. **353**(9159), 1119 – 1126.

Rony, F. (1996). Taxidermy & Romantic Ethnography. In: Rony, F. (ed.) *The Third Eye: Race, Cinema & Ethnographic Spectacle*. London: Duke University Press, 99 – 128.

Ross, C. (2012). Women & Conflict. In: Hogan, S. (ed.) *Revisiting Feminist Approaches to Art Therapy*. New York and Oxford: Berghahn Books, 150 – 158.

Rothman, W. (1997). Chronicle of a Summer. In: Rothman, W. (ed.) *Documentary Film Classics*. Cambridge: Cambridge University Press, 69 – 108.

Rouch, J. (2003a). The Camera & Man. In: Feld, S. (ed. & trans.) *Cine-Ethnography Jean Rouch*. Minneapolis & London: University of Minnesota Press, 29 – 46.

Rouch, J. (2003b). On the Vicissitudes of the Self: The Possessed Dancer, the Magician, the Sorcerer, the Filmmaker, & the Ethnographer. In: Feld, S. (ed. & trans.) *Cine-Ethnography Jean Rouch*. Minneapolis & London: University of Minnesota Press, 87 – 101.

Rouch, J. *et al.* (2003c). The Politics of Visual Anthropology. In Feld, S. (ed. & trans.) *Cine-Ethnography Jean Rouch*. Minneapolis & London: University of Minnesota Press, 210 – 225.

Rouch, J. (1985). Documentaries: Limitless Eyes Recording Civilization. *New York Times*. 3 November.

Ruby, J. (2008). A Future for Ethnographic Film. *Journal of Film & Video*. **60**(2), 5 – 14.

Ruby, J. (2005). The Ethics of Image Making: or “They’re Going to Put Me in the Movies. They are Going to Make a Big Star Out of Me.” In: Rosenthal, A. & Corner, J. (eds.) *New Challenges for Documentary*. Manchester: Manchester University Press, 209 – 219.

Ruby, J. (2000a). Introduction. In: Ruby, J. (ed.) *Picturing Culture Explorations of Film & Anthropology*. Chicago: University of Chicago Press, 1 – 39.

Ruby, J. (2000b). Researching with a Camera. In: Ruby, J. (ed.) *Picturing Culture Explorations of Film & Anthropology*. Chicago: University of Chicago Press, 41 – 66.

Ruby, J. (2000c). The Aggie Must Come First: Robert Flaherty’s Place in Ethnographic Film History. In: Ruby, J. (ed.) *Picturing Culture. Explorations of Film & Anthropology*. Chicago: University of Chicago Press, 67 – 93.

Ruby, J. (2000d). Exposing Yourself: Reflexivity, Anthropology & Film. In: Ruby, J. (ed.) *Picturing Culture. Explorations of Film & Anthropology*. Chicago: University of Chicago Press, 151 – 180.

Ruby, J. (2000e). In The Belly of the Beast: Eric Michaels & Indigenous Media. In: Ruby, J. (ed.) *Picturing Culture: Explorations of Film & Anthropology*. Chicago: University of Chicago Press, 221 – 238.

Ruby, J. (1995). The Moral Burden of Authorship in Ethnographic Film. *Visual Anthropology Review*. **11**(2), 77 – 82.

Ruby, J. (1991). Speaking For, Speaking About, Speaking With or Speaking Along Side: An Anthropological & Documentary Dilemma. *Visual Anthropology Review*. 7(2), 50 – 67.

Ruby, J. (1975). Is an Ethnographic Film A Filmic Ethnography? *Studies in the Anthropology of Visual Communication*. 2(2), 104 -111.

Russell, C. (1999a). Preface. In: Russell, C. (ed.) *Experimental Ethnography*. Durham & London: Duke University Press, xi – xviii.

Russell, C. (1999b). Another Look. In: Russell, C. (ed.) *Experimental Ethnography*. Durham & London: Duke University Press, 3 – 25.

Saalfeld, C. (1995). Videography. In: Juhasz, A. (ed.) *AIDS TV: Identity, Community & Alternative Video*. London: Duke University Press, 271 – 299.

Sayad, C. (2013). *Performing Authorship. Self-inscription & Corporeality in the Cinema*. London & New York: IB Tauris.

Seale, C. (2002). *Media & Health*. London, Thousand Oaks, New Delhi: Sage.

Sidén, A. S. (2007). The Politics of Display: Ann-Sofi Sidén's *Warte Mal!* Art History & Social Documentary. In: MacDonald, S. & Basu, P. (eds.) *Exhibition Experiments*. Oxford: Blackwell, 157 – 158, 168 – 169.

