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# OTOBIOGRAPHY OF A CANCER: LIFE WRITING AND INDIAN RHYTHM IN TRANSDISCIPLINARY COMPOSITION

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Thesis submitted for the degree of PhD

2024

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## <u>ABSTRACT</u>

At an intersection of composition, practice research, and performance autoethnography, this research examines the creative possibilities for the development of corporeal acoustemology: a sonic and auditory knowledge of the body, health, and therefore, illness. Using autoethnographic experience of cancer treatment as a primary focus, key elements of Indian rhythmic theory, medical humanities, and life writing actively coalesce in the pursuit of a new form of transdisciplinary composition called sonic life writing. While life writing is an expanding field, especially in literature and film, its relationship with music is a nascent one within the academy; the possibilities of life writing beyond words are the focus of this practice research in the composition of music and sonic arts.

The primary aim of this project is to find ways of bypassing problematic tropes and metaphors of standardised, lexical cancer narratives, inquiring as to how we might tell a story through rhythm, how we might better understand disease through reparative listening, and how music can express complicated relationships of care and connection. In these experiments in sonic life writing, the portfolio draws on themes from psychoanalysis, oncology, expanded radio arts, aesthetics, and ethnomusicology.

This project is the first to investigate the transduction of breast cancer experience in performance autoethnographic music and sonic arts. Key findings include the application of Karnatak rhythmic theory in expressing the nature of side effects from chemotherapy, the possibilities for a re-imagining of hospital radio as broadcast of patient experience, and the role of rhythm in exploring bonded relationships of care and the qualities of time experienced during illness.

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Eminent botanist Dr Sandy Knapp (Natural History Museum/UCL) is one of many wonderful people I never expected to meet during the course of this project. Sandy, like me, received successful treatment for breast cancer and is keen to present her experience publicly. After reading her excellent article *Nature and breast cancer: the plants that saved a botanist's life* (2020), I felt compelled to contact her. We met over lunch at the Holly Bush pub in Hampstead and have since worked together in making recordings of biodata and bioelectricity from plants used in various anticancer drugs. These recordings were made at the Chelsea Physic Garden and I am very grateful to Nell Jones, Head of Plant Collections at Chelsea, for her support for my work. I would also like to thank Yasmin Khan (curator of the *Outwitting Cancer Revolution* exhibition at the Science Museum) for being so enthusiastic and encouraging of my work.

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This research is dedicated to my lovely, much-missed Dad who died peacefully with cancer in 2012.

Otobiography of a Cancer:

Life Writing and Indian Rhythm in Transdisciplinary Composition

PREFACE

I didn't see it coming.

I neither planned nor wanted to write this.

In September 2018 I began my PhD research investigating the Swathi Sangeethotsavam Karnatak music festival in Thiruvananthapuram, Kerala: a unique celebration of South Indian classical music organised by the titular royal family of Travancore. I wanted to explore the social, spatial, and musical relationships at play during the festival and find ways of re-sounding and transducting my ethnographic research through experimental composition for piano. As a professional pianist specialising in new and experimental music, it seemed a natural step onwards from my recent Masters degree at SOAS in South Asian performance and musicology. Through 2018 and 2019, I spent eighteen months learning the fundaments of Karnatak rhythmic theory; getting to grips with the intricate, rhythmic vocal artform of konnakol; spending time with the royal family; and beginning archival research on the Swathi Sangeethotsavam. This festival celebrates the music of Maharaja Swathi Thirunal (1813-1846) and is held every January in the gardens of what was his palatial residence, the Kuthiramalika, or "mansion of horses" (Somarajan and Esmail, 2023). Kuthiramalika palace is located on the south-eastern side of the famed, golden Shree Padmanabhaswamy Temple, a much-visited site by Hindu pilgrims, and reported by a host of global media organisations to house \$20 billion dollars' worth of treasures (Das Acevedo, 2015). The Swathi Sangeethotsavam is organised by the descendants of Swathi Thirunal, the current royal family of the south-westerly tip of India, what was the old kingdom of Travancore before the end of British rule in 1947 and the formation of the state of Kerala in 1956.

Having visited Kerala several times in previous years, attended the festival, and formed good relationships with members of the royal family, I felt confident when organising my second year fieldwork. I planned a three-to-four month visit which would incorporate the festival attendance, plus time spent with the family and their archive. I had also organised a month of musical study and collaboration with the excellent Karnatak violinists the Mysore Brothers (who are regular performers at the festival), and with percussionist and konnakol giant BC Manjunath in Bangalore. I booked my outgoing flight to Mumbai for the morning of December 28th, 2019.

The afternoon before my flight, I was diagnosed with cancer. I had just turned 38 years of age. Throughout the latter half of 2019 I had been experiencing pains in my right breast; I thought little of it and put it down to an existing and benign lump, diagnosed five years earlier as a common fibroadenoma. Unfortunately, however, scans, tests, and biopsies revealed not one fibroadenoma but two, a large area of calcification, and an aggressive Grade 2 Stage 3+ invasive carcinoma on my chest wall. At the time of writing this in late 2023, almost four years on from diagnosis, my faded recall hosts a compressed and disordered sense of episodic chronology which shouts loudly with embodied painful memories but murmurs mutedly with waning recollections of the precise medical goings on. My jumbled memories of that time are partially beclouded by post-traumatic fear and part-erased by shock.

Whilst I openly and willingly share elements of personal medical information concerning my cancer diagnosis here in this thesis, and include three short diary extracts in subsequent chapters, I am not interested in fleshing out my experience as a textual illness narrative, or (auto)pathography, for reasons I shall explicate in detail in the introduction and subsequent chapters. Illness-related, autoethnographic, and biographical terminology such as "autopathography" — defined by Smith and Watson (2001, p.261) as "personal narratives about illness or disability that contest cultural discourses stigmatizing the writer as abnormal, aberrant, or in some sense pathological" — will also be discussed later in this introduction. Whilst I believe my particular story has disruptive value in connection with the work of Barbara Ehrenreich (2001, 2010, 2018) and with what I will later explain as the feminist cancer "killjoy" movement (Ahmed, 2010; Nielsen, 2014, 2019), my intent is to share my

autoethnographic experience as an intervention through sound and music, not with the arc of a textual autopathography.

Following diagnosis, treatment commenced with urgency. I underwent a gruelling 15 month regime comprising chemotherapy, surgery, radiotherapy, short-term hormone therapy, and immunotherapy. The acute suffering that intensive cancer treatment brought, especially with chemotherapy, was compounded by the Covid-19 situation: the first UK lockdown came into force just 6 weeks into my treatment. As the global pandemic situation progressed through 2020, and the debilitating side effects of my treatment accumulated, it became clear that my original PhD plans to carry out fieldwork in India were not going to happen. I had hoped, naïvely, to simply postpone my plans by one year and to conduct research in a condensed timeframe, whilst still receiving treatment, in 2021.

Despite the loss of my original research plan, I continued to read about Karnatak music and sporadically practise konnakol exercises when feeling well enough. During days receiving chemotherapy in hospital I would try, very quietly, and after the initial sedatives had worn off, to complete long konnakol exercises as a means of passing the time. Karnatak rhythm is a notoriously complex system, sharply mathematical and packed with subdivisions. I quickly noticed ways of incorporating the medical and therapeutic numerical data printed on my chemotherapy drip bags into the short rhythmic patterns and compositions given to me by my teacher, Prathap Ramachandra. Given the cyclical nature of cancer treatments and the inherently cyclical nature of Karnatak rhythmic theory, and Indian music generally, I sensed a potentially useful, artistic connection. A simple example of such incorporation would be as follows:

I look at the drip bag hanging from the stand above my left shoulder and see that this particular chemotherapy drug, Docetaxel, is 8mg/4ml in solution. If I think about those numbers rhythmically I can make a composition which is 4 cycles long, each cycle containing 8 beats. That gives a total composition length of 32 (8x4).

Months later, I discussed these rhythmic possibilities and connections between medical data and Karnatak rhythmic theory with my supervisor, Dr Richard Williams. He suggested I explore Life Writing as a potential avenue for new doctoral research. Although still undergoing treatment, I returned from official interruption of study at the end of 2020. This was good timing. I enrolled to audit Professor Neil Vickers' online MA course, Illness Narrative as Life Writing, at King's College London, beginning in January 2021. It was during this course that I was first introduced to the work of Susan Sontag ([1966] 2009, 2012, [1978] 2013), Audre Lorde (1980), Eve Kosofsky Sedgwick (1997, 2000, 2003), Barbara Ehrenreich (2001, 2010a), Denise Riley (2012), Gillian Rose (1995), and many more. The work of these writers is fundamental to this thesis. The research of associated commentators, psychoanalysts, and theorists such as Arthur W. Frank (1995, 2002, 2010), G. Thomas Couser (1997, 2004, 2009), Melanie Klein (1984), Donald Winnicott (1971, 2016), Lennard J. Davis (2014, 2016), Angela Woods (2011, 2017), Galen Strawson (2004, 2019) and others, was also introduced to me by Prof Vickers and informs the discussion throughout this thesis.

Before the core themes of this research project revealed themselves and unfolded with any substantial detail, I first considered the similarities between musical and medical language as a jumping off point. Throughout my diagnostic and treatment processes, I recognised a group of recurring words which bore meaning to me as descriptors in music analysis: cell, cycle, expression, process, treatment, modality. When encountering these words I found them to be flavoured with memories of analytic and aesthetic study from my undergraduate music degree at the University of Sussex, twenty years ago. Seminars with Professors Martin Butler

Butler and the provocative musicologist David Osmond-Smith would be peppered with discussions about, for example, the treatment of rhythmic cells in the work of Luciano Berio or Steve Reich, the way modality operates in Debussy's piano music, or how the expression of a motif in a Stravinsky ballet score functioned within the compositional process. These linguistic connections, through disciplinary translation, suggested the possibility for an artistic sounding of cancer-related information, biomedical data, and human experience of treatment: the story of a cancer — the rhythm of its cell proliferation or destruction, the tumour expression, the treatment modality — can be conveyed and shared through sound and music in a new form of sonic life writing. Processes of sounding, sounding out, re-sounding, sonating, and sonifying run through this portfolio of compositions; each term and process slightly different, none mutually exclusive, and all discussed in detail later in this thesis.

Having read the illness narratives of the King's College London course and appraised the possibilities for a portfolio of soundings of my autoethnographic experience, I needed to consider within which disciplines and praxes my research would be situated and/or be in conversation with. I was unable to do this at first and had to wait until a certain amount of experimentation had happened, trying out new ideas and abandoning many along the way. Larry Polansky's question of "what if?" (2014) guided my efforts in artistic experimentation: asking "clear" and "fecund" questions with the understanding that "there are many interesting questions, far fewer interesting pieces" (2014, p.181). My unorthodox, practice-based project could not be controlled within the standard, non-practice-based parameters of academic planning and I questioned whether or not to plan at all. A certain amount of organic development married to a small selection of successful responses to festival open calls (including CTM festival in Berlin and Huddersfield Contemporary Music Festival hcmf// 2022) determined my programme of research and production.

Dirk Vis' Research For People Who Think They Would Rather Create (2021) has been a valuable resource for working within and across multiple genres, styles, and disciplines. I have followed Vis' advice for assembling this introduction, and research document as a whole, and am grateful to him for the straightforward clarification of terms regarding working with different disciplines:

The terms multidisciplinary, interdisciplinary and transdisciplinary are often used interchangeably - despite a general acknowledgement that there are in fact subtle differences. For example, the term transdisciplinary is often used to stress how this particular approach can lead to an entirely new field of inquiry. The whole is more than the sum of the parts. 1 + 1 = 3. (2021, p.77)

It is with this explication that I title my thesis and with the hope that this research is substantial enough to qualify as an "entirely new field of inquiry:" that of a defiant new form of sonic life writing about illness.

# **INTRODUCTION**

Cancer is not one disease but many diseases. We call them all "cancer" because they share a fundamental feature: the abnormal growth of cells. And beyond the biological commonality, there are deep cultural and political themes that run through the various incarnations of cancer to justify a unifying narrative.

Siddhartha Mukherjee, The Emperor of All Maladies: A Biography of Cancer,

2011, p.xvii

I would never call myself a cancer survivor because I think it devalues those who do not survive. There's this whole mythology that people bravely battle their cancer and then they become survivors. Well, the ones who don't survive may be just as brave, you know, just as courageous, wonderful people.

> Barbara Ehrenreich in Terry Gross, A Nonbeliever Tries to Make Sense of the Visions She Had as a Teen, 2014

Listening may show us the very limit of ourselves, attuning one to the body's metabolism, along with the flows and rhythms defining our social bonds.

Brandon LaBelle, Acoustic Justice, 2021, p.5

What does breast cancer sound like? Experiences of breast cancer and its treatment have been expressed and shared in the form of textual accounts for many decades. These accounts fall under the broader category of illness narrative, a form of autobiographical life writing which has seen a steep increase in publication since the 1990s, according to Hawkins (1999) and Vickers (2016). Visual accounts of the lived experience of breast cancer — such as Lynn Kohlman's Lynn, Front to Back (2005) and Catherine Lord's queer feminist photo-narrative The Summer of Her Baldness: A Cancer Improvisation (2010) – have also become more prevalent and have impacted the cultural discourse regarding this life-threatening disease.<sup>1</sup> But what about sonic or musical accounts of breast cancer? During this period of doctoral research, I have not found any non-lexical music or sound works that provide an account of the experience of breast cancer and its treatment. There are important sound works and installations such as John Wynne's and Tim Wainwright's I Am Not The Cancer (2013) and commercially successful pop/rock songs such as Sheryl Crow's Make it Go Away (Radiation Song) (2008) that share auditory cancer narratives but the expression of these narratives is through speech and through lyrics respectively. This thesis and collection of compositions explores the possibility for the development of non-lexical, sonic, instrumental, and musical breast cancer narratives.

Throughout and beyond my own treatment for breast cancer, I have assumed the role of auto-ethnographer as both "research instrument" (Ellingson, 2017, p.81) and musical instrument, investigating potentials for the sounding of my biomedical and experiential findings in qualitative methodologies. Across this thesis and portfolio, I explore the embryonic possibilities for a defiant new form of sonic life writing about illness; I have endeavoured to introduce sound's and music's benevolently disruptive qualities as an intervention in standardised and sometimes

<sup>&</sup>lt;sup>11</sup>See DeShazer (2013, pp.17-39) for discussion of postmillennial breast cancer photonarratives and their description as "mammographies."

problematic breast cancer cultures. I hope for the development of a reparative mode of listening which may support a transformation in the understanding of breast cancer narratives and experience, one which bypasses issues of metaphor, of restitution and status, and of commercial influence.

"How, then, can the tales of illness be heard?" (Charon, 2006, p.97) There are subtle, intimate, and powerful insights into the experience of breast cancer treatment to be gained from musical expressions of biomedical and experiential information. For example, I will show how the damaging oral side effects of chemotherapy can be explored through a non-lyrical work for voice, and how the flexible relationship of dependence between ill person and carer can be expressed through rhythm. I wish to make very clear that these experiments in sonic life writing do not include any text or lyrics: I am interested only in musical and sonic material as autoethnographic, communicative descriptors. The reason for this exclusion, or even rejection, of the lexical narrative is the sometimes limiting and often misleading nature of language used in connection with cancer. As Laurel Richardson notes, "writing is never innocent" (2001, p.36) and, at least in English, loaded and warfare-related language such as "survivor," "warrior spirit," and "winning/losing the battle" has become so common that a culturally-produced ignorance, known as agnotology, of the actuality of cancer treatment has developed. Also, the growing collection of published breast cancer narratives demonstrate corrupted tendencies to streamline and homogenise stories, as expounded by Arthur W. Frank (1995), sometimes through the agnotological use of inadequate and problematic metaphor of warfare.<sup>2</sup> I will discuss in detail the problems with some standardised cancer narratives and tropes, as studied in the fields of life writing and medical humanities, later in this introduction.

<sup>&</sup>lt;sup>2</sup> See Sontag ([1978] 2013) for a fundamental reference point regarding the difficulty of talking about the actuality of illness and how that difficulty results in the use of metaphor.

Through unorthodox applications of South Indian Karnatak rhythmic theory and *konnakol*, and with experiments in autoethnographic transduction (or musical transformation) as compositional process, I have tried to provide an honest and commercially untainted testimony of my physical and emotional experience of breast cancer; a testimony which circumvents the problems of textual and visual narratives, providing details great and small, abstruse and plain, and all in the interest of illuminating broader and non-solipsistic issues. As Brandon LaBelle explains:

If listening takes us somewhere it is into the ebbing and flowing of life, the deep pulse and resonant reach of becoming-with; it is toward intimacy and a world of touch, as well as to the edges of the familiar, what is unidentifiable yet no less present, from the invisible to the less-than-linguistic, the untold and the not-yet. (2022, pp.7-8)

It is through sound and music that the listener may develop a uniquely intimate, embodied, and creative engagement with core issues concerning the experience of cancer, illness narratives, acoustic justice, and themes of care.

Drawing from critical study of illness narrative life writing and from issues in the medical humanities, my transversal and transdisciplinary compositions attempt, in experimental fashion, to forge a future course for the critical and socially-engaged use of music as resource, rather than, or distinct from, music as therapy. Whilst I acknowledge that this nascent field — which may or may not prove viable in its future development beyond this doctoral research — is significantly more likely to be only available, at the point of creation, to practitioners with musical training, I nonetheless regard its potential contribution to be significant enough to deserve recognition and consideration in the spheres of life writing, medical humanities, socially-engaged practice, and the capacious umbrella of creative health.

Before moving into discussions about life writing, medical humanities, and representations of breast cancer in commercial and mainstream culture, I wish to

provide some clarity on terms relating to illness narratives and my use of these categories in this thesis. Firstly, this thesis draws an important distinction between illness and disease. Illness is regarded as a state or a lived experience of suffering which may or may not be biomedically-credited, whilst disease refers to the pathological case at hand, the biological process, as separate or detached from the person suffering from or with it (Boyd, 2000). Sickness, as understood in the field of medical/health humanities, describes a "public mode of unhealth... a social role, a status, a negotiated position in the world" (Boyd, 2000, p.10). The term "illness narrative" was first coined by Harvard physician and medical anthropologist, Arthur Kleinman, in his 1988 book, The Illness Narratives. Kleinman, like Frank (1995, 1996) and Mattingly & Garro (2000), regards the illness narrative as a mechanism for giving meaning to the experience of suffering, "to make over a wild, disordered natural occurrence into a more or less domesticated, mythologized, ritually controlled, therefore cultural experience" (Kleinman, 1988, p.48). I have tended to opt for the terms "ill person" or "sick person" in this work, as opposed to "patient." An uncomfortable passivity is suggested by the word "patient:" an objectification of the healthcare user in an unequal relationship with the medical professionals involved may be implied, as noted by Julia Neuberger (1999). Alternatives such as "user" or "client" feel too commercial and cold and so I have chosen the imperfect but plain descriptors of "ill" or "sick" person.

The sick, or formally sick, person who shares their first-person account of illness is described by Frank (1995) as the "wounded storyteller," a figure somewhat akin to Carl Jung's "wounded healer" archetype (Jung, [1951] 1993), and with similar goals in the making of meaning and the "healing of wounds afflicted by the trauma of stigma" (Hankir et al, 2021). Frank's interest was not in the literary quality of the writing but in "the sick person's presence in all its vitality and obscenity" as testimony (Vickers, 2016,

p.391). Vickers notes the derivation of Frank's position from the work of Emmanuel Lévinas (1969) in which the emphasis on the encountering of the "sick other" is at the "pre-cognitive core of all ethical witnessing" (Levinas, 1969, p.86; Vickers, 2016, p.317). The importance of testimony and witnessing is a vital theme of this thesis with related ideas concerning acoustic justice discussed later in this introduction and again in chapter two. Frank's analysis of illness narratives has been widely discussed by Hawkins (1999), Rimmon-Kenan (2002), Nielsen (2019), and many others; his distinction between (the non-mutually exclusive) categories of "restitution," "chaos," and "quest" narratives, so keenly applicable to breast cancer stories, being a major contribution to the critical study of illness narratives.<sup>3</sup>

Three very closely related terms have been used in the critical study of illness narratives since the 1990s: pathography, thanatography, and somatography, all of which may be introduced with the reflexive prefix "auto." Pathography is by far the most commonly used term and denotes only illness narratives in written form, not in any other art form (Hawkins, 1999, p.xviii). Hawkins describes the basis of pathography:

[as the pursuit of returning] the voice of the patient to the world of medicine, a world where that voice is too rarely heard, and it does so in such a way as to assert the phenomenological, the subjective, and the experiential side of illness. (1999, p.12)

Key features of pathography include ideas such as illness as resource and opportunity (Ehrenreich, 2010; Young et al, 2014); symptoms as identity (Couser, 2009; Raemen et al, 2023); and stigma as wounding phenomenon (Goffman, [1963] 1990). A subcategory of pathography is thanatography, casually described as "death writing."

<sup>&</sup>lt;sup>3</sup> Vincent (2019, p.3) neatly encapsulates Frank's three categories as follows: "the restitution narrative seeks to maintain the past, the chaos narrative speaks to someone paralyzed in the present and the quest narrative speaks to someone moving forward into a new if uncertain future."

This term is applied to "autobiographical texts that confront illness and death by performing a life at a limit of its own, or another's, undoing" (Smith & Watson, 2010, p.261). Couser (2009) proposed the term autosomatography to describe a first-person narrative which addresses social attitudes regarding the disabled body and offers "a counter-narrative of survival and empowerment that reclaims the individual's... body from the social stigmatization and the impersonalization of medical discourse" (Smith & Watson, 2010, p.261). Such autosomatographical accounts relate to Frank's quest narrative of transformation.

If pathography, thanatography, and somatography refer only to written illness narratives, are there alternatives which can usefully be adopted to describe illness narratives in the arts more generally? Jennifer A. Gonzalez's (1995) term autotopography relates only to visual art and describes the presentation of autobiographical objects imprinted with the "psychic body" and playing the role of aide-memoire for revelation or traumatic moment (Smith and Watson, 2010, p.262). I have not encountered a term which sufficiently represents the work of this portfolio and so I am adopting a loose term: sonic life writing, or sonic life writing about illness.

I regard my work as aligned with, or adjacent to, pathography in general but also with the methodology of (illness) autoethnography, as explicated by Susan Greenhalgh (2001, p.51): "auto-ethnography differs from autobiography in that the focus is not on the writer, but on certain experiences in the writer's life that illuminate important or previously hidden aspects of the larger culture." I have attempted a non-solipsistic approach wherein the emphasis is not on myself, *per se*, but on narrative episodes of my experience which bring forth details and questions regarding cancer treatment and its social perception and understanding more generally.

As yet there is no effective descriptor for illness narratives in non-lexical sonic

and/or music form and so, for the title of this thesis, I have playfully borrowed the term "otobiography" from Jacques Derrida's The Ear of the Other: Otobiography, Transference, Translation: Texts and Discussions with Jacques Derrida (1985).<sup>4</sup> A homophone of autobiography, I enjoy the prefix "oto" — relating to the ear, and therefore to the listening to sound and music – as a pointer towards an auditory biography, or pathography, which can convey narrative and meaning without text or lyric. I therefore regard the term "otobiography," in this context, as a synonym for sonic life writing. Meliz Ergin (2017, p.342) describes the "autobiographical thread" in Derrida's work and his shift from "auto" to "oto" due to dissatisfaction with "the twin problem of identity and writing... [of] the entanglement of self and alterity." Derrida's shift to otobiography speaks very much to the fundamental principles of listening and sounding - as explicated throughout this thesis - as entangled, connected, social, and socially-engaged practices: moving from the single "auto" to the anonymised and potentially plural "oto" "seals-or, in phenomenological terms, affects- itself in the completion of a circuit between voice and hearing, mouth and ear" (Smith, 1995, p,76).

The pathographical canon is a "capacious category" which has shown significant growth in recent decades (Vickers, 2016, p.388). Salient examples of the genre include Hilary Mantel's *Giving Up The Ghost* (2003), John Updike's *Self-Consciousness* (1989), Gillian Rose's *Love's Work* (1995), and Anatole Broyard's *Intoxicated By My Illness* (1992). Cancer pathographies count for a weighty proportion of this capacious category and breast cancer memoirs, in particular, are strong in number. Vickers distinguishes between literary memoirs of illness which "tend to range far into the surrounding life" and more "lowbrow" publications, such as the

<sup>&</sup>lt;sup>4</sup> The prefix "oto" is derived from the Greek "*ous*," meaning "ear" (Ramoutsaki et al, 2004). Derrida foregrounds the place of the listener, from various perspectives, in testimonial life writing.

diaries of celebrities and non-professional writers, which "would not disgrace the category of 'misery lit' (2016, p.388)." In *Reconstructing Illness*, Anne Hunsaker Hawkins lists 53 breast cancer pathographies in the appendix of the second edition, published in 1999, which includes key examples of the genre by Audre Lorde (1980) and Kathlyn Conway ([1996] 2007). Since 2000 there have been countless further popular breast cancer pathographies, or memoirs, made available including publications from Lisa Lynch (2010), Christine Hamill (2014), Sara Liyanage (2019), and Kris Hallenga (2021).

Breast cancer narratives extend beyond published prose with many examples in poetry,<sup>5</sup> film,<sup>6</sup> and theatre.<sup>7</sup> Photographic breast cancer narratives have been shared (see Mammographies by Mary K. DeShazer and Kit Morris' Radiation Collage (1998)) and there have been exhibitions about the experience of women with breast cancer such as the aforementioned video and sound installation by Tim Wainwright and John Wynne, I Am Not The Cancer. Sculpture about breast cancer, such as Prune Nourry's The Amazon (2018), has been critically-acclaimed, as have the confronting portraits by multi-disciplinary artist Hannah Wilke in Portrait of the Artist with her Mother, Selma Butter (1978-81). In popular music, there have been songs released about breast cancer: Sheryl Crow's Make It Go Away (Radiation Song) (2008) and the Susan G. Komen fundraising song, Pink, sung by Dolly Parton et al<sup>8</sup> (2020) are famous cases in point.

As breast cancer is such a well-documented experience across the arts and in

<sup>&</sup>lt;sup>5</sup> such as inclusions in *Art.Rage.Us* collection (1998)

<sup>&</sup>lt;sup>6</sup> see Decoding Annie Parker (2013) starring Helen Hunt and directed by Steven Bernstein, and Miss You Already (2015) starring Drew Barrymore and Toni Colette and written by Morwenna Banks

<sup>&</sup>lt;sup>7</sup> examples including Linda Park-Fuller's A Clean Breast Of It ([1993] 2009) and Polly Toynbee's Breast (2003)

<sup>&</sup>lt;sup>8</sup> also featuring Monica, Jordin Sparks, Rita Wilson, and Sara Evans on vocals

mainstream culture, I have been surprised to discover not one work regarding breast cancer in any form of sonic arts and/or classical, contemporary, experimental, instrumental new music; I have not even come across any work of experimental opera concerning this subject. In fact, instrumental/contemporary/experimental new music has, on the whole, shied away from the corporeal and the medical.<sup>9</sup> I note here that artist Mira Calix designed a soundscape for the *Outwitting Cancer: Making Sense of Nature's Enigma* exhibition at the Francis Crick Institute in London (2021-2022) but, as far as I am aware, and having consulted the curator of the exhibition,<sup>10</sup> it was not a sonification of, or a sound work expressing, a cancer-related process, nor was it breast cancer specific. It was a work commissioned to accompany and complement an immersive visual installation featuring moving images of cancer cells and blood vessels.

What do I mean when I refer to sound and music about cancer? What compelling possibilities does "about" harbour in relation to sound and music? I refer to Segal's (2007) distinction between fact and value in considering the potentials for sonic and musical life writing in connection with breast cancer. Biomedical facts, such as cellular process or pharmaceutical data, may be expressed through sound and music, be that through simple sonification or through a more complex and artistic transduction into compositional process (as I have explored in chapter two). Phenomenological, experiential, and relational value can, as I show throughout this thesis and portfolio, be expressed in a variety of ways, not least rhythmically, texturally, and timbrally. I will show that not only is there intrinsic fact and value in sound and music about cancer, but that the complex relationships regarding matters of hearing and listening bring rich rewards in the forms of

<sup>&</sup>lt;sup>9</sup> I will discuss the bodily sound works of Gregory Whitehead in Chapter Two.

<sup>&</sup>lt;sup>10</sup> Outwitting Cancer was curated by Yasmin Khan of Covalent Creatives.

acoustic justice and of care. The importance of being heard and the entanglements of care are themes which pervade this thesis and are explored throughout.

The following sections of this introduction offer a literature review regarding the central themes of this research: cultural, commercial, and narrative representations of breast cancer, standardised breast cancer narratives, acoustemology, modes of listening, aesthetic critical realism, and modes of sounding. A methodological discussion regarding musical fusion, performance autoethnography, and practice research follows the literature review. This introduction concludes with a brief outline of the subsequent three chapters.

## CULTURAL AND CORPORATE REPRESENTATIONS OF BREAST CANCER

My reason for including this discussion on cultural and commercial representations of breast cancer is a motivational one. Like Ehrenreich (2001), I regard facets of breast cancer culture to be problematic and ill-judged. I use the umbrella term breast cancer culture as a succinct descriptor that encompasses the ways that women with breast cancer are treated both medically and socially; the traits and behaviours involved in fundraising for research and awareness; and the colours, symbols, associations, and representations of breast cancer in media and advertising. With a defiant spirit, this practice-based research hopes to provide an artistic intervention in breast cancer culture that not only circumvents the standardised tropes and metaphors of illness narratives but that also offers new artistic works that reject what Ehrenreich (2001, p.53) describes as the "cult of pink kitsch."

Twenty-two years after Barbara Ehrenreich's eloquent and seminal article *Welcome to Cancerland* (2001) critiqued the pink ribbon culture and the pressure on women to be cheerful throughout their cancer experience, little seems to have

changed in breast cancer culture.<sup>11</sup> From the logo-printed T-shirts of fundraising marathon runners to the pastel covers of breast cancer memoirs, the symbols and iconography of breast cancer seem unrelentingly pink. This ubiquitous colour provides a recognisable branding to the disease and its associated charities, fundraising activities, and merchandise: but might this also be to the detriment of women? Whilst this unified colourfield makes marketing sense due to its easy identifiability with the "cause," it also trivialises women's experience of this life-threatening disease, infantilises adult women, and divests dignity from those who experience this gravely serious illness (Ehrenreich, 2001, 2009; King, 2006; Nielsen, 2019).

The pink hues of the breast cancer world mirror those of the clothing and toys of young girls in the twentieth and early twentieth first centuries. The faux-handwritten, trite platitudes of inspirational cancer-related quotes disseminated online; the cheap, ribbony trinkets of Breast Cancer Awareness Month; and the various cartoon-style breast health awareness posters in medical consulting rooms evoke the palette of *Barbie* and *My Little Pony*. Not only have medical and charitable bodies adopted pink, but innumerable corporations have struck fundraising partnership deals with charities, adding pink ribbons to their products and packaging to boost profits. Whilst I acknowledge Klawiter's (2008) important point that this mainstreaming of breast cancer awareness brought great benefits in terms of the double diminution of stigma and isolation faced by women with the illness before the 1990s, I challenge the manner in which this has been achieved.

Pickert's Radical: The Science, Culture, and History of Breast Cancer in America (2019) discusses the array of pink-ribboned consumer products available in America which are marketed with breast cancer fundraising connections. Whilst, of course,

<sup>&</sup>lt;sup>11</sup> Here I focus my discussion on this culture as manifested in the UK and USA.

charities are keen to make these partnerships to increase their funding, the corporations themselves want to improve their reputations and their sales figures (King, 2006; Segal, 2007; Pickert, 2019).

In any given year, you can support the cause of breast cancer by purchasing windshield wipers, blenders, downhill skis, sneakers, tool sets, perfume, water bottles, lipstick, sunglasses, golf balls, jeans, hamburgers, yogurt, chicken sausage, wine or beer... You could even watch porn to support the cause (Pornhub). (Pickert, 2019, p.81-82)

Breast cancer has been big business since the 1990s (Klawiter, 2005) when, as Ehrenreich (2001, p.45) described, it "blossomed from wallflower to the most popular girl at the corporate charity prom". Whilst a few other cancers are now catching up with the historically very strong research funding figures of breast cancers, no other cancer has begun to rival the pink culture of breast cancer, neither culturally nor commercially. After all, as Pickert (2019, p.81) notes, "what's a better sales pitch than promising consumers that the products they buy will help save the lives of America's mothers, daughters and sisters?"

Corporate philanthropy can deflect attention from a business' potentially harmful activities and can pinkwash corporations involved in what Segal (2007) describes as the cancer-industrial complex.<sup>12</sup> Building on work by Carson (2002), an important voice in the exploration of environmental and chemical triggers for cancer is Canadian journalist Wendy Mesley whose 2006 renegade television documentary *Chasing the Cancer Answer* investigates the inclusion of known carcinogens in grocery store products in Canada. Mesley, like Ehrenreich, is one of what I will later in this introduction describe as a member of the "cancer killjoys"

<sup>&</sup>lt;sup>12</sup> The cancer-industrial complex describes not only corporate activity which harms human and environmental health (and international pharmaceutical companies producing drugs to treat cancers caused by those harms) but also activity which aims to pinkwash carcinogenic pollution by adding pink ribbons to packaging of products containing known carcinogens (Sulik, 2011).

group: a number of powerful voices in this area who buck the trend of standardised tropes and narratives. Léa Pool's documentary *Pink Ribbons, Inc* (2012) also investigates corporate philanthropy, the cancer-industrial complex, and the high pink energy, mass fundraising events of North America. Pool juxtaposes emotional interviews with women experiencing terminal stage 4 cancer with documentary footage of energetic fundraising activities showing thousands of people dressed in pink and cheering wildly, as if at an intense children's party, to show how the devastating reality of breast cancer is obfuscated by the pink and cheery events, behaviours, and symbols of modern breast cancer culture.

I confess to being somewhat ignorant of the incongruous qualities of breast cancer culture until my own diagnosis, at which point I frequently began to see pink cartoons, ribbons, and marketing materials relating to breast cancer which felt completely discordant with my lived experience. In *Smile or Die: The Bright Side of Cancer* (2010a) following an explanation of various cancer teddy bears available, Ehrenreich describes a support "goody bag" given to some breast cancer patients in the US at the point of diagnosis which is somewhat reminiscent of children's party bags given out at the end of birthday celebrations.

The ultrafeminine theme of the breast cancer marketplace — the prominence, for example, of cosmetics and jewelry — could be understood as a response to the treatments' disastrous effects on one's looks. No doubt, too, all the prettiness and pinkness is meant to inspire a positive outlook. But the infantilising trope is a little harder to account for, and teddy bears are not its only manifestation. A tote bag distributed to breast cancer patients by the Libby Ross Foundation (through places such as the Columbia-Presbyterian Medical Center) contained, among other items, a tube of Estée Lauder Perfumed Body Crème, a hot pink satin pillowcase, a small tin of peppermint pastilles, a set of three small, inexpensive rhinestone bracelets, a pink-striped "journal and sketch book," and — somewhat jarringly — a box of crayons. (2010a, p.23)

Breast cancer culture's gendered peculiarity and reductionist tendency towards the obfuscation of reality is clear in this example from Ehrenreich. The sexism inherent in this passage is clear: it is difficult to imagine men recently diagnosed with testicular or prostate cancer being given crayons, cheap jewellery, or perky teddy bears. Ehrenreich posits the idea, connecting to notions of medical patriarchy,<sup>13</sup> that women in receipt of a breast cancer diagnosis are persuaded into a regressed position through pinkness and perkiness, and that a childlike state of trust and dependency results.