Sidén, A. S. (2002), *Warte Mal! Prostitution After the Velvet Revolution*. London: Hayward Gallery.

Silverman, D. (2013). Evaluating Qualitative Research. In: Silverman, D. (ed.) *Doing Qualitative Research*. 4th edition. Washington DC: Sage, 304 – 323.

Silverstone, R. (1985). *Framing Science: The Making of a BBC Documentary*. London: BFI.

Sontag, S. (1991). Illness as Metaphor. In: Sontag, S. (ed.) *Illness as Metaphor & AIDS & its Metaphors*. London: Penguin, 1 – 87.

Spence, J. (2005). *Cultural Sniping. The Art of Transgression*. London & New York: Routledge.

Spence, J. (1986). *Putting Myself in the Picture; A Political, Personal & Photographic Autobiography*. London: Camden Press.

Spence, J. & Martin, R. (2005). Phototherapy. Psychic Realism as Healing Art? (with Rosy Martin). In: Spence, J. (ed.) *Cultural Sniping. The Art of Transgression*. London & New York: Routledge, 164 – 180.

- Stanton, A. L. (2006). Psychosocial Concerns & Interventions for Cancer Survivors. *Journal of Clinical Oncology*. **24**(32), 5132 – 5137.
- Stanton, A. L. *et al.* (2013). Mechanisms in Psychological Interventions for Individuals Living with Cancer: Opportunity for Integration of Theory, Research, & Practice. *Journal of Consulting & Clinical Psychology*. **81**, 318 – 335.
- Stanton, A. L. *et al.* (2005a). Promoting Adjustment After Treatment for Cancer. *Cancer*. **104**(S11), 2608 – 2613.
- Stanton, A. L. *et al.* (2005b). Outcomes From the Moving Beyond Cancer Psychoeducational, Randomized, Controlled Trial With Breast Cancer Patients. *Journal of Clinical Oncology*. **23**(25), 6009 - 6018.
- Sternberg, R. (2010). *Discovery as Invention: A Constructivist Alternative to the Classic Science Documentary*. University of Westminster.
<http://westminsterresearch.wmin.ac.uk/8884/> [Accessed April 2015]
- Stoller, P. (2014). *Yaya's Story. The Quest for Well-being in the World*. Chicago & London: The University of Chicago Press.
- Stoller, P. (2004). *Stranger in the Village of the Sick: A Memoir of Cancer, Sorcery and Healing*. Boston: Beacon Press.
- Stuckey, H. & Nobel, J. (2010). The Connection Between Art, Healing, and Public Health: A Review of Current Literature. *American Journal of Public Health*. **100**(2), 254 – 263.
- Sulik, G. (2011). *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health*. Oxford: Oxford University Press.
- Sussex, E. & Grierson, J. (1972). Grierson on Documentary: The Last Interview. *Film Quarterly* **26**[1], 24 – 30.
- Taylor, L. (1998). Introduction. In: MacDougall, D. (ed.) *Transcultural Cinema*. Princeton, New Jersey: Princeton University Press, 3 – 21.
- ten Brink, J. (2007). *Building Bridges. The Cinema of Jean Rouch*. London: Wallflower Press.
- Thomas-MacLean, R. (2005). Beyond Dichotomies of Health & Illness: Life After Breast Cancer. *Nursing Inquiry*. **12**(3), 200 – 209.
- Thomas-MacLean, R. (2004). Memories of Treatment: The Immediacy of Breast Cancer. *Qualitative Health Research*. **14**(5), 628 – 643.