Furthermore, this dependent and trusting state might actually be, for some people and in some ways, beneficial or advantageous when it comes to agreeing to undergo challenging procedures and toxic treatments (Nielsen, 2014, p.97). In *Welcome to Cancerland* Ehrenreich contends:

obedience is the message behind the infantilizing theme in breast-cancer culture, as represented by the teddy bears, the crayons, and the prevailing pinkness. You are encouraged to regress to a little-girl state, to suspend critical judgment, and to accept whatever measures the doctors, as parent surrogates, choose to impose. (2001, p.52)

As I discovered during my own treatment, much of breast cancer treatment involves yielding and passive acceptance on the patient's part, not the gung-ho warrior attitude so commonly referenced in inspirational quotes or standardised illness narratives. Expectations are that one must quietly and graciously trust groups of strangers who perform painful and dangerous actions upon one's body; such themes of trust and passivity have been examined by Hurwitz and Bates (2016) and Burchardt (2020). Susan Sontag ([1978] 2013) also explored her experience of passivity and loss of ownership of her body; I shall return to this idea in the following literature review section on breast cancer narratives.

<sup>&</sup>lt;sup>13</sup> See Raymond (1982), Gannon (1998), Denz (2023), and Dyer (2023) for discussions of patriarchy in allopathic Western medicine.

Before moving on to a discussion of breast cancer narratives, I wish to provide further examples of the regressed and infantilised position of women as manifest in commercial breast cancer culture. My first such example is the small British company Drain Dollies: a manufacturer of shoulder bags designed to securely hold and conceal the drain bags that mastectomy patients typically need for 7 to 10 days following surgery in order to safely collect fluid from the wound site(s). Whilst I in no way wish to denigrate these products nor the benefits they provide in aiding women, postsurgery, to move about more easily, I do question the company's name, logo, materials, and website banner.<sup>14</sup> With a pink and purple logo design featuring floating love hearts to dot the "i"s of drain and dollies, the infantilising theme is reinforced by an image of drain bag fabrics one might expect to see in a kindergarten. Cute cartoon dachshunds and pink rose printed fabrics, a cartoon logo design of a slim young woman with a feather boa, and the choice of the word "dollies" itself, all reinforce the regressed state of the woman undergoing breast cancer treatment. Whether referencing the dolls (or "dollies") of childhood in the logo and fabrics or whether inferring that those women who buy these products for use after surgery are "dollies," both divest dignity from adult women through the promotion of a reductively sunny and childish attitude. I wish to make clear that I am not advocating for a radical commercial swing towards a dark and morbid aesthetic but that women experiencing the enormous challenges of breast cancer and its treatment deserve to be treated with dignity and maturity, and that related products and media reflect this through consideration and implementation of more sophisticated design values.

My final example showing the infantilising and inappropriate nature of a significant part of the breast cancer experience and its cultural and corporate brand goes hand in hand with what King (2006, p.101) describes as the "tyranny of

<sup>&</sup>lt;sup>14</sup> See https://www.draindollies.co.uk/
cheerfulness." The UK supermarket chain ASDA, at the time of writing in 2023, currently operates breast cancer themed delivery vans.<sup>15</sup> These vans are wrapped in a baby pink vinyl material, emblazoned upon which is an instruction to "handle yours with care" next to an apple and a lemon in a cartoon bra. Underneath this instruction are two logos. On the left side is ASDA's own breast cancer awareness campaign logo sporting the bizarre and ill-judged name of *Tickled Pink* (with *Pink* printed in the style of a ribbon); and on the right is a logo for breast cancer awareness charity *Coppafeel!* that would not look out of place on a police station's noticeboard given that it features an inky handprint<sup>16</sup> that suggests being groped by a criminal.

The choice of the name *Tickled Pink* is a clear example of King's (2006) "tyranny of cheerfulness." Dating back to 1922, the American colloquial term "tickled pink" describes the flushed colour of one's cheeks from giggling while being tickled (Jackson, 2007). To connect playful giggliness with the potentially deadly and very frightening disease of breast cancer seems, at best, unjust and, at worst, calumniating and offensive. This unsuitable cheeriness is intensified by the combination of cartoon drawings, pink ribbons, and fruit. The inclusion of the criminal handprint logo of *Coppafeel!* adds a sinister and aggressive edge to the van's wrap design. Pink and seemingly carefree childlike designs of breast cancer-related products and media misrepresent the grave severity and challenging lived experience of breast cancer through agnotology (Segal, 2007; Pool, 2012). Likewise, the "tyranny of cheerfulness" (King, 2006) is evident in cultural and commercial use and in standardised tropes in breast cancer narratives. The following section explores some key issues regarding language, metaphor, and narrative in published breast cancer pathographies.

<sup>&</sup>lt;sup>15</sup> Image available here: https://corporate.asda.com/asda-wheatley-201951

<sup>&</sup>lt;sup>16</sup> evoking the fingerprinting of criminal suspects

# BREAST CANCER NARRATIVES AND COUNTER-NARRATIVES

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag, [1978] 2013, p.3)

This opening paragraph from Sontag's *Illness as Metaphor* describes the ineluctability and reluctance most people experience in accepting, and coping with, serious illness. This oft-used quote is frequently cited by academics and artists alike (Larsen and Lubkin, 2009: Elbaz, 2014; Crossley, 2022) as it neatly encapsulates the separate, dichotomous identities we manifest, individually and culturally. Many cancer narratives begin with the shock of diagnosis and the pain of acquiring a new, sick identity: an unexpected and unwelcome exchange of passports and emigrant passage to the "night-side" (Sontag, [1978] 2013, p.3). Sontag argues that the "healthiest way of being ill" (ibid.) is being truthful about illness: resistance to metaphoric thinking, especially in relation to cancer, is essential in the pursuit of liberation from the "punitive or sentimental fantasies" that Western society has concocted regarding cancer and the experience of cancer treatment. Over forty years on from the publication of Illness as Metaphor, use of warfare-related metaphor and "sentimental" ideas (ibid.) regarding the enriching nature of the breast cancer experience are prevalent in breast cancer narratives. This section reviews the field of breast cancer narratives, and counter-narratives, and the problems with the cancer vernacular in the English language.

As Nielson (2014, 2019) has noted, the practice of sharing the experience of breast cancer through storytelling has become commonplace. For most of the twentieth century, breast cancer was to be kept secret due to shame, fear, and stigma (Goffman, [1963] 1990; Else-Quest and Jackson, 2014) whereas now the disease is widely talked about and "no longer fits squarely into Goffman's classic taxonomy of stigmatized conditions," according to Knapp et al (2014). This may be, in no small part, due to the aforementioned cultural and commercial breast cancer culture which, while infantilising and problematic, has helped to increase the disease's visibility and make it a regular subject of cultural and social discourse. Breast cancer narratives most commonly conform to Frank's (1995) quest narrative trope of positive transformation with alternative expressions of experience often subjugated or silenced. This standardised narrative trope was encouraged by the American Cancer Society (2012) in their appeal for the submission of "inspirational stories" which may provide "hope" or "comfort and courage" to those "touched" by cancer (Nielsen, 2019, p.3). This campaign concisely encapsulates two key issues which I regard as problematic and which I will discuss in this section; these are the standardisation of narrative and the inaccuracy and inadequacy of cancer-related language in English.

Dissatisfaction with commercial representations and textual trammels relating to breast cancer has precipitated my practice-based inquiries into sonic life writing, with issues regarding the limiting nature of language at the heart. Gayle A. Sulik in *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health* (2011, p.317) writes:

After Kristen Garrison's mother died of cancer, she wrote about the difficulty she had writing her mother's obituary. In a scholarly article about breast cancer rhetoric, she wrote:

"Describing her life was easy enough. Describing who survived her straightforward. But I had no words to describe her death, and I stumbled over, resisted, what dad, my sister, and my aunts finally advised: she lost a four-year battle with cancer. I had the most difficulty with the verb."

As a university-level English instructor, Garrison's inability to access words beyond the typical cancer vernacular had nothing to do with her command of the English language. The cancer dictionary has a finite number of words.

The cancer vernacular, with its emphasis on metaphor of warfare — battles lost and won, survivor status celebrated, warrior mentality lauded — has certainly helped the perpetuation of what Proctor and Schiebinger (2008) describe as agnotology, the

cultural production of ignorance. In *Agnotology: The Making and Unmaking of Ignorance*, Proctor and Schiebinger present a programmatic discussion of ignorance as being much more than "the not yet known" (2008, p.3) and, in fact, being a structural system of production which is generated by "secrecy, stupidity, apathy, censorship, disinformation, faith, and forgetfulness" (ibid., p.2), also "neglect... myopia, extinction... and suppression" (ibid., p.3). The standardisation of narrative — i.e. the social and commercial encouragement of only quest narratives of positive transformation — draws upon almost all of the above qualities of ignorance production: secrecy, censorship, disinformation, faith, forgetfulness, neglect, myopia, and suppression. Judy Z. Segal, a researcher of breast cancer cultures and narratives who was herself diagnosed with breast cancer after having published many papers and books on the subject, was inspired by Proctor's and Schiebinger's (2008) idea of agnotology<sup>17</sup> and argues that misunderstanding, misinformation, and ignorance is perpetuated through language and through the standardisation of narrative.

Segal's agnotology thesis is as follows: "personal breast cancer stories are one means of producing and maintaining ignorance about breast cancer. They do this, in part, generically" (2007, p.4). Segal argues that ignorance about cancer is maintained, in part, by the rehearsal of stories that have standard plots and features, and that suppress or displace other stories. As such breast cancer "quest narratives" exist in great number and now dominate the pathographical space, they surely must inform the creation of new breast cancer narratives. If someone were to hypothetically experience breast cancer in a vacuum, with no prior knowledge of or exposure to breast cancer narratives or culture, would they be less likely to create a standard quest narrative extolling the positively transformative benefits from having been diagnosed with and treated for breast cancer? Segal (ibid.) describes the standard features of breast cancer narratives and how these stories typically begin

<sup>&</sup>lt;sup>17</sup> in relation to science studies

with the discovery of a lump. This detection of unwanted tissue marks not only a change in social status from well to sick but also the structural start of the comedy,<sup>18</sup> according to Couser (1997); the fact that the author has lived to tell the tale qualifies it as having a happy ending.

Frankian breast cancer quest narratives insist on a form of positive transformation, as this story by Donaldson (2007, p.26) in *Beyond* magazine shows:

Cancer inspires me. I've been given a wake-up call that many people will never receive. I have been reminded that life is never a guarantee, and with that knowledge, I am happy to simply be alive.

Such stories of gratitude for the experience of breast cancer and the learnings it may engender have now been embedded in scholarship in the fields of Psychology and Medical Humanities; these stories are now phenomenologically referred to as examples of post-traumatic growth (Ruini and Vescovelli, 2012; Ruini et al, 2012; Parikh et al, 2015; Groarke et al, 2016; Fujimoto and Okamura, 2021). Furthermore, a "prescriptive coda" (Segal, 2007, p.4) is added to these quest narratives, one which Diane Price Herndl (2006, p.232) neatly sums up as "be like me." Price Herndl is distrustful of what Busch et al (1998, p.5) describe as the "Cancer Enlightenment Program" and of a writer's sense of self that "sees itself as a model to follow" (Price Herndl, 2006, p.232). A generic gratefulness for the experience of cancer as some kind of wake-up call coupled with publishers' desires to produce only inspirational

<sup>&</sup>lt;sup>18</sup> Couser does not liken the breast cancer quest narrative, in general, to hilarious lighthearted comedies but refers to the distinctions between tragedies and comedies. Dadlez's and Lüthi's (2018) paper exploring the importance of incongruity in constituting and distinguishing comedy and tragedy is pertinent in this context: both genres of drama addressing "phenomena and scenarios that violate established patterns or expectations" (ibid., p.82), i.e. a cancer diagnosis and subsequent treatment being an unexpected disruption and suspension from normal life. See chapter three for further discussion of disruption and suspension of predictable, everyday life as experienced during cancer treatment.

stories combine to suppress and replace the sharing of alternative narratives (Nielsen, 2019).

Of course, many people diagnosed with breast cancer will die from the disease and many people will have experiences which are not positively transformative. In Malignant: How Cancer Becomes Us, S. Lochlann Jain (2013, p.14) explains how "cancer is not solely a biological phenomenon but a politics with which to engage and struggle." Political engagement, descriptions of struggle, and expressions of rage are important characteristics of a sub-genre of breast cancer stories which Nielsen (2019) identifies as "counter-narratives," written by feminist cancer "killjoys" (Ahmed, 2010). Moving beyond the publicly and socially acceptable feelings expressed in standardised narratives, the killjoys (writers including Ehrenreich, Mesley, Sontag, and Lorde) do not shy away from expressing dissatisfaction or from questioning institutional, social, and cultural oppression. Killjoy writers recognise that more negative feelings, fears, and anxieties are totally valid and not to be discredited or silenced. The killjoy counter-narrative repositions the individual as an active and engaged participant in sociocultural life rather than a passive recipient of healthcare (Nielsen, 2019) and asks the reader to bear witness to injustice and suffering.

One very important example of the cancer killjoy counter-narrative is Audre Lorde's *The Cancer Journals* (1980). Lorde, as a Black lesbian feminist poet, described the intersectional struggles she faced throughout her experience of cancer. Her *Journals* have had significant social and academic impact. By challenging dominant narratives and widening the discourse on cancer to include intersections of race, gender, sexuality, and healthcare disparities, Lorde's powerful work has shed light on the experiences of marginalised communities in the healthcare system. Sara Ahmed, in *The Cultural Politics of Emotion* (2014), describes Lorde's productive ability

to integrate anger in her many writings to provide visionary insights for future change. In Sister Outsider, published four years after The Cancer Journals, Lorde argues:

Every woman has a well-stocked arsenal of anger potentially useful against those oppressions, personal and institutional, which brought that anger into being. Focused with precision it can become a powerful source of energy serving progress and change ([1984] 2007, p.127).

Whether it be anger about environmental pollution, inclusion of known carcinogens in North American grocery items, the medical patriarchy, or the "cult of pink kitsch" (Ehrenreich, 2001), the feminist cancer killjoys harness the power of anger in their work to foreground injustice and wrongdoing. As Lorde (1980, p.75) writes, "the idea that happiness can insulate us... is a rumour circulated by our enemies to destroy us."

The enforced or expected happiness and gratitude celebrated in quest narratives relate to the concept of magical thinking in psychology and psychoanalysis (Tylke, 1992; Ogden, 2010; Vyrgioti, 2022): what Sedgwick (2007) describes as a form of Kleinian projective identification. Magical thinking is a "mediator of stress" (Tylke, 1992) and a mechanism for coping with uncertainty: the faux filling of a knowledge gap, sharing qualities of agnotology such as faith, censorship, and suppression. Tendencies towards magical thought and the favouring of positively transformative narratives are opposed to the work of cancer killjoys such as Ehrenreich (2001, 2010, 2018) and Sontag (2012; [1978] 2013) who actively engage with themes of suppression, passivity, pain, and regression in their work.

In As Consciousness is Harnessed to Flesh: Diaries 1964-1980 (2012), Sontag describes feelings of the loss of ownership of her own body, returning "it" to the hospital to be interfered with by doctors:

I return/haul myself to the hospital and present my opaque body to Doctor Green or Doctor Black, so they can tell me how I am. One pushes and pulls

and pokes, admiring his handiwork, my vast scar. The other pumps me full of poison, to kill my disease but not me.... I feel like the Vietnam War.... they're using chemical weapons on me (2012, p.35).

Sontag describes the passivity widely expected of breast cancer patients: the handing over of the body to be inspected, cut, and poisoned. She clearly expresses a metaphor here which is so often skewed in standardised cancer narratives and breast cancer culture: that of warfare. Although her body is like a war zone - a site of devastation, disfigurement, and injury – she is not an active participant in that war. She is not a noble, proud fighter whose bravery and positive-mindedness are rewarding her with survival; she is not an example of the strong warrior attitude so commonly referenced in bromide platitudes and T-shirt slogans. Sontag is a submissive, yielding member of a joint production, her body (which she repeatedly presents at the hospital) a locale of amputation and contamination, her surrender so abject she relies on doctors to tell her how she is. Sontag expresses the emotional and physical pain of cancer treatment, sheds light on medical patriarchy, and describes the injustice and inadequacy of the English language in connection with cancer. By sharing her authentic experience (written before the 1990s quest narrative boom) in ways that engage with social and political issues, she, like Ehrenreich and Lorde, very much qualifies as a cancer killjoy (Ahmed, 2010; Nielsen, 2019).

Sontag's *Illness as Metaphor* ([1978] 2013) explores how we deny illness' essential nature through the use of metaphor. By examining the cultural and metaphorical associations Western societies, past and present, have attached to cancer and tuberculosis, Sontag argues against the harmful clichés and stigmatisation that often accompany diseases and reveals how metaphors can distort and trivialise the lived experiences of the sick. Advocating for a more nuanced and compassionate approach to cancer discourse in the English language, Sontag

critiqued the metaphors of warfare and portrayals of cancer as an enemy that needs to be fought and defeated. Such metaphorical framing can lead to feelings of guilt or failure if the person with cancer is not diagnosed early enough, does not respond positively to treatment, or experiences a recurrence (Harrington, 2012; Penson et al, 2004). The simplistic metaphor of warfare disregards the complex and entangled emotional experience of living with cancer and overlooks the multifaceted and constellational nature of the disease.

A simplistic attitude towards cancer was prevalent in America from the late 1960s. From 1969 to 1971, American socialite Mary Lasker and president Richard Nixon declared a "war on cancer" (Coleman, 2013, p.31). Given that cancer is a varied constellation of diseases affecting all mammals (Vincze et al, 2022)<sup>19</sup> and is "intrinsic to our cellular biology" (Coleman, 2013), a pledge to eradicate cancer from America within seven years was not just bold, but impossible. The aggressive language of war, as used by Nixon and as explicated by Sontag ([1978] 2013), hinders and prevents realistic understanding of the actualities of this complex disease and warps people's expectations and judgements. As Coleman notes:

'War' is more than just a metaphor. It distorts political thinking about cancer with the illusory clarity of victory and defeat. Therapeutic attacks on the 'enemy' are prioritised over strategies to prevent the disease occurring, and where there is 'war', there goes the medical-industrial complex. The therapeutic armamentarium has improved out of all recognition since the 1970s, but it now threatens to bankrupt the health system in the world's richest country, where millions still await access to health insurance under the Affordable Care Act. Elsewhere, entire countries have no access to radiotherapy. The inequalities are glaring. (2013, p,31)

<sup>&</sup>lt;sup>19</sup> And is now known to have affected dinosaurs too (Ekhtiari et al, 2020; Vogel, 2020)

Connecting cancer with warfare also creates a false pathological conception of the disease, setting out the cancer as an enemy "other" when in fact it is a natural expression of one's own cellular biology.

To recapitulate, the cancer vernacular of the English language is inadequate. The development and use of harmful metaphor, perpetuating agnotology, remains rife, and language of battles won and lost, victimhood, and survivorship oversimplify and distort the complex reality of a challenging and deadly disease. A discourse on the dominating positive attitudinal bias concerning breast cancer continues to develop and brings into question moralistic ideas about "healthy mindedness" (Hawkins, 1993) and magical thinking; normative expectations of breast cancer becoming an enriching experience and a rite of passage (Ehrenreich, 2010); and the testimonies of feminist cancer "killjoys" (Ahmed, 2010; Nielsen, 2019) disrupting the predominant trend of cancer narratives, cultural representation, and corporate symbolism. If the standard testimonial culture is so problematic, can sound and music offer new directions to explore? Without lexical information, one is not subject to or captured by normative expectations or standard symbolism. The work of this portfolio stands close to that of the killjoy faction, presenting testimonial creative work.

To create a non-lexical sonic life writing account of cancer bypasses the pitfalls of rhetoric, iconography, and symbolism, and presents the experience in a very different way which is potentially more engaging, less frightening, and somewhat edifying in regards to details, emotions, and relationships. These defiant experiments in sonic life writing about breast cancer reject and circumvent the problems of language and narrative and reject the pink cult of contemporary breast cancer culture. You can't stick a pink ribbon on a composition.

Before moving on to discuss modes of sounding and listening, I note here that

much of the pertinent discourse in the fields of illness narratives, narrative medicine, and medical/health humanities draws on the work of psychologists and psychoanalysts such as Melanie Klein and D W Winnicott. Throughout subsequent chapters of this thesis, I draw on the work of Klein, Winnicott, and Michael Balint in exploring issues relating to the lived experience of cancer and I do so through the work of writers who were influenced by them, such as Eve Kosofsky Sedgwick and Neil Vickers. I have not studied psychology or psychoanalysis and therefore am not qualified to provide an appropriately astute and detailed literature review of the relevant research, theories, and methods of Klein or Winnicott at this stage.<sup>20</sup> I do, however, wish to posit the idea that psychoanalysis and psychotherapy can involve the undoing of rehearsed stories and normative expectations; the undoing of multiple agnotologies regarding gender, sexuality, race, class, abuse, oppression, and more; and the exploration of the actuality of our inner and outer lives. This undoing happens through sounding (or voicing) and listening.

# ACOUSTEMOLOGY

Combining "acoustics" and "epistemology," acoustemology is a term used to describe sounding and listening as ways of knowing and was developed by ethnomusicologist, Steven Feld, in his 1996 essay, *Waterfalls of Song: An Acoustemology of Place Resounding in Bosavi, Papua New Guinea.* While the term itself is relatively contemporary, the ideas and concepts it encompasses have longer histories in disciplines including anthropology (Merriam, 1964; Nettl, 1991), ethnomusicology (Blacking, 1974), sound studies (Schafer, 1977), phenomenology (Merleau-Ponty, [1945] 2013; Oliveros, [1974] 2005; Ihde, 2007), and cultural studies (Williams, 1983).

<sup>&</sup>lt;sup>20</sup> See Klein (1984, 1986), Winnicott (1953, 1971, 2016), and Balint (2018).

Feld's concern with how the world is "constituted relationally, by the acknowledgements of conjunctions, disjunctions, and entanglements" (2015, p.12) compelled him to theorise sounding and listening as relational practices, integral to "connectedness of being" as built on "the between-ness of experience" (ibid, p.13).

Feld's acoustemology does not follow epistemology in the traditional sense – exploring the metaphysical or transcendental underpinnings of assertions about truth (referred to as "epistemology with a capital E" by Rorty (1979)) – but, instead, involves examining how knowledge is produced in a relational manner, akin to what John Dewey referred to as contextual and experiential understanding (Dewey and Bentley, 1975). Feld developed his idea of acoustemology through the study of Bosavi songs in Kaluli culture, the "vocalised mappings" (Feld, 2015, p.16) of the tropical locality and deep engagement with space, place, and body led Feld to an understanding of listening and sounding as habitus and co-habitus (Feld, 1996, 2015; Rice, 2018).

Feld's acoustemology shares commonalities with Brandon LaBelle's concept of acoustic territories ([2010] 2019) and his explorations of listening as social practice ([2010] 2019, 2020a, 2020b, 2022, 2023). LaBelle argues that the environments and spaces which humans inhabit are not only visual and physical but also cultural and social, shaping and being shaped by the sounds sounded and listened to within them. Also in concordance with Feld, LaBelle articulates listening as a dynamic practice that is fundamental to the understanding and construction of shared experience, in co-habitus.

In Tom Rice's interview with Feld (2020), the pair discuss the open-ended and non-prescriptive possibilities of acoustemology and the prospects for generative, shifting acoustemologies in a variety of contexts. With discourse concerned with acoustemology's potentially converse relationship to culture and to fundamental human instinct, Feld and Rice examine the "routinised habitual forms of knowing

through the body and the ears and the hands and the tongue" (ibid, p.4), building on work by Mauss (1973) and Bourdieu (1987). Such enquiry seeks to counter what Douglas Khan (2001, p.158) describes as "visuality overwhelming aurality in the cultural balance of the senses" by rebalancing perception away from ocularcentrism (Kavanagh, 2004; Kitireanglap, 2022) in favour of connected, temporal, spatial knowing through sound.

Rice has developed the acoustemological principle of "being grounded in the basic assumption that life is shared with others in relation" (Feld, 2015, p.15) in his sensory ethnographic work on medicine and the hospital environment. Whilst his writings (Rice 2010, 2012, 2013) on the generalities of hospital acoustic environments — the bleeding of sounds, exposing and intruding — are pertinent to this research and to the consideration of medical soundscapes and acoustic profiles, it is the examination of diagnostic acoustemologies that chimes with my primary research questions regarding knowledge of the medicalised body through and with sound.

Typically with the use of a stethoscope, auscultation, described by Rice (2010), is the process of listening to the lungs, heart, or abdomen, generally as part of a physical examination and potential diagnosis (Chizner, 2008; Sarkar et al, 2015). This process of auditory engagement with the body is a mechanism of embodied knowledge production: a specific acoustemological situation which depends, to a great degree, on the auditory skill acquisition of the medical student or trained professional. Rice (2010) describes the technique of stethoscopic listening and the difficulty experienced by medics who must recognise and interpret a variety of different bodily sounds. This auditory endeavour and engagement with the medicalised body echoes Feld's acoustemological idea of hearing as an embodied mastery of locality (2015): the medical professional must master the body of the examinee by the production of knowledge through listening, developing command

over a corporeal sonic geography. The difficulties and decline of auscultation (Rice, 2010, 2012, 2013), speak to a general under-valuation of the sonic (Chattopadhyay, 2021), a lack of auditory skill acquisition and development (Thompson, 2017; Hafke-Dys et al, 2019), and a reinforcement of Kahn's idea of visuality overwhelming aurality. Not only is the visual afforded primacy in the "cultural balance of the senses" (Kahn, 2001, p.158) but so much so that we have become aurally disconnected from our bodies for the majority of our lives.

Human lives typically begin and end in liminal and almost exclusively acoustic environments. Audition is thought to be the only source of sensory stimulation in utero: the faculty of hearing is commonly appreciated to be fully formed and functional by the end of the second trimester (Querleu et al, 1988; Jardri et al, 2012; Thompson, 2021; Henriques et al, 2023). Whilst it is difficult to argue that a foetus' acoustic environment is an acoustemological one, given that the unborn child may not be cognitively developed enough to make meaning from sound or to interpretively understand its environment through sound, it is true to say that their acoustic territory is nonetheless a corporeal one. Sounds from the mother's digestive system, the beating of her heart, and the vibrations of her voice – generated by the larynx and transmitted through the spinal column – are at least recognised by the foetus at around 33-34 weeks of gestation (Jardri et al, 2012; Henriques et al, 2023). Given that our first-heard sounds are corporeal, it seems remiss, or even counterintuitive, to exclude the auditory in artistic research regarding the body, health, and therefore illness.

Also, at the end of life, it is widely understood that the sense of hearing continues to operate even into the final hours and minutes, even when other senses have ceased and a liminal, unconscious state has become established, prior to death (Tapson et al, 2015; Blundon et al, 2020). Electrophysiological evidence has shown

awareness of sound, and of bodily sound, in the final stages of expected natural death (Blundon et al, 2020).

For most people, at least in Western societies, the body is not conceived of, or appreciated, in audition throughout life. An auditory disconnection from the corporeal occurs at birth and — with exceptions including tinnitus (Farmer, 2023) and hearing aid problems (Bennett et al, 2020; Greasley et al, 2020) — lasts until end of life. We may pick up on aural clues as signs of ill health (from a bad cough, a clicking joint, or a medic's cardiac auscultation) but we do not aurally engage with the body like writers or visual artists do. This thesis, therefore, offers a proposal for a creative corporeal acoustemology, an artistic auscultation of a cancer.

#### LISTENING AND/AS CARE

Contemporary research in sound studies offers an entangled approach to understanding listening, considering it not a passive reception of sound but a complex, intricate, and culturally-mediated phenomenon. Listening as an active and context-dependent process of engagement with, and making meaning of, acoustic stimuli involves cognitive (Chion, 1994; Santaella, 2017; Bonnet 2019), perceptual (Merleau-Ponty, [1945] 2013; Clarke, 2005; Nancy, 2007; Zelenka, 2021), social (Bourdieu, 1987; Clarke and Cook, 2004; Sterne, 2012; Eidsheim, 2015), political (Voegelin, 2010, 2018, 2023; Cox, 2018; LaBelle, 2020), and cultural dimensions (Cox and Warner 2017; Eyene, 2019; LaBelle 2019; Licht 2019; Lane 2016, 2019, 2020; Lane et al, 2016). The field of sound studies hosts substantial discourse on a panoply of listening practices, and relationships to and with sound, which are too numerous for this literature review to honour and so I will focus more specifically on listening and/ as care.

The relationship between listening and care has become a significant focus in interdisciplinary research (Mullane, 2010; Bourgault, 2016; Kannenberg, 2020;

Stefánsdóttir and Östersjö, 2022), which acknowledges that listening can extend beyond aesthetic activity to encompass a form of (temporal) care and ethical engagement. Sharing many commonalities with the principles of acoustemology and aesthetic critical realism, contemporary interdisciplinary research shows how listening practices can contribute to the wellbeing of individuals (Groarke and Hogan, 2015; Black et al, 2017; LaBelle, 2020) communities (Voegelin 2018, MacDonald and Wilson 2020), and environments (Westerkamp, 2002; Ouzounian, 2017). I shall explore a variety of ways that listening contributes to wellbeing.

Firstly, listening has been explicated by Clarke, DeNora, and Vuoskoski (2015) as a means of empathy cultivation. Whether listening to interpersonal communication, engaging with sonic environments, or listening to music, Clarke et al have examined neuroscientific, psychological, sociological, and ethnomusicological approaches to empathy cultivation. Akin to the acoustemolgical principle of life being shared in relation with others (Feld, 2015), empathy facilitated by listening is considered a form of care for, and about, the experience of others, and fosters affiliation (Vuoskoski, Clarke, and DeNora, 2017). Cultivation of empathy and affiliation is one mechanism of developing community and interconnectedness through listening. DeNora (1999, 2000, 2003) examines the socialising media of sound and music and how attentively engaging with the sounds around us forges stronger social and spatial bonds, contributing to a shared sense of space and experience. Attention and so-called mindfulness also play a part (Oliveros, [1974] 2022, 2005, 2022; Jones et al, 2019) in bonded experience as do listening practices related to acoustic ecology and environmental stewardship which foster care and develop a sense of responsibility through listening (Paine et al, 2015; Paine, 2017; Ritts and Bakker, 2021).

Simultaneously, listening extends beyond the individual, weaving a social

fabric that defines its contours. The social dimension of listening is intertwined with interpersonal dynamics (Manusov et al, 2020); communication goals (Keaton et al, 2015); cultural practices, norms, and values (Bourdieu, 1987, [1980] 1990; Grenfell, 2014); and power structures (McLeod, 2007; Bassel, 2017; Murphy, 2020). Listening practices are also strongly connected to matters of ethics and justice, as explored adeptly by Voegelin (2018) and LaBelle (2020). LaBelle asks:

What particular ethical and agentive positions or tactics may be adopted from the experiences we have of listening and being heard? Might the knowledges nurtured by a culture of sounding practices support us in approaching the conditions of personal and political crisis? (2018, p.1)

This thesis explores these two questions, recognising power dynamics (such as medical patriarchy, facets of breast cancer culture, and the censorship powers of publishers) and adopting responsible and considerate approaches to sounding and listening that operate against the structures of agnotology and in the pursuit of sociopolitically engaged discourse and authentic testimony.<sup>21</sup> The entangled and constellational nature of listening and/as care shares myriad commonalities with Wilson's exploration of Aesthetic Critical Realism, as summarised in the following section and explored in depth in Chapter Two.

# AESTHETIC CRITICAL REALISM

Nick Wilson's *The Space That Separates* (2019) introduces principles of social scientific critical realism, as developed by Roy Bhaskar (1975, 1986, 2008; Collier 1994), to the fields of art and aesthetics. At the root of Bhaskar's original theory of

<sup>&</sup>lt;sup>21</sup> Listening is also deeply linked to social justice and advocacy efforts. Actively listening to marginalized or silenced voices is considered a form of care that can lead to more inclusive, reparative, and equitable social practices. Listening as reconciliation is explored by Ananda Breed (2006) in *Performing Reconciliation in Rwanda*; theatrical and musical activities have been used as tools for forgiveness and for reconstructing identity and community in post-genocide Rwanda.

critical realism (CR) is the assertion that observable and unobservable reality exists independently of our perceptions. In emphasising the ontological stratification of CR theory, Bhaskar, and later Wilson, state that events are dependent or established upon underlying structures and both Bhaskar and Wilson advocate for a dialectal relationship between the empirical and the deeper, non-observable aspects of reality. Wilson's development of CR as aesthetic critical realism (ACR) comes at a "persecutory time" (2020, p.398) when oversimplified and binary notions of us/them, right/wrong, and good/bad have come to dominate many areas of life, not least in contexts of so-called culture wars and post-truth, polarising politics (Hawks and Uzunoğlu; 2019; Naím, 2021). Wilson's laminated explication of the bonded and dialectical strata of ACR makes clear the simplistic inaccuracy of contemporary binary notions and posits complex entanglements of being by illustrating "the space that separates" (2019).

Wilson's jumping off point, a development of Desmond's (1995) inbetweenness of human life, is the idea that "to be alive is to be-tween... we are, all of us, between being and becoming, self and other, potential and actual, known and unknown" (2019, p.ix). Wilson's liminal life, as recognised by Norrie (in Elder-Vass et al, 2023), is powerfully influenced by aesthetic experience with art not merely being a pleasant frothy extra, such as a night at the opera, but as a multi-layered structured experience with the power to impact our daily behaviours, change opinions on social and environmental matters, and guide us towards emancipation. It is undervaluing and separating aesthetic experience, syphoning it off into "the arts box" (Norrie in Elder- Vass et al, 2022, p.107), from daily life that diminishes our power as human beings.

Wilson's schema of ACR offers a detailed development of the concept of acoustemology and experience more generally, by examining both ontological and epistemological perspectives on the aesthetic, and is described in the list of seven overlapping and interrelated experiences below.

Aesthetic experience — Being-inrelation Axiological experience — Value(s) Metaxological experience — Between Cultural experience — Value recognition Alethic experience — Truth Constellational experience — Beauty Living artfully — Good

Like Feld's acoutemology, Wilson's theory of ACR concerns itself with experience, that is, "the human capacity for cognitive conscious and nonconscious, i.e. thought and unthought, knowledge gained through inter-action with our environment" (in Elder-Vass et al, 2022, p.113). Although Wilson's use of "aesthetic" as a determining descriptor has garnered criticism in the *Symposium on The Space that Separates: A Realist Theory of Art* (ibid.) due to its discrete specificity and distinction from "normal" experience, Wilson defends its use as an umbrella term under which the above strata are carefully set out and examined.