- Tighe, M. *et al.* (2011). Coping, Meaning & Symptom Experience: A Narrative Approach to the Overwhelming Impacts of Breast Cancer in the First Year Following Diagnosis. *European Journal of Oncology Nursing*. **15**(3), 226 – 232.
- Toon, E. (2007). Cancer as the Lay Population Knows It: Knowledge, Fear & Lay Education in 1950s Britain. *Bulletin of the History of Medicine*. **81**(1), 116 – 138.
- Turner, T. (1991). The Social Dynamics of Video Media in an Indigenous Society: The Cultural Meaning & the Personal Politics of Video Making in Kayapo Communities. *Visual Anthropology Review*. **7**(2), 68 – 76.
- Turner, T. (1990). Visual Media, Cultural Politics, & Anthropological Practice. Some Implications of Recent Uses of Film & Video among the Kayapo of Brazil. *CVA Review*. **Spring**, 8 – 13.
- Ukadike, N. F. (1994). Banishing the Exotic: Towards a Positive Image. In: Ukadike, N. F. (ed.) *Black African Cinema*. London, Berkeley & Los Angeles: University of California Press, 48 – 58.
- Ukadike, N. F. (1990). Western Film Images of Africa: Genealogy of Ideological Formulation. *The Black Scholar*. **21**(2), 30 – 48.
- Ukadike, N. F. (1987/88). Depictions of Africa in Documentary Film. *Black Film Review*. **4**(1), 13 – 15.
- Ungar, S. (2003). Whose Voice? Whose Film? Jean Rouch, Oumarou Ganda & *Moi, un Noir*. In: ten Brink, J. (ed.) *Building Bridges. The Cinema of Jean Rouch*. London: Wallflower Press, 111 – 123.
- Van Dijck, J. (2002). Medical Documentary: Conjoined Twins as a Mediated Spectacle. *Media, Culture & Society*. **24**(4), 537 – 556.
- Vaughan, D. (1999). The Aesthetics of Ambiguity. In: Vaughan, D. (ed.) *For Documentary*. California: University of California Press, 54 – 83.
- Verbrugghe, M. *et al.* (2013). Determinants & Associated Factors Influencing Medication Adherence & Persistence to Oral Anticancer Drugs: A Systematic Review. *Cancer Treatment Reviews*. **39**(6), 610 – 621.
- Vertov, D. (1984). Kinoks: A Revolution. In: Michelson, A. (ed.) O'Brien, K. (trans.) *Kino Eye: The Writings of Dziga Vertov*. Berkeley: University of California Press, 11 – 20.
- Vickberg, S. M. (2003). The Concerns About Recurrence Scale (CARS): A Systematic Measure of Women's Fears About the Possibility of Breast Cancer Recurrence. *Annals of Behavioral Medicine*. **25**(1), 16 – 24.

Vickberg, S. M. (2001). Fears About Breast Cancer Recurrence: Interviews with a Diverse Sample. *Cancer Practice*. **9**(5), 237 – 243.

Waldrop, D. P. *et al.* (2011). “Waiting for the Other Shoe to Drop”: Distress and Coping During and After Treatment for Breast Cancer. *Journal of Psychosocial Oncology*. **29**(4), 450 – 473.

Watney, S. (1986). Jo Spence. *History Workshop Journal*. **21**(1), 211 – 212.

Weatherall, D. J. (2003). Scientific Method & the Art of Healing. In: Warrell, D. A. *et al.* (eds.) *Oxford Textbook of Medicine: Volume 1*. 4th edition. Oxford: Oxford University Press, 10 – 13.

Weatherford, E. (1990). Native Visions: The Growth of Indigenous Media. *Aperture*. **119**(early summer), 58 – 61.

Winston, B. (2008a). Film as Ethnography. In: Winston, B. (ed.) *Claiming The Real II. Documentary: Grierson & Beyond*. London: Palgrave Macmillan, 172 – 180.

Winston, B. (2008b). The Voluntary Consent of the Human Subject. In: Winston, B. (ed.) *Claiming the Reel II. Documentary: Grierson & Beyond*. London: Palgrave Macmillan, 242 – 252.

Winston, B. (1988a). The Tradition of the Victim. In: Gross, L. *et al.* (eds.) *Image Ethics. The Moral Rights of Subjects in Photographs, Film & Television*. Oxford: Oxford University Press, 34 – 57.

Winston, B. (1988b). Documentary: I Think we are in Trouble. In: Rosenthal, A. (ed.) *New Challenges for Documentary*. London, Berkeley & Los Angeles: University of California Press, 21 – 33.

Worth, S. & Adair, J. (1997). *Through Navajo Eyes. An Exploration in Film Communication & Anthropology*. Revised edition. Albuquerque: University of New Mexico Press.

Yakir, D. & Rouch, J. (1978). Cine-transe: The Vision of Jean Rouch. An Interview. *Film Quarterly*. **31**(3), 2 – 11.

Yates, L. (2010). The Story They Want to Tell, & the Visual Story as Evidence: Young People, Research Authority & Research Purposes in the Education & Health Domains. *Visual Studies*. **25**(3), 280 – 291.

Films Cited

Absolutely Positive (1991). Dir. Peter Adair [DVD]. USA: Adair & Armstrong Productions.

Agatha's Curse (1994). Dir. Fred Schepisi. [DVD]. Australia: RMI Media.

Amazonia (2001). Dir. Nandini Sikand [DVD]. USA.

Angela's Dying Wish (2006). Dir. Nick Watts [Channel 4] UK: Touch Productions.

Animated Minds (2003). Dir. Andy Glynne [Channel 4]. UK: Mosaic Films.

Beating Breast Cancer: Marsha's Journey (2005). Dir. Eamon O'Connor [ITV]. UK: Liberty Bell.

Being Breast Aware is for Life (1994). [DVD]. UK: Healthcare Productions.