For Wilson, art serves as the nexus between the individual and the collective, facilitating a reciprocal transition between the two spheres. Functioning as a communicative practice, it entails the intentional transformation of personal aesthetic experiences into shareable forms. This process is characterized by a nuanced and adept approach to fostering affiliations (DeNora, 2000; Clarke et al, 2015; Vuokoski et al, 2017), necessitating the deployment of faculties such as creativity (MacDonald and Wilson, 2020), play (Reichling, 1997), imagination (Elliott, 2006), and additional cognitive dimensions (Clarke et al, 2010). These themes of ACR speak to the research of this thesis and accompanying portfolio.

#### <u>SOUNDING</u>

Scholars within the field of sound studies often employ diverse methodologies such as ethnography (Feld, 2012; Isoke, 2018), archival research (Hoffmann, 2015;

Bijsterveld, 2016), psychoacoustics (Cook, 2001; Toole, 2017), and critical theory (LaCapra, 1989) to explore the multifaceted nature of sounding. This thesis, in its engagement with themes of sounding, considers and uses ideas of sonic agency, elements of soundscape, techniques relating to sonification as transformed into artistic sonation, and compositional and performance methods in the mode of sonic life writing. I shall review these themes in turn.

Sonic agency is perhaps most commonly associated with the contemporary work of Voegelin and LaBelle, both key figures in shaping the "culture of sonic thought" (LaBelle, 2018, p.1) and developing notions of "sonic sensibility" (Voegelin , 2010). It is LaBelle's introductory questions in the exploration of sonic agency (2018) which have provided the most meaningful inspiration for this thesis:

I'm concerned to not only contribute to an in-depth culture of sonic thought, but to also shape such thinking by locating it against social and political realities: the figures and voices that are lifted up, negotiated, interfered with, and assembled through and by sonic means and imagination. Is there a potential embedded in sonic thought that may lend itself to contemporary struggles? What particular ethical and agentive positions or tactics may be adopted from the experiences we have of listening and being heard? Might the knowledges nurtured by a culture of sounding practices support us in approaching the conditions of personal and political crisis?

The consideration of "figures and voices that are lifted up, negotiated, interfered with" connects with criticism in the field of illness narratives and life writing: how choices and interferences made by publishers and PR companies perpetuate agnotology and push dominant tropes in the public consciousness. The consideration of sounding practices in conditions of personal, social, and political crisis spoke to my desire to attempt to "sound out" my personal experience as an intervention in the often problematic space of contemporary breast cancer culture.

Given the sheer lack of non-lexical sonic accounts of illness, and specifically breast cancer, my work provides a tentative but nonetheless agentive jumping off point: a place from which to start exploring possibilities of a new sounding culture in

relation to the body, health, and illness. One of the potential agentive outcomes of the sonic is a movement towards, or an arrival at, a state of acoustic justice, of truths and testimonies heard, and cared for and about. The lexical illness narrative is shaped within an existing ecosystem of production, publishing, promotion, criticism, reception, and expectation. As Ahmed (2006, p.14) notes, from a queer phenomenological perspective, "when we follow specific lines, some things become reachable and others remain, or even become, out of reach." By continuing only along the path of the lexical illness narrative, we encounter new iterations of Frank's wounded storyteller archetypes (1995) and (potential) examples of new cancer killiov counter-narratives. By opening up a nascent space of sonic life writing we may reach previously unreached cultures and states of interconnected being and relating through active listening. Echoing the critical realist drive for freedom, LaBelle calls for a sonic agency which emphasises social productions and experiences of sound and audition with sonic sensibility informing emancipatory practices (2018, p.2). This research is the first step in exploring whether it is possible to emancipate breast cancer culture and narrative from the cultivated tropes previously discussed and the dominant pink representations so common in UK and US fundraising spheres.

In Chapter Two of this portfolio, I include some short home-made reproductions of field recordings in the composition, >>KRANKENHAUSFUNK and the extrinsic death receptor pathway<<.<sup>22</sup> These field recording re-productions are distinct from what R. Murray Schafer described as the "soundscape" in his pioneering work in acoustic ecology (1977). As Krause (2008, p.73) notes, "Schafer's definition of soundscape includes all of the sound from a particular environment that reaches the human ear." Because the recordings focus on the sounds of chemotherapy infusion pumps, not the total acoustic profile of a hospital ward, the descriptor of "soundscape" is not appropriate. The recordings used in this portfolio are sonic documentations of an object(s) and therefore fall more neatly into the capacious category of field recording, as explored by Lane and Carlyle (2013), Carlyle (2020), Benson and Montgomery (2019), and Westerkamp (2021).

<sup>&</sup>lt;sup>22</sup> These recordings also feature quietly as a supporting audio bed in TCH-P.

The main focus of these first explorations of a new sonic life writing mode is not in the re-producing of recorded sounds of a specific time and place, but an attempt to develop a new compositional approach related to, but distinct from, sonification. Commonly understood as "the use of non-speech sound to convey information" (Vickers, 2017 and 2021), sonification makes the inaudible audible and is a means of auditory display. Following the emergence of the International Community for Auditory Display, established by Greg Kramer, sonification became an increasingly common modality of sounding for the analysis and exploration of data (Roddy and Furlong 2014, Vickers 2021). Sonification deals with quantitative research; it depends on numerical data. Some fascinating and compelling examples of sonification related to health data include Jamie Perera's powerful sonification of the recored UK deaths due to Covid in 2020, called First Wave (2020). Each death is assigned a sound and over the course of the ten-hour sonification, numerous interviews and field recordings (which Perera describes as soundscapes) are polyphonically woven together with the sounds of deaths. More recent work by Perera includes the sonification of Target Malaria's 2016 Cr-Z4050E5 Cage Trials by Imperial College London in a two-minute piece titled Swarm (Mitchell, 2023).

My research concerns itself not with the quantitative but with the qualitative and, therefore, sonification is not a suitable methodology for this project. I have chosen to explore and develop a new way of sounding — which I am calling artistic sonation — in order to achieve a richer level of performative expression and representation. Sonation means the bringing forth of sound; to sonate is to sound. Commonly associated with the natural world, and especially with birds, sonation typically involves mechanisms of sound production unconnected to the larynx or syrinx (Gómez-Bahamón, 2020). My aim is to make the inaudible past experience of cancer treatment audible through the unconventional means of qualitative, process-

related (rather than numerical data-related) compositional representation. This portfolio of practice-based research concerns itself with sharing artistically-sonated qualitative information about the experience of cancer, from an auto-ethnographic perspective, and attempts to express process-related (rather than numerical data-related) information. The expression of qualitative and process-related information has been attempted with a performance autoethnographic perspective, in accordance with principles of practice-based research, and through intercultural and interdisciplinary compositional methodologies.

# INTERCULTURAL MUSIC, EXOTICISM, AND FUSION

The least interesting form of influence, to my mind, is that of imitating the sound of some non-Western music... This method is the most superficial way of dealing with Non-Western music, since the general sound of these musics can be absorbed in a few minutes of listening without further study. Imitating the sound of non-Western music leads to "exotic music" - what used to be called "Chinoiserie."

Alternately, one can create a music with own's [sic] sound that is constructed in the light of one's knowledge of non-Western structures...... One can study the rhythmic structure of non Western music and let that study lead one where it will, while continuing to use the instruments, scales, and any other sound one has grown up with. This brings about the interesting situation of the non-Western influence being there in the thinking but not in the sound. This is a more genuine and interesting form of influence...... Instead of imitation, the influence of non-Western structures on the thinking of a Western composer is likely to produce something genuinely new.

Steve Reich, Writings on Music 1965-2000, 2002, p.70

Originally published under the title *A Composer Looks East* in the New York Times in 1973, Steve Reich discusses the influence of Balinese and African music on his compositional output, touching on issues of exoticism and fusion. The distinction Reich draws between merely imitative music written by Western composers and music that is informed by the study of structures and theories of non-Western musics is at the crux of the debate concerning musical exoticism and fusion. A simple definition of musical exoticism is the use, or borrowing, of musical material to evoke distant locales which, in turn, manifests in the compositional process as "making notes do something different from what they usually do" (Bellman, 1998, p.ix). Western composers have had a propensity for appropriation and musical borrowing from at least as far back as Jean-Philippe Rameau in the early eighteenth century (MacKenzie, 1995; Born and Hesmondhalgh, 2000; Corbett, 2000; Landy, 2003).<sup>23</sup>

Examples of Karnatak musical appropriation from the time of British and French colonial power in India include two noteworthy works by the early modernist composer Maurice Delage. With a commitment to sound colour typical of musical Impressionism during that time in France, and following in the footsteps of Debussy's gamelan-inspired timbres and textures (Howat, 1983; Boyd, 1991; Tamagawa, 2020), Delage was inspired to compose the works *Quatre poèmes hindous* (1913) and *Ragamalika* (1922).<sup>24</sup> These works are of an essentially impressionistic nature (Lipscomb, 1951; Palmer, 1974): using, or borrowing, Tamil poetry for lyrics, as in *Ragamalika*, and peppering the vocal line with imitative Karnatak-esque gamaka (ornamentation) serves to produce a piece of exoticised Western chamber music.<sup>25</sup> After visiting India, Delage found that the Indian music he had enjoyed provided him with "new sounds with which to enrich a composer's palette" (Pasler, 2008, p.418).

<sup>&</sup>lt;sup>23</sup> For instance, Rameau's tepidly-received opera *Les Indes Gallantes* from 1735; see Sadler (1997). Also Purcell's *The Indian Queen* (1695) points to an earlier Orientalist interest but there is little Indian reference in the musical material itself, if any; it is narratively exotic.

<sup>&</sup>lt;sup>24</sup> Ragamalika, meaning a garland of ragas, has both a general and a specific use in Karnatak music. If the different sections of a vocal performance are set to different ragas then the form is said to be in ragamalika. The word also refers to a specific vocal tripartite form comprising a *pallavi*, *anupallavi*, and *charana* and where each charana is sung in a different raga. For more detail, see Sathyanarayana, 2004, p.121

<sup>&</sup>lt;sup>25</sup> What is interesting, however, is the decision to imitate an unspecified Indian drum by using a simple "prepared piano" technique of dampening the strings of a B flat key in the bass with cardboard. Written three years earlier than Cowell's *The Banshee* (1925), a groundbreaking work for piano using extended technique, and well in advance of Cage's Sonatas and Interludes for Prepared Piano (1946-48) (which were composed whilst Cage was reading the works of the Indian art historian and critic Ananda K. Coomaraswamy), *Ragamalika* certainly points to the ensuing radical developments in Western piano music.

Through the lens of Said's theory of Orientalism ([1978] 2014),<sup>26</sup> one can view the enriching of his composer's palette as a clear example of cultural acquisition. This borrowing of Tamil poetry and gamaka ornamentation falls directly into the artistic lineage Said ([1978] 2014, p.6) describes as "a systematic discipline of accumulation."

Within ethnomusicology and anthropology (MacKenzie 1995; Bellman, 1998; Locke, 1998; Scott, 2000; Peltre, 2004; Pasler, 2008), the relationships between culture, power, ethnicity, and class add a sinister edge to the practice of exotic (and sometimes fusion) music; historically there are many examples, such as Delage and Benjamin Britten,<sup>27</sup> of Western composers demonstrating the relationship between political domination and cultural production with Orientalist and exoticised music. Nicholls (1991), Born (2000), Hesmondhalgh & Born (2000), Baldacchino (2001), and Landy (2003) examine musical borrowings and appropriations by Western composers with emphasis on the relations between culture, power, ethnicity, and class. Primarily concerned with post-colonial and post-structuralist theoretical views that involve Said's Orientalism in understanding the work of late-nineteenth and twentieth century composers, questions are rightly asked regarding "the relationship between political domination and cultural-and knowledge-production" as well as the role that "Western and non-Western cultural producers and intellectuals play in various processes of representation" (Born, 2000, p.6).

Born's post-colonial approach presents an arguably unrealistic view of the world in its support of a potentially unhealthy idea(I) of musical purity. This ideological standing is unworkable in a modern globalised world: music defies monoculturalism (Nicholls, 1991; Landy, 2003). Just as language evolves with new generations and the migration of peoples, music too has permeable boundaries and

<sup>&</sup>lt;sup>26</sup> Edward Said's seminal book *Orientalism* asserts the idea that the Western world (the Occident) has constructed a distorted, biased representation of the East (the Orient) which perpetuates a power dynamic of dominance and subordination. Said argues that this representation serves to validate and sustain Western imperialism and economic exploitation of the East.

<sup>&</sup>lt;sup>27</sup> For discussion of Britten's exotic work Prince of the Pagodas, see Sorrell's Gamelan: Occident or Accident? (1992)

shifting aesthetic and cultural identities. With the developments in music technology and global travel since the late nineteenth century, the promulgation of hybridity constitutes an ever-increasing facet of music. Regardless of the relative ease with which many musicians can travel to collaborate with each other, intercultural music is now a "fact of life" (Landy, 2003, p.107) with consumers having access to music from across the world, on various formats, and available not just through retail but via numerous streaming platforms.

If we accept that, historically, exoticism in musical composition involves imitation, sometimes with underlying culturally appropriative tendencies, we might consider Reich's alternate situation: the concept of fusion in composition and the informed influence of non-Western structures to produce something genuinely new by way of what Mantle Hood originally described in 1960 as "bi-musicality" (Hood, 1960; Sorrell, 2007).<sup>28</sup> Bi-musicality, also advocated by Baily (2001),<sup>29</sup> involves a musician's ability to understand and perform/create music from different cultural traditions which in turn enables the musician to integrate diverse elements into their own musical praxis in a mode of genuine fusion. T M Krishna, in agreement with Reich and Sorrell, values the potential of a respectful union of musical elements which leads to a

"the recent preoccupation with fusions that has almost come to characterise so-called 'world music' amply demonstrates that simple mixing can be even more unsatisfactory and facile than the palest of pastiches. Fusion music is typically (though of course not always) the result of musicians from different cultures pooling their respective traditions in the hope of a viable synthesis, and often stems from the idealistic but flawed belief in music as a 'universal language'. The real aim of 'bi-musicality', on the other hand, has the more modest aim of bringing from within the individual an awareness of contrasting music's grammars and vocabularies, and – perhaps most crucially of all – idioms."

<sup>&</sup>lt;sup>28</sup> make an important distinction here between bi-musical fusion and collaborative fusion. The term fusion has been applied as a marketing category to collaborations between different musicians and their musics, such as the groups Afro Celt Soundsystem or Lokkhi Terra. These deliberate composites rarely produce anything genuinely new as the identities and styles remain both true to their customs and easily identifiable. Collaborative fusion is more like playing two different musics at the same time — layering or mixing — rather than what Krishna describes on the next page as "melting," with the hope of achieving a blend. Neil Sorrell (2007, p.38) writes:

<sup>&</sup>lt;sup>29</sup> Although Baily questions the term "bi-musicality" with regard to its lack of precision and its connection to childhood bilinguality (Hamers and Blanc, 2000), he very much advocates for the development of musicians' and ethnomusicologists' theoretical, practical, and embodied knowledge of musics.

new form or reinterpretation (2013, p.244):

Fusion is a fascinating word. It is derived from the word 'fusio' meaning 'to melt' - the union of diverse elements using heat. The word also indicates a state of fluidity... Fusion suggests the melting together of elements of music. Here, the heat source is the action that initiates this melting, leading to the evolution of a cohesive musical idea. The melting of musical elements as a result of active minds leads to the emergence of a new idea, form, interpretation. Once the fluidity that results from the fusion has settled down, we have a new and different entity.

The value of imitative or pastiche music is limited, even if technical skill and merit may be abundantly evident (Sorrell, 2007); what must drive the composer is the desire to create something new, something worthwhile, and, in this case, something transdiciplinary, bringing her background into fusion with the detailed and authentic study of a chosen music through creative endeavour. This practice-based research attempts to forge a new musical pathway in the mode of sonic life writing, fusing principles of Karnatak rhythm (studied authentically over a number of years with leading rhythmic practitioners in the tradition) with elements of contemporary Western composition and performance autoethnographic research.

# PERFORMANCE AUTOETHNOGRAPHY

Rose Richards, in her investigation of writing the othered self, notes that the experience of illness is "not always as well documented as one might expect" (2008, p.1717), with accounts authored by medics, academics, and caregivers crowding out the illness narrative space to the sometimes casual occlusion of the firsthand, expert patient account. Whilst this may not be the case with breast cancer narratives, so many firsthand accounts now published,<sup>30</sup> Richards highlights the potential pitfalls and tensions of rendering people as other and abnormal "at a cost to

<sup>&</sup>lt;sup>30</sup> A notable anomaly in the breast cancer narrative field is Dr Liz O'Riordan who has written about her career as a breast cancer surgeon and has also shared her own autopathography of her personal experience of breast cancer treatment (2023).

their humanity" (ibid.) and simplifying their experience to a level of objectification which can perpetuate agnotology. This thesis regards Richards' views as particularly pertinent to the written illness narrative and therefore adopts the methodology of performance autoethnography in order to circumvent some of the aforementioned tension and pursue a just performative and performance-based testimony in sound and music.

As a qualitative research approach involving reflexivity and personal experience to understand cultural, social, and political phenomena, performance autoethnography (PA) has been described as "a genre of doubt" (Bochner, 2017, p.67) situated at the intersection of autoethnography and performance studies. Transgressing boundaries which distinguish modes of truth telling and testimony in literary and scientific inquiry, PA has achieved standing in the academy in great part due to the work of Carolyn Ellis (1999, 2004, 2020), Arthur P. Bochner (1997, 2017), Ellis and Bochner (2000, 2006) and Norman K. Denzin (2003, 2006, 2013, 2018a, 2018b, 2019). Ellis' explication of autoethnography as "heartful" inquiry into the vulnerable self (1999) echoes the work of Sedgwick (1997, 2000, 2003) and the concurrent reparative turn (discussed in chapter 2); this thesis is positioned in harmony with the modes and positionalities of the heartful and the reparative.