Breast Cancer (2001).[DVD]. UK: Health Education Video Unit. Leicester General Hospital.

Breath (2010). Dir. Christine Douglass, Helen Wollner & Lizzie Boulton. UK: Imperial College.

Busting Out (2004). Dir. Francine Strickwerda & Laurel Spellman-Smith [DVD]. USA: Stir It Up Productions.

Caught in the Machine (2010). Dir. Ricardo Pollack [BBC2]. UK: Films of Record.

Chronicle of a Summer (1960). Dir. Edgar Morin, Jean Rouch [DVD]. France: Argos Films.

Herceptin: Wanting the Wonder Drug (2006). [BBC Panorama] UK: BBC Productions.

Home Truths : A Woman in Twelve (1997). Dir. Bruce Batten [BBC2]. UK: BBC Northern Ireland.

Hospital. (1970) Dir. Frederick Wiseman [DVD]. USA: Osti Films.

Ich Will Ja Leben, Oder? (2009). Dir. Katherin Spielvogel & Nicholas Fuestel [DVD]. Germany.

I was a Soldier (1970) Dir. Krzysztof Kiewslowski [DVD]. Poland: Czolowka.

Jaguar (1957 – 1967). Dir. Jean Rouch [DVD]. France: Les Filmes de la Pleiade.

Kissed by Angles (2003). Dir. Daniela Zanzotto [Channel 4]. UK: Disruptive Element Films.

Kris: Dying to Live (2014). Dir. Neil Bonner [BBC3]. UK: October Films.

La Pyramide Humaine (1961). Dir. Jean Rouch [DVD]. France: Les Filmes de la Pleiade.

Les Maitres Fous (1955). Dir. Jean Rouch [DVD]. France: Les Filmes de la Pleiade.

Lion in the House (2006). USA. Dir. Steven Bogner & Julia Reichert [DVD]. USA: Docurama Films/New Video.

Magda, Love and Cancer (2009). Dir. Alina Mrowińska [DVD]. Poland: TVP Film Agency.

Moi Un Noir (1958). Dir. Jean Rouch [DVD]. France: Les Filmes de la Pleiade.

Miranda's Chest (1998). Dir. Kate Woods [Channel 4]. UK: Twenty Twenty Television.

My Breasts or My life (2006). Dir. Siobhan Sinnerton [ITV]. UK: ITV Productions.

My Left Breast (2002). Dir. Gerry Rogers [DVD]. Canada: Pope Productions.

Nanook of the North (1922[1999]). Dir. Robert Flaherty [DVD]. USA: The Criterion Collection.

No you nor I (2008). Dir. Felicity Aulion [DVD]. USA: The Sensory Ethnography Lab.

Petit a Petit (1968 – 1969). Dir. Jean Rouch [DVD]. France: Les Filmes de la Pleiade.

Remember The Day (2010). Dir. Christine Douglass, Helen Wollner & Lizzie Boulton. UK: Imperial College.

Scenes from a Teenage Killing (2011). Dir. Morgan Matthews [BBC]. UK: Minnow Films.

Shadow of Breast Cancer (1992). Prod. Christopher Riley & Jana Bennett. UK: BBC Productions.

Sooner or Later (2003). Dir. Jurg Neuenschwander [DVD]. Switzerland: Carac Films.

Surviving Memories (1991). Jo Spence & Mike Clode. Prod. Jeremy Gibson. UK: BBC Community Programme Unit.

Taking Our Bodies Back (1974). Dir. Margaret Lazarus & Renner Wunderlicht [DVD]. USA: Cambridge Documentary Films.

The Breast Cancer Diaries (2006). Dir. Linda Patillo [DVD]. USA: Linda Patillo Productions.

The Lion Hunters. (1957 – 64). Dir. Jean Rouch [DVD]. France: Les Filmes de la Pleiade.

To Courtney with Love (2005). Dir. Mark Wilkinson [BBC]. UK: Mosaic Films.

Titicut Follies (1967). Dir. Frederick Wiseman [DVD]. USA: Zipporah Films.

We Care: A Video for Care Providers of People Affected by AIDS (1990). Dir. Alexandra Juhasz [DVD] USA: Women's AIDS Video Enterprise.

You, Me and Cancer (2010). Dir. Mark Wilkinson [BBC]. UK: Mosaic Films North.

The Wellcome Collection Moving Image & Sound Collection, and BFI National Archive house many of these films. I am grateful to their archivists for facilitating access.

For information about the early American Society for the Control of Cancer & the American Cancer Society Educational Films I recommend: Cantor, D. (2009). Choosing to Live: Cancer Education, Movies, and the Conversion Narrative. *Literature & Medicine*. **28**(2), 278 – 332.