The methodological trajectory of PA, via Schechner (1977, 1985, [1988] 2003, [2002] 2013), and Turner (1974, 1979, 1986),<sup>31</sup> is sundry and continues to diversify, however, what unites all approaches to PA are the foundations of embodied performance, personal narrative, and artistic expression in applications of knowledge production, social critique and activism, and artistic transformation (Denzin, 2018). By investigating subjective experiences, PA, much like Wilson's Aesthetic Critical Realism (ACR) (2020), engages in knowledge production by adding depth and detail to the understanding of social and cultural phenomena, and by manifesting marginalised perspectives which may counter the culturally-produced ignorance of agnotological representations or expressions, as detailed earlier in this introduction. PA's attention to subjective detail can provide social and political critique with interventionist or

<sup>31</sup> See also Shepherd (2016)

activist potential, especially through artistic transformation.

Performance autoethnography, therefore, is a powerful and conscious approach. It is evolving as an increasingly potent methodology within qualitative research yet one that eludes sturdy, compact definition.

Performance autoethnography is a blurred genre. It is many things at the same time. It bends and twists the meanings of ethnography, ethnographer and performance. There is no separation between the writer, the ethnographer, the performer and the world. Performance autoethnography makes the writer's self visible through performance, through performance writing, through the writer's presence in the world. Performance auto ethnographers are committed to changing the world one word, one performance at a time. The community is global. Autoethnography is easily confused with other terms. It is not: ethnography, autobiography, biography, personal narrative, personal history, life history, life story, or personal experience story. It is not deeply theoretical. It is more than performance. It is transgressive. It is resistance. It is dialogical. It is ethical. It is political, personal, embodied, collaborative, imaginative, artistic, creative, a form of intervention, a plea for social justice... challenging the dividing line between performer and performed, observer and observed. (Denzin, 2018, p.viii)

Denzin's discussion presents an appealing and non-doctrinal manifesto which makes space for the exploration of the possibilities of sonic life writing with performance autoethnography as its primary methodology. Although performance autoethnography generally refers to the performance of the lexical, in combination with the physical, the field also incorporates important dance-related work by Barbour (2012) (exploring narrative and embodied ways of knowing through dance, stating that language is inadequate in expressing our lived experiences), and musical storytelling through (lexical) song by Bakan (2016) and Carless (2017, 2021). The generosity of Denzin's unbounded explanation, although concerned with lexical performance, does not negate the inclusion of non-lexical sound and music.

In her work exploring music and sound as autoethnography, Darla Crispin points to the acuteness of the "objective/subjective paradox" in PA, and practice research more generally, with emphasis on the balance between "the unique and personal with the shared and replicable" (2019). This mindfulness and prioritisation of the applications of PA (knowledge production, social critique and activism, and artistic transformation) — rather than the foundational characteristics of embodied performance, personal narrative, and artistic expression — ensure that this qualitative methodology remains as research, not me-search. Crispin has been a leading figure in the contemporary development of artistic or practice-based research in music with her inquiries into knowing in, through, and as performing (2021, p.63).

### PRACTICE RESEARCH

Across the arts and within the academy, there is a multiplicity of practice-led and practice-based methodological research approaches. Practice Research (PR),<sup>32</sup> and also Artistic Research (AR), are umbrella terms, often used interchangeably, that capture a variety of approaches to knowledge production in the performing arts (Allegue et al, 2009; Borgdorff, 2012; Nelson, 2013; Barrett and Bolt, [2007] 2014; Arlander et al, 2017; Barton, 2017). With the development of PR in academic and arts training institutions over the last two decades, there has been a pressure to articulate a precise definition for this mode of inquiry; however, the elastic and embodied nature of this form of research is not easily assigned a rigid institutional definition given its relative immaturity, constantly evolving creativity, and cross-disciplinary nature (Crispin and Gilmore, 2014; Klein, 2017).

Described as a "discipline" (Barrett & Bolt, [2007] 2014), an "anti-discipline" (Kershaw & Nicholson, 2011) a "methodological abundance" (Hannula et al, 2014), and a "trendy business" (Jobertová and Koubová, 2017), PR covers a plethora of nuanced, focused approaches. Whilst there are many very closely related methodologies, the most important distinction, according to Linda Candy (2006), is the difference between "practice-based" and "practice-led" research. If a creative work is the basis of the

<sup>&</sup>lt;sup>32</sup> Frequently referred to as Practice as Research (PaR) during the 2010s

contribution to knowledge (Lesage, 2009; Frodeman et al, 2017), then the research is practice-based; if the research leads primarily to new understandings about practice then it is practice-led (Smith, 2009). I am reluctant to assign only one of these descriptors to my research as this thesis and portfolio provide contributions to knowledge that are both practice-based and practice-led. For example, TCH-P (chapter one) offers a practice-led opportunity to explore the ableist, classical vocal form of konnakol from expressive and non-virtuosic an perspective; >>KRANKENHAUSFUNK and the extrinsic death receptor pathway<< (chapter two), meanwhile, is more practice-based in its creation of a work that makes the biological cellular process of apoptosis audible in sonic and musical form.

Important organisations in Practice Research (particularly concerned with sound and music) include bodies such as the British Practice Research Advisory group (PRAG-UK) and the AEC European Platform for Artistic Research in Music (EPARM); centres such as the Orpheus Institute in Ghent and University of the Arts London's (UAL) Creative Research into Sound Arts Practice (CRiSAP); and interdisciplinary platforms including Instrument Inventors (iii) in the Hague<sup>33</sup> and the Oxford Artistic and Practice Based Research Platform (OAR). Research from the Orpheus Institute (with its emphasis on cross-disciplinary activity incorporating composition, performance, performance studies, musical analysis, aesthetics, reception theory, historical and critical musicology, and more), and my completion of

<sup>&</sup>lt;sup>33</sup> iii is an artist-run platform which contributes to "international developments in the field of Art, Science & Technology, functioning both as a cultural incubator supporting research and creation, and as an agency connecting creators to a broad audience via a wide (inter)national partner network" (iii, 2023).

their Artistic Research in Music online course in 2021,<sup>34</sup> has informed my praxis during this period of doctoral research.

In Artistic Experimentation in Music: An Anthology (Crispin and Gilmore, 2014), published by the Orpheus Institute, experimentation is supported and explained as "an attitude" rather than a continuation and development of twentieth and early twenty-first century Western experimental art music (2014, p.10). As Graeme Sullivan (2009) has shown, an experimental attitude is required in order to face the unknown and disrupt the known by delving into theoretical, conceptual, dialectical, and contextual practices through musicking and sounding. My research methodologies have embraced such an experimental attitude and have reflected the experimental and improvisational nature of my experience of living with a life-threatening disease such as breast cancer. I explore the improvisatory and experimental attitude has enabled me to embark on performance autoethnographic activities such as the reinterpretation of Karnatak rhythmic models and performance practices; this attitude may best be summed up by Larry Polansky's (2014) simple question: "What if?"

Duality plays an important part in practice research. Primarily, PR offers a duality of freedom and responsibility, a tension between elastic experimentation and careful circumscription (Hannula et al, 2014; Barton, 2018; Crispin, 2021); the imaginative "what if?" work of PR is married to the disciplined and systematic documentation required by the academy. Jobertová and Koubová (2017) have deconstructed further dualities such as those between perception and cognition,

<sup>&</sup>lt;sup>34</sup> Over a number of months in 2021 I completed the Orpheus MOOC (Massive Open Online Course) which introduced me to a variety of research questions, techniques, and methodologies, as well as many important concepts, theories, and discourses in artistic research. For details, see Orpheus Institute (2023).

science and art, subjectivity and objectivity, and also ways in which PR may be characterised by "heteronomy, heterotopy, in-between space<sup>35</sup> or polyphony of sources, procedures and results" (ibid., p.7). The importance of duality in research shows why PR can be considered both a discipline and an anti-discipline (in accordance with Denzin's generous manifesto on Performance Autoethnography); the practice-researcher must have the freedom to make choices and take risks but also take responsibility for them, and for the interpretation of conditions and materials in the reflexive and cyclical transformation of knowledge into work of art or cultural product.

The expansive, dualist nature of PR requires both flexible creativity and rigorous academic procedure and documentation. The Arts and Humanities Research Council's (AHRC) definition of a practice research project states that research activities should primarily be concerned with research processes, rather than outputs, and must be based on three fundamental features:

1. It must define a series of research questions, issues or problems that will be addressed in the course of the research. It must also define its aims and objectives in terms of seeking to enhance knowledge and understanding relating to the questions, issues or problems to be addressed

2. It must specify a research context for the questions, issues or problems to be addressed. You must specify why it is important that these particular questions, issues or problems should be addressed; what other research is being or has been conducted in this area; and what particular contribution this project will make to the advancement of creativity, insights, knowledge and understanding in this area

3. It must specify the research methods for addressing and answering the research questions, issues or problems. You must state how, in the course of the research project, you will seek to answer the questions, address the issues or solve the problems. You should also explain the rationale for your chosen research methods and why you think they provide the most appropriate means by which to address the research questions, issues or problems.

<sup>&</sup>lt;sup>35</sup> See Wilson's The Space that Separates: A Realist Theory of Art (2019)

## (PRAG-UK, 2018)

Each chapter of this doctoral research project identifies and makes clear a series of research questions, positions the research in appropriate context(s), shows contributions to knowledge, and explicates research methods chosen and applied. I conclude this introduction with an outline of the subsequent three chapters and their satisfaction of the above principles set out by AHRC.

### CHAPTER OUTLINE

Chapter one, *TCH- P*, is a performance autoethnographic and illness acoustemological video featuring an unorthodox performance of the South Indian vocal artform of *konnakol*. By adopting Denzin's aforementioned manifesto of performance autoethnography as disruptive practice (2018), I explore how iatrogenic experience may be sounded to make the inaudible side effects of chemotherapy audible. In doing so, TCH-P asks how iatrogenesis, and illness more generally, can inform and transform an ableist artform, specifically the performance of Karnatak *konnakol*. Foregrounding disruption, process, and energy over formal perfection (Hamilton and Pearson, 2020), TCH-P rejects the traditional tendency towards virtuosity and, instead, investigates the integration of iatrogenic experience not just as a compositional device but as a new means of expressive, sonic life writing.

Chapter two, >>KRANKENHAUSFUNK and the extrinsic death pathway<<, is an electronic music performance piece using recycled, rewired, and repurposed chemotherapy machines. This research asks how hospital radio may be radically reimagined as broadcast of patient experience, providing a benevolent intervention in this current, dwindling radio practice. Also, this chapter explores important concepts concerning modes of listening and sounding. Drawing on work by Sedgwick (1997), this research explores the possibilities for a mode of reparative listening, and also experiments with a new compositional method which I am calling artistic sonation, employed to make the inaudible biological process of apoptosis (cell death) audible, and using musical gifts sent to me whilst in hospital and incorporating reproduced hospital field recordings I made during my time in a chemotherapy ward in Brighton.

Chapter three, *Anuvāram Jugalbandī* (for the time beings), examines how major diagnoses of serious illness interrupt lived and felt time, bringing about new and previously unrealised temporalities which fall outside the conventional structures of academic, industrial, social, and economic schedules. In a recorded duo performance for piano and percussion, this work explores how the South Asian musical concept of jugalbandi — an intricate and entangled form of duo performance — may be applicable to non-musical contexts and particularly to the relationship between ill person and caregiver. This performance also explores the qualities and intensities of time experienced during treatment for cancer and investigates how rhythm can express the fluctuating dependancy of ill person on carer.

# **CHAPTER ONE**

TCH-P

"Can you confirm your name and date of birth please?"

MaryLou checks she is administering the correct drug to the correct patient, and, in doing so, ritually asks for my consent to be poisoned again. Yet another iteration of my personal details confounds my fate as she hangs up the killer bag of poisonous liquid and connects it to my drip. A sequence of nine clear bags of fluid need to pass from the stand, via the drip chamber, down the tube, through the cannula, and into my vein today. An efficacious and predictable order of drugs, called TCH-P, structures my day spent in the lime green, wipe clean, reclinable chair in the corner of the ward. An unwanted ride of drowsiness, cold, fear, and agitation shapes the day which, at least, is easier than the last time: known quantities and firmer expectations. We talk sometimes, eat, and try to make the best of it while others sleep, fading in and out. I watch the trolleys of needles and cannulas traverse the room, usually accompanied by some good cheer to soothe the fear or the resignation. The regular, metronomic sounds of the chemotherapy machines offer an electronic thala - a dependable framework for my unreliable calculations and compositions to fall away from. Solkattu disintegrates under my breath, faintly supported by a limp kriya. My cannulated hand taps, claps, forgets, and waves, like a curious incantation. Hopefully my veins won't blow this time.

\*
Can she still feel music in her body can she Vocalize even without technology of the Mouth tongue palate glottis vocal chords Kazim Ali, The Voice of Sheila Chandra, 2018

Are words actually any use to describe what pain (or passion, for that matter) really feels like?

Alphonse Daudet, In the Land of Pain, 1929

TCH-P is a performance autoethnographic and illness-acoustemological video featuring a performance of the South Indian vocal artform of *konnakol*. It is a work exploring knowledge with voice and hands (Voegelin, 2023). Through reflexive performance, I investigate my experience of cancer treatment, more specifically one particular day, Thursday 13th February 2020, in the chemotherapy department of the Sussex Cancer Centre in Brighton, UK. The abbreviation, TCH-P, describes the combination and regime of four intravenously administered chemotherapy and

\*

immunotherapy drugs which treat HER2+ breast cancer.<sup>36</sup> HER2+ is the particular nonhormone responsive cancer subtype that I was diagnosed with and a type of cancer whose cell surface expresses a high level of the protein human epidermal growth factor receptor 2 (Wu et al, 2015; Kreutzfeldt et al, 2020; Koirala et al, 2022). TCH-P is a neoadjuvant systemic anti-cancer treatment protocol, i.e. it is a combination of drugs given before surgery (neoadjuvant) and delivered to the whole body (systemic). The protocol is usually prescribed in six cycles of 21 days in order to shrink the tumour before surgery (Tiwari et al, 2016; Arora et al, 2021; Kim et al, 2022). The TCH- P drugs are administered on the first day of each 21 day cycle, with a variety of other drugs taken throughout the cycle to treat the side effects caused by the chemotherapeutic and immunotherapeutic agents (Jang et al, 2022). These side effects are known as iatrogenesis (Mignotte et al, 1998; Peer & Shabir, 2018). Although actually administered in the order PHTC, TCH-P, as it is always described, comprises two immunotherapy drugs, Pertuzumab (brand name Perjeta) and Trastuzumab (brand name Herceptin), plus two chemotherapeutic agents, Docetaxel (brand name Taxotere) and Carboplatin (brand name Paraplatin but mostly referred to with its generic name, Carboplatin). For clarity, the order of drug administration, and therefore the order of sections in this video, is Perjeta, Herceptin, Taxotere, and finally Carboplatin.

<sup>&</sup>lt;sup>36</sup> Between 10% and 25% of women with breast cancer in the UK exhibit HER2 positivity (Costa & Czerniecki, 2020; Bergamino et al, 2022). The vast majority of breast cancer cases are HER2 negative but hormone receptor positive (abbreviated to either HR+ in the US or ER+ in the UK). HER2+ breast cancer was associated with higher mortality rates than other breast cancer molecular subtypes until the development in the 1990s (and subsequent approved prescription in the 2010s) of the immunotherapy antibody drug Trastuzumab (Herceptin), and later Pertuzumab (Perjeta) (Costa & Czerniecki, 2020; Bergamino et al, 2022; Henneberg et al, 2022). These two targeted therapies have significantly altered the treatment paradigm with HER2+ patients now experiencing much better outcomes and a higher rate of event-free survival (Henneberg et al, 2022; Kim et al, 2022).

Due to the Covid-19 outbreak in early 2020, I received only three of the prescribed six cycles of TCH-P; each of these three protocols took between 7 and 10 hours to administer intravenously. To help pass the time and keep my brain active whilst receiving these drugs, I would practise konnakol exercises in different time cycles. These time cycles are called thalas in Karnatak music (Pesch, 1999; Krishna, 2013). These very simple exercises were suggested to me by my teacher and musical collaborator, Prathap Ramachandra. They are formed of two types of short repetitive phrases which vary according to the mathematical structure of the *thala*. These two short phrases are Thaka dimi thaka jhonu, and Tha Di Gi Na Thom. When receiving my TCH-P drug regime in the ward, I quickly realised that I could use the numerical data printed on each of my drip bag labels to determine the length of the konnakol phrases and the *thala* within which they were recited. Regarding knowledge with voice and hands, it is these exercises that provide the vocal material in this video while the hand manually expresses the thala, performing what is called kriva. The metronomic hand gestures of kriya in Karnatak performance indicate the speed and the subdivision of the thala (Pearson, 2013; Bindu, 2019; Pulijala and Gangashetty, 2020).

By adopting Denzin's manifesto of performance autoethnography as disruptive practice (2018), as discussed in the introduction, I explore how iatrogenic experience may be sounded to make the inaudible side effects of chemotherapy audible. In doing so, TCH-P asks how iatrogenesis, and illness more generally, can inform and transform an ableist artform, specifically the performance of Karnatak *konnakol*. From setting out the performance and training conventions of Karnatak music, followed by a discussion of the aesthetics of musical imperfection and connections with theories of ableism, I will describe how TCH-P rejects the traditional tendency towards virtuosity and, instead, integrates iatrogenic experience not just as a compositional device but

as a means of expressive, sonic life writing.

I deliberately aim for imperfection in this performance piece — foregrounding disruption, process, and energy over formal perfection (Hamilton and Pearson, 2020) — which not only challenges Karnatak performance norms in the creation of a more expressive and inquiring rendition of standard *solkattu*,<sup>37</sup> but challenges the descriptions of treatment-induced side effects in standardised illness narratives, literally and non-lexically giving voice to suffering.<sup>38</sup> Furthermore, I examine how the mouth performs as a localised site for illness-related autoethnography and how the voice, which passes through, functions as an emancipated messenger of extreme bodily experience.

Before discussing the main themes of this chapter, I wish to make clear that the accompanying video (and audio) was recorded in my home studio, not in any healthcare setting.<sup>39</sup> I created a mock hospital scene at home on 15th April 2023, three years after my chemotherapy treatment at the Sussex Cancer Centre, using cotton sheets that were a muted green colour (a particular hue often associated with the NHS). The cannula and tubing taped to my hand did not have a needle attached and these simple pieces of medical equipment were purchased from a seller on Ebay. The hospital sounds that can be heard are transductions of the hospital soundscape I experienced three years before, and muffled vocals and sounds of machines were, again, created in my home studio using infusion pumps purchased on Ebay.<sup>40</sup>

<sup>&</sup>lt;sup>37</sup> Solkattu is a Tamil word which describes the various syllables used in *konnakol*, each of which represents a different drum stroke technique (Nelson, 2008).

<sup>&</sup>lt;sup>38</sup> See Dolar's A Voice and Nothing More (2006) and LaBelle's Lexicon of the Mouth (2014) for philosophical examination of the voice, how the voice is from/of the body yet separated, and the voice as self and yet alienated.

<sup>&</sup>lt;sup>39</sup> Please see the addendum on p.94 for the metadata showing the date of video.

<sup>&</sup>lt;sup>40</sup> In Chapter Two, I will describe the purchase of these secondhand machines for the making of >>KRANKENHAUSFUNK and the extrinsic death receptor pathway<<.

# KARNATAK RHYTHM AND KONNAKOL

Scholars and practitioners underline the importance of rhythm for cultivating the signature sound of Karnatak music (Pesch, 1999; Krishna, 2013). Rhythmic concepts of Karnatak music are "arguably the most developed and sophisticated in any musical tradition" (Subramaniam and Subramaniam, 2018, p.70) and subtleties of rhythm "reign supreme" (Viswanathan & Allen, 2004, p.34). The traditional Sanskrit saying "*Shruti Mata Laya Pita*," meaning *Shruthi* (pitch) is the mother and *Laya*<sup>41</sup> (rhythm) is the father (Subramaniam & Subramaniam, 2018, p.71), is testament to the power and importance of rhythm in Karnatak music. Governing all rhythmic movement is the *thala* system which is an intricate network of metric, rhythmic cycles. Traditionally classified into *marga* (classical) and *desi* (folk) systems (Subramaniam & Subramaniam, 2018), it is thought that the *Suladi* network of 35 *thalas* has been the most commonly used system in Karnatak music since the time of Purandaradasa<sup>42</sup> (Reina, 2015).

When learning Karnatak percussion, such as the *mridangam* drum or the *ghatam* clay pot, the student is taught to vocalise rhythmic patterns before playing them. For example, the very first *mridangam* lesson with any teacher begins with the introduction of four syllables — *Tha*, *Di*, *Thom*, and *Nam* — which represent the fundamental technical playing strokes (Nelson, 2008).<sup>43</sup> These four syllables, plus a variety of others such as *Dhin* and *Kita*, are collectively known as *solkattu* (ibid.). In

<sup>&</sup>lt;sup>41</sup> Laya, in both a generic and a practical sense, refers more specifically to speed than rhythm.

<sup>&</sup>lt;sup>42</sup> Purandaradasa (1484-1564) moved away from the complex and disparate shadanga (meaning six-limbed) system to create a simpler, unified Suladi system which uses only three angas (laghu, drutam, and anudrutam) rather than the six angas of shadanga (laghu, drutam, anudrutam, guru, pluta, and kakapada) (Reina, 2015).

<sup>&</sup>lt;sup>43</sup> These four syllables are mentioned in the *Nātyaśastra* Sanskrit treatise dating from between 200 BCE and 200 CE (Nelson, 2008, p.5).

Tamil, the word *solkattu* means "words bounds together" (ibid., p.1). The nature of this binding is twofold. On a micro level, syllables such as *Ta*, *Ka*, *Di*, and *Mi* are bound together to form phrases of differing numerical lengths. And on a macro level, these phrases are combined in larger arrangements and designs, conforming to six different types (or shapes) called *yathis*, which are bound within the metric framework system of *thala* (ibid.). The word *konnakol* describes the art of *solkattu* performance, as separate and distinct from the *mridangam* (or other percussion instruments), and as a singular and independent musical entity.

Away from traditional performance and practice spaces, *konnakol* has spread to popular music contexts and gained popularity in Europe and in North and South America. Much of this increase in popularity has been, and continues to be, engendered by the rhythm artists BC Manjunath, Somashekar Jois, and Dr Trichy Sankaran, whose virtuosic performances and educational workshops achieve many thousands of views on YouTube. Examples of *konnakol* in popular music contexts include the track *The Warrior* on the Aditya Prakash Ensemble's 2020 album *The Diaspora Kid* in which BC Manjunath features within a combination of rock and jazz styles. Also, Mumbai-based Vivieck Rajagopalan's track *Ta Dhom* (featuring the collective of socially conscious artists Swadesi) which The Times of India described as "Carnatic goes ghetto as konnakol meets desi rap" (Ghoshal, 2019).

Konnakol, like Karnatak percussion playing as a whole, is predominantly a male practice. Notable exceptions include konnakol practitioners Charu Hariharan, V Shivapriya, Loire Cotler, and Sheila Chandra. The work of Cutler and Chandra is particularly pertinent to my research as Cotler's music therapy-based work at The New School in New York City has engaged with health-based enquiries, whilst Chandra's output has explored unconventional and expressive konnakol performances free from conventions of *thala*. Both Cotler and Chandra have

developed passionate *konnakol* styles which deviate from Karnatak norms. For Cotler's performance-based work, conventional *konnakol* fuses with a variety of other vocal practices including Mongolian throat singing and jazz scat singing (Cotler, 2013). And in her music therapy practice, in settings including hospitals and psychiatric units (ibid.), Cotler has been inspired to explore questions such as "what is the rhythm of anxiety?" Whilst no academic literature or documentation of Cotler's music therapy practice is publicly available, the idea of "the rhythm of anxiety" appears to blend disciplines of both music therapy and music as resource (as discussed in the introduction). Using rhythm in music therapy is a common tool in a variety of health contexts (Aldridge, 1994; Thaut, 2005; Bharathi et al, 2019; Devlin et al, 2019; Shi and Zhang, 2020; Chen et al, 2021; Wang et al, 2021) but using rhythm expressively to describe mental illness is neither widely practised nor covered in academic literature. Rhythm as expression of personal experience strongly pertains to the ideals of sonic life writing about illness, sounding the emotional or physical state of one suffering, and to the life and work of Sheila Chandra.

Chandra's personal story has become somewhat mythologised, as evidenced by Kazim Ali's volume of three long poems collectively titled *The Voice of Sheila Chandra* (2020). Chandra's ability to perform, sing, or even talk, has been significantly compromised by her diagnosis with the neurological condition glossodynia, also known as burning mouth syndrome (Gieler et al, 2022). Chandra achieved fame as a childhood star playing Sudhamani Patel in BBC One's *Grange Hill* from 1979 to 1981 before going on to become the lead singer of the band Monsoon, reaching Number 12 in the UK charts in 1982 with the single *Ever So Lonely*. Jazeel (2005) notes how remarkable the success of *Ever So Lonely* was at a time when representations of Asian and British-Asian people were few and generally less than favourable; to have a danceable hit with a song sung in an Indian raga with sitar and tabla, plus

synthesisers and guitars, was a rare feat.

I mean the amazing thing about that record is that in the middle all the other synth instruments are pulled out and in the middle eight, people on the dance floor are essentially dancing to a classical *raga*, and they've got so used to the cross rhythms that that's what they're dancing to and they don't think twice about it. And that was the really subversive thing. (Chandra, in Jazeel, 2005)

Chandra, along with artists including Talvin Singh and Asian Dub Foundation, constructed "new worlds of sound" (Jazeel, 2005) cutting through conventional, symbolic boundaries and idiosyncratically cultivating immanent political geographies (Revill, 2000; Smith, 2000). It is Chandra's 1990s output, chiefly the solo albums released on Peter Gabriel's Real World label, that is especially relevant to this chapter.

The albums Weaving my Ancestors' Voices (1992) and The Zen Kiss (1994b) feature tracks titled Speaking in Tongues I to IV. These distinctive solo voice tracks combine recognisable elements of classical konnakol with Chandra's own innovative vocal stylings, electronic voice treatments, and unconventional variations in speed and phrasing. A progression in virtuosity and invention is clear through the course of the four tracks. Speaking in Tongues I ([1992] 2017) adheres, mostly, to conventional solkattu with a series of complementary short compositions, called korvais, evocative of traditional percussionists' konnakol recitations. Speaking in Tongues I also ends with a traditional, intricate phrase repeated three times and ending on thala sam, the first beat of a thala cycle. Such cadential phrases repeated three times are a hallmark of Karnatak music (Nelson, 2008). Speaking in Tongues IV (1994) is more than three times the duration of Speaking in Tongues I and displays the same virtuosity of articulation. This later track breaks new ground, however, with the effective commixing of traditional konnakol with sung phrases, electronic production effects including reverb and chorus, and interludes of rhythmic breathing. Variation of style and expression is wide-ranging throughout this track, from the fun and flamboyant phrases from 00:30 to 00:44 to the breathy intimacy of the section from 02:57 to 03:20. Chandra's flexible expression creates pleasingly ambiguous

fluctuations away from any dependable "flow of time" (Sankaran, 1994, p.41): the track oscillates between rhythmic stability, called *sarvalaghu* (Viswanathan & Allen 2004, Nelson 2019), and unpredictable and often complex rhythmic variation, akin to the Karnatak concept of *kanakkul*. Amanda Weidman (2006, p.32) describes *kannaku* as "calculating, floating and adjusting."

Sadly, Chandra's innovative and unorthodox career, breaking with numerous South Asian aesthetic norms (especially her development of *konnakol* and of drone), ended with her retirement in 2009. Following the onset of agonising symptoms of burning mouth syndrome, even simple speech became too painful for Chandra, let alone the complex articulations of her extended *konnakol* performances. Chandra has now been rendered effectively mute, denying her fans of future innovative developments in her music.<sup>44</sup> Whereas Chandra is no longer able to give *konnakol* performances due to illness, projects such as TCH-P and recent work from University College London's Performance Lab aim to use *konnakol* to bring testimonial voice to suffering and even use the artform as a rehabilitation technology in recovery from cancer.

Before addressing issues of imperfection and ableism in music, I wish to briefly draw attention to the 2020 collaboration between rhythm artist and renowned *konnakol* practitioner Bernhard Schimpelsberger and Shout at Cancer's Laryngectomy Voice Orchestra, supported by UCL's Performance Lab. Shout at Cancer is a British organisation which brings together medics, researchers, speech therapists, actors, and musicians in projects which support the rehabilitation of people who have had laryngectomies to remove throat cancer. During the first UK Covid lockdown of 2020, Schimpelsberger led online workshops with the Orchestra, using *konnakol* exercises as a means of speech recovery, practising repetitive and sometimes challenging *solkattu* combinations (Shout at Cancer, 2020). This

<sup>&</sup>lt;sup>44</sup> Sheila Chandra is now a non-fiction author in the fields of self-help, decluttering, and career coaching (Chandra, 2010, 2020).

therapeutic programme employing *konnakol* for voice rehabilitation is a counter example of the experience of singer and voice artist, Sheila Chandra. Like TCH-P, the Laryngectomy Voice Orchestra's *konnakol* performances embraced imperfection: participants were physically unable to perform with virtuosic speed or with authentic intonation, instead using the artform as both a coping and rehabilitative technology.

## IMPERFECTION, VIRTUOSITY, AND ABLEISM IN KARNATAK MUSIC

Imperfection in sound and behaviour is important as it serves the forging of intimacy between people.

Samuel Horlor, A Social Aesthetics of Imperfection, 2020

In considering the aesthetic issues relating to Karnatak music and to imperfection in its practice and performance, I shall concentrate on what Hamilton & Pearson (2020, p.1) describe as the "socialized values and expectations held by insiders regarding a cultural practice or product," rather than aesthetic theories of art and beauty from and in the global North, such as the work of Baumgarten ([1750] 2014), Kant ([1790] 2000), Adorno ([1970] 2013), Zangwill (2007, 2017), and Scruton (1999, 2018).<sup>45</sup> These insider values must be understood before an aesthetic evaluation can be arrived at. Three aesthetic considerations most pertinent to TCH-P are virtuosity, articulation, and presentation. I shall discuss these in turn.

Virtuosic display is an integral and expected component of a Karnatak performance (Viswanathan & Allen, 2004; Krishna, 2015; Pearson, 2016). The vocal rendering of a *kriti* composed by Thyagaraja (Jackson, 1992) or the competitive game-

<sup>&</sup>lt;sup>45</sup> I do not wish to engage with the discourse regarding cross-cultural aesthetics at this point. However I do recognise the debate regarding 'aesthetics as cross-cultural category' from the 1996 publication *Key Debates In Anthropology* (Ingold, 1996), and subsequent related discussions by Coleman (2005); Born, Lewis, and Straw (2017); Polak et al (2021), and Pearson (2022).

play of a tani avartanam percussion solo (Pearson, 2021) are perfect examples of the programmed expectations of both musicians and audiences who collectively engage in the tension and delight brought about by the challenges of complex and virtuosic musical performance. It is complexity, and therefore the ineluctable risk of failure, that makes Karnatak music an inherently ableist artform. Viswanathan's and Allen's (2004, p.170) theory of continuum in Karnatak music (applicable to South Asian classical musics more generally) describes its core tenets of devotion and virtuosity. At one end of the continuum scale are the devotional songs, such as bhajans and kirtanas, and at the other are the musical forms such as the kritis by Swathi Thirunal or Thyagaraja, examples of highly virtuosic Karnatak compositions and performances. Percussion playing and konnakol recitation belong very much to the virtuosic end of the continuum with their often thrilling displays of skill and articulation. Viswanathan and Allen define virtuosity (in the context of their continuum theory) as "tending toward individual expression in public, professional performance" (2004, p.17). Can the aesthetic value of virtuosity still be honoured without the expression of ableist complexity in performance? Somewhat paradoxically, TCH-P conforms to this definition, despite the extreme simplicity of the composition and performance; this is due to its individual and expressive nature.

Some qualities most valued in Karnatak performance, specifically those involving great complexity and technical facility, would not be possible for musicians undergoing systemic cancer treatments such as chemotherapy and also experiencing the resultant iatrogenesis. The complex *gamaka* (fast, shaking ornamentation) of a vocal performance or the speedy recitation of *konnakol* are simply not possible when one's mouth, throat, and digestive tract have developed numerous bleeding ulcers which require anaesthetic medications (Sonis, 1998; Chaveli-López and Bagán-

Sebastián, 2016; Lalla et al, 2019).<sup>46</sup> The ability to accurately remember and repeat the intricate rhythmic phrases of another percussionist is significantly hampered when experiencing psychoactive antiemetic- and antihistamine-related somnolence coupled with menopause- and chemotherapy-induced cognitive dysfunction (Ahles and Saykin, 2002; Barton and Loprinzi, 2002; Bounous et al, 2019). The tuning and pitching of the voice are difficult when experiencing ototoxicity, and its associated aural hallucinations, caused by the chemotherapeutic agent, Carboplatin (Rybak, 1999; Skinner, 2004; Gersten et al, 2020; Romano et al, 2020). Great physical skill, memory, and understanding are required of musicians and so experiences of physical disability, cognitive dysfunction, and toxic iatrogenesis, in its many forms, are all barriers to the performance of Karnatak music.

If complexity and challenge are embedded in the aesthetic value system of Karnatak music that, in turn, also means that the possibility of failure is endemic. Pearson (2021) explains that processes of competitive, rhythmic game-play, with the failures that those interactions sometimes produce, make Karnatak music more embracing and accepting of failure and inaccuracy than other classical musics, such as the Western tradition. Indeed, these failures, or simply the risk of failure, are a built- in aesthetic norm within the artform. In comparison, the Western art music tradition does everything it can to guard against failure and inaccuracy by producing detailed scores instructing musicians exactly what must be played, and how. With the adoption of a sonic life writing compositional modality, TCH-P invites a shifting of the spotlight from the achievement of complex musical challenges to the acceptance of inaccuracy and musical deviation; expression of suffering and temporary disability; and an exposure of the paired-down, almost minimalist consideration of foundational

<sup>&</sup>lt;sup>46</sup> Oral mucositis, a painful inflammation of mucosal tissue in the mouth, is a common side effect of a TCH-P regime and other systemic cancer treatments (Cawley & Benson, 2005; Pulito et al, 2020; Saito et al, 2023). A more detailed examination of mucositis is given later in this chapter.

building blocks of the artform, never heard in performance. And so, TCH-P is virtuosic in its depth of individual expression but not in terms of its technical challenge.

Before progressing to a discussion of the other two aesthetic considerations of presentation and articulation, I wish to briefly make a connection here between virtuosity and perfection. Just as the notion of normalcy makes the idea of disability and discourse concerning disableism<sup>47</sup> possible (Davis, [1995] 2014; Couser, 2009; Harding and Figueroa, 2013; Goodley, 2014; Thomas and Sakellariou, 2018), ideals of musical perfection (inherent in an aesthetic value system) engender ideas regarding musical imperfection, failure, and inferiority. The hegemony of musical perfection and the resultant adherence to aesthetic norms therefore deprive audiences of opportunities to hear transgressive voices and, in the first instance, for those transgressive voices to even be voiced. Karnatak musical perfection(ism) can be judged in terms of accomplished adherence to expectations of articulation, pronunciation, style (bani), dexterity, reliability, stability, imitation, guality of tone, mathematical intricacy, and accuracy, to name but a few. An audience wishes and expects to be impressed by technical prowess as well as, and if not more so than, musical expression; a performance that deviates from these aesthetic performance values is hence considered inferior (Pearson, 2021). Therefore, a performance or work that integrates experiences of iatrogenesis in the performance of a Karnatak discipline (such as *konnakol*) is deemed and doomed to be, in its very nature, inferior. This is because the iatrogenic consequences of TCH-P treatment make Karnatak musical perfection an impossibility, not least at the point of intravenous administration: the time during which this work is set.

<sup>&</sup>lt;sup>47</sup> Goodley (2014) defines disableism as the political, cultural, social, and psycho-emotional exclusion of people with physical, sensory and/or cognitive impairments, and ableism as the contemporary ideals on which the autonomous, productive, able citizen is based.

# ARTICULATION AND INTONATION IN KONNAKOL RECITATION

One of the major components of a virtuosic Karnatak performance is a display of precise and speedy articulation. For vocalists and *konnakol* artists, the site of articulation is, primarily, the mouth; without an instrument which is separate and distinct from the body (such as a violin or a *mridangam*), the vocal artist's mechanism for musical production involves the respiratory system and the mouth. Before moving on to describe the articulation in the video performance of TCH-P, I wish to draw attention to Brandon LaBelle's examination of the mouth as an articulate and active cavity:

The mouth, in other words, is an extremely active cavity whose movements lead us from the depths of the body to the surface of the skin, from the materiality of things to the pressures of linguistic grammars - from breath to matter, and to the spoken and the sounded ... The mouth is thus wrapped up in the voice, and the voice in the mouth, so much so that to theorize the performativity of the spoken is to confront the tongue, the teeth, the lips, and the throat; it is to feel the mouth as a fleshy, wet lining around each syllable, as well as a texturing orifice that marks the voice with specificity, not only in terms of accent or dialect, but also by the depth of expression so central to the body. (2014, p.1)

I will return to LaBelle's *Lexicon of the Mouth* (2014) towards the end of this chapter but include the above passage at this point to emphasise that TCH-P is an exercise in confrontation. In confronting the gums, tongue, teeth, lips, and throat in their imperfect and toxified state, the performance offers a completely new way of appreciating articulation through listening and bearing witness to compromised elements of the oral mechanism.

Returning specifically to konnakol, Atherton (2007, p.3) notes that *konnakol* has its own set rules of grammar and syntax with intonation which is "based on the sound of drums." Fast, intricate phrases tend to be executed at a higher pitch; long *solkattu* syllables, such as *dhin*, are generally expressed at a lower pitch, often with a sliding intonation. Performances by practitioners such as BC Manjunath and Somashekar Jois display tremendous virtuosity with speedy articulation and varying musical intonations being primary elements of their performances which delight and impress global audiences. With four different tongue position variants available just for the pronunciation of the sound 't' alone, *konnakol* recitation involves a large repertoire of movements requiring deft and subtle mastery of action of the tongue, jaw, and facial muscles. As well as the ability to execute small oral movements at rapid speed, the practitioner must use wide-ranging and variable musical intonation, representative of the technical strokes of the *mridangam* drum.

TCH-P features standard *konnakol* intonation patterns and pronunciations in combination with a variety of deviations and transgressions from Karnatak performance norms. A discussion regarding matters of articulation and intonation in all four parts of the video now follows.

# Part 1 - Perjeta (P) - 00:00 - 01:44

The first section of the video represents the administration of immunotherapy drug Perjeta and begins with standard articulation and intonation, as explained to me by my teacher Prathap Ramachandra and by BC Manjunath during various workshops given by him which I attended. Instead of pitching every syllable of the repeated phrase, *Thaka dimi thaka jhonu*, I adopt what BC Manjunath described to me as "swing" intonation, emphasising the first, the fourth, and the seventh syllables: *Tha* - *mi* - *jho* -. The intonation pattern of these three syllables is triangulated as middle (*Tha*), high (*mi*), and low (*jho*). This "swing" style of BC Manjunath gives a bounce quality which resists consistent and predictable emphases on even numbered beats. I still articulate the consonant sounds of the other *solkattu* syllables in the phrase, *Thaka dimi thaka jhonu*, but only 'give voice' to the aforementioned syllables, *Tha* - *mi* - *jho* -. The second repeated phrase, *Tha Di Gi Na Thom*, is articulated with

standard intonation but with often anglicised vowel pronunciation. During *konnakol* lessons, Prathap and I would be strict about correct pronunciation, but when in hospital, I became less interested in pronunciation, allowing incorrect vowel sounds, such as 'a,' to creep in to my imperfect recitations.

The first deviation from standard practice occurs at 00:44 when a short paraverbal sound of uncertainty punctuates a four second pause, marking the onset of effects from pre-medications. Before the TCH-P protocol is administered to a patient, they must first take a mandatory antiemetic pre-medication, the steroid dexamethasone, and a somnolence-inducing antihistamine in order to better tolerate

the cytotoxic substances of the intravenous regime. My experience of this premedication was an unsettling drowsiness, forgetfulness, and sinking panic that would last for at least a couple of hours and made movement, conversation, and *solkattu* recitation challenging. This temporary, mental state bears great similarities with, and represents more broadly, the serious, longer term, iatrogenic experiences of chemotherapy-induced cognitive dysfunction.

Experiences of mental impairment during and after cancer treatment are often described colloquially as "chemo brain." Hermelink (2015, p.1), in her research in psycho-oncology, notes that "in the past two decades, neuropsychological studies have accumulated evidence of corresponding cognitive deficits that have mostly been attributed to neurotoxic effects of chemotherapy." Determinants and non- determinants of so-called "chemo brain" were called into question by Hermelink et al (2010) and Hutchinson et al (2012), suggesting that the cognitive impairment described by patients might be, at least partially, caused by levels of anxiety and psychological distress brought about by the treatment protocol rather than chemotherapy itself. However, Kovalchuk & Kolb (2017) have developed an epigenetic theory of brain ageing induced by the oxidative DNA damage caused by cytoxic

chemotherapeutic agents, and Nguyen & Ehrlich (2020) present conclusive findings about the cellular mechanisms of chemo brain from an ageing and neurodegenerative disease perspective. It is important to note that memory loss and confusion during and after HER2+ breast cancer treatment<sup>48</sup> are strongly linked to both the chemotherapy regime *and* the effects of menopause, be that either a temporary, reversible, medical menopause during the use of the drug Zoladex,<sup>49</sup> or a permanent and irreversible menopause caused by the chemotherapy (Ibrar et al, 2020; Mounier et al, 2020).

Pre-medication-induced somnolence is evident at 01:17 when a yawn breaks the standard pattern of intonation. The hand, performing *kriya*, becomes less animated at this point; tiredness setting in brings about slower, lazier movements. A slowing down and a further yawn at 01:44 marks the start of the second section. Such decelerations in Karnatak performance are extremely rare; standard practice in changes of *laya* (speed) turns to the system of beat subdivision rather than modification of the underlying *matra* pulse itself.

## Part 2 - Herceptin (H) - 01:44 - 03:21

Articulation at the start of this section is careful and deliberate as recitation becomes increasingly challenging due to the unfavourable effects of medications. The "swing" intonation is barely detectable as the repeated phrases sound quietly laborious. At 02:11, the hand disappears from the screen; when it returns at 02:18, accompanied by

<sup>49</sup> Zoladex (generic name Goserelin) is a hormone therapy which can be used as part of the treatment protocol for non-hormone sensitive breast cancers. It is a medication used to temporarily suppress the production of sex hormones during the course of chemotherapy treatment; it induces a severe but temporary medical menopause in order to protect the reproductive system during chemotherapy. Most patients regain their ovarian function, to some degree, months after the cessation of Zoladex injections (Urruticoechea et al, 2008).

<sup>&</sup>lt;sup>48</sup> Kovalchuk & Kolb (2017) note that one third of breast cancer patients experience chemotherapy-induced persistent cognitive dysfunction with symptoms lasting as long as ten years after the cessation of cancer treatment. See also Ahles et al (2002) and Ahles et al (2005).

sounds of eating, its movements are smaller and more compact, showing a decrease in physical energy.

One of the most extreme transgressions of Karnatak performance norms arrives at 02:21 when *konnakol* recitation is attempted whilst eating a sandwich. The repeated phrase *Thaka dimi thaka jhonu*, is partly replaced by short, rhythmic, hummed articulations, and a murmur supported by subvocal recitation, devoid of consonants or vowels. This radical deviation shows the preparation, advised by my nurses, for the administration of Docetaxel. In contrast to de Groot et al's research (2019) on the benefits of short-term fasting when receiving chemotherapy, I was encouraged to eat as much as comfortably possible on the morning of my chemotherapy days and also shortly before starting the Docetaxel administration. I was informed that eating would reduce feelings of nausea and would promote increased toleration of the extremely cytotoxic substance. Part 2 ends at a considerably slower speed than the opening of the video, showing the memory loss and somnolence experienced.

### Part 3 - Doctetaxel (T) - 03:21 - 05:01

The third movement, T, is distinct in character. Although Docetaxel (T - Taxotere) is the most potent and iatrogenic of the four substances given, its administration was, to me, the most pleasant. Docetaxel is a chemotherapeutic agent which inhibits cellular microtubule structures, resulting in cell death (Heys et al, 2005; Balachandran and Kipreos, 2017; Imran et al, 2020).<sup>50</sup> Docetaxel is also one of the two epochmaking taxane drugs derived from plants of the genus *Taxus* (yews), the other being Paclitaxel (Taxol). Taxane drugs cause many unpleasant side effects including nail toxicities (Lau et al, 2011); neuropathy (numbness) (Chan, 2019; Mo et al, 2022); febrile neutropenia (low white blood cell count causing increased risk of infection) (Nomura et al, 2020; Kimura et al, 2021; Peltekian et al, 2023); oedema and lymphoedema (fluid

<sup>&</sup>lt;sup>50</sup> Chapter 2, >>KRANKENHAUSFUNK and the extrinsic death receptor pathway<<, discusses cell death in detail.

retention) (Keeley, 2020; Fuse et al, 2022); skin toxicity (Schrijvers et al, 1993; Poi et al, 2013); pain (Ventzel et al, 2016); and mucositis (inflammation of mouth and gastrointestinal tract) (Cawley & Benson, 2005; Pulito et al, 2020; Saito et al, 2023), to name a few. One particularly distressing side effect of Docetaxel, for me, was chemotherapy-induced alopecia (CIA). In order to reduce hair loss, a device called a 'cold cap' is offered to patients receiving the drug: the cold temperature of the cap causes the blood vessels below the scalp to narrow, reducing blood flow, and therefore reducing the amount of Docetaxel reaching the hair follicles (Lemenager et al, 1997; Betticher et al, 2013; Cigler et al, 2015). Before applying the cap, hair must be wet and covered in a conditioner in order to prevent adhesion to the cap and resultant breakage. Anecdotally, these cold caps are said to be painful, headache-inducing, and very unpleasant. I found the experience of the cold cap to be quite the opposite: it was very soothing and most enjoyable.

This third section expresses the calming and soothing sensations of wearing the cold cap. *Konnakol* recitation and its accompanying *kriya* settle at a steady and unfluctuating speed with no hesitations throughout the section. The hand moves serenely and calmly in its execution of *kriya* and the voice gently and competently articulates each *solkattu* syllable of the two repeated *konnakol* phrases. The performance style of this section represents the ease of the experience of wearing the cold cap and the peaceful pleasure that it sensorially provided.

#### Part 4 - Carboplatin - 05:01 - 06:06

The final part of the video is the shortest of the four sections. An acceleration begins at 05:18, representing my eagerness to leave the hospital as the final drug is administered. This acceleration also marks the subsidence of the drowsy and confusing effects of the earlier pre-medications and return of psycho-active

restlessness brought about by the dexamethasone<sup>51</sup> taken at breakfast. By the time Carboplatin was administered I was often one of the last people remaining in the ward that day. Most chemotherapy sessions do not require as much as four separate substances to be given, interspersed with periods of plain, saline solution administration. By the end of a 9 hour chemotherapy session, the somnolence passed and a loquacious and somewhat agitated steroidal state would manifest.

At 05:15, the swing intonation, emphasising *Tha - - mi - - jho -*, returns and by 05:53, recitation becomes punchy and confident, with a return to standard *konnakol* intonation. By the end of the administration of Carboplatin, I became restless and eager to leave the hospital as soon as the nurses agreed I was safe to go home.

## PRESENTATION OF KONNAKOL

As established, *konnakol* performances present complex and virtuosic displays of musical skill. Practitioners perform advanced mathematical combinations of rhythmic phrases with speedy and articulate execution of *solkattu*, often with accompanying facial expressions showing intense concentration. TCH-P, however, presents an unconventional and unstable rendering of basic *konnakol*, using only very simple building blocks of the rhythmic practice. Such simple and unembellished exercises would never normally be heard in public but kept only as private exercises during lessons and practice sessions.

The *thalas* used in TCH-P, within which the very simple exercises are recited, were mathematically determined by the numerical data printed on the drip bags containing my immunotherapy and chemotherapy drugs. Unfortunately, I did not

<sup>&</sup>lt;sup>51</sup> Dexamethasone is a potent corticosteroid (i.e. steroid), a synthetic version of hormones usually produced by the adrenal glands. Dexamethasone's common and very common side effects include anxiety, abnormal behaviour, cognitive impairment, and psychotic disorder, among many others (Stuart et al, 2005; Polderman et al, 2019; Janowitz et al, 2021).

make a note or take a photo of the bags and so I no longer have evidence of the numbers which determined the selection of *thala*. As the dosage and biomedical information differed on each bag label, the *thala* for each section is distinct. The variety, irregularity, and interruption of *thalas* in this work are a re-interpretation of the concept of *thalamalika*. Just as the term *ragamalika* means a 'garland of ragas' (Nair and deSouza, 2020), so *thalamalika* refers to a variety of different *thalas*, or time cycles, connected to each other, garlanded, in performance. The four *thalas* are shown in the table below:

Part 1 - Perjeta	khanda jaathi matya thala	12 beats per cycle (5+2+5)
Part 2 - Herceptin	mishra jaathi jhampa thala	10 beats per cycle (7+1+2)
Part 3 - Doctetaxel	sankeerna jaathi rupaka thala	11 beats per cycle (2+9)
Part 4 - Carboplatin	thishra jaathi ata thala	10 beats per cycle (3+3+2+2)

The four parts flow continuously from one to the next using a silent bridging *avartana* (one time cycle) at the beginning of each section, showing the new *kriya* being performed by my cannulated hand.

The focus of the video is on my cannulated hand throughout. Standard presentation of *konnakol* recitation focuses on the performer's face but because this work is an experiment in sonic life writing, I have chosen to draw focus away from the engaging visually stimuli of facial expressions so as not to detract from the audio. The cannulated hand, in its performance of *kriya*, gently supports the voice without significantly distracting attention from the recitation; also, the cannulated hand clearly locates the work in a medical, hospital setting. I have included in the audio, at low volume, home-produced recordings which represent the sounds I heard in the chemotherapy ward during treatment. These recordings, looped, provide a supportive texture to the voice without being intrusive, and again, reinforcing the medical,

# THE MOUTH AS SITE FOR ILLNESS AUTOETHNOGRAPHY

In researching the voice, I was led to the mouth. I couldn't get around it; it always interrupted my discursive gaze, demanding attention, as well as critical consideration. I wanted the voice, in all its complexity: it was my desire, my aim. Yet I recognised that in speaking of voice, I found the mouth — I fell into it; and in following this direction, by going in, I came to recognise how voicing is most often what I call "mouthing." To *mouth* is that instance of oral gesturing, whether in the drama of the yawn or in the sinister potential of the whisper; an action, in other words, that circulates in and around voicing, encapsulating it — *mouthing the words* should thus be taken literally, for the mouth wraps the voice, and all such wording, in its wet and impressionable envelope, its paralanguages.

Brandon LaBelle, Lexicon of the Mouth, 2014, p.7

In experimenting with possibilities of sonic life writing through *konnakol*, the mouth undoubtedly became the prime site for autoethnography and I will attempt to describe some of its interconnected and boundary-making functions in relation to this work. Although I describe TCH-P as a work for voice and hands, it is the invisible mouth that is the true theatre of testimony. LaBelle notes that "the mouth delivers an epistemology founded on processes and experiences of ingestion and incorporation, emanation and expulsion, attachment and loss: a series of knowledge paths defined by this orifice and its generative and volatile movements" (2014, p.7). I will explore pertinent elements of these processes and experiences to form a constitutive, corporeal appreciation of this active and performative cavity during cancer treatment.

The somatic and social functions of the mouth are multidirectional. Sounds and substances may travel in, out, through, and around the oral cavity in connected, confluent, concurrent, or contradictory operations. In examining the mouth specifically in a chemotherapy-related context, the behaviours with which it engages are governed by medical advice, social expectations, bodily needs, and physical capabilities. I shall first consider what goes in and what goes out of this orifice. It is obvious that air, foods, and liquids enter the mouth; we ingest in order to live and the mouth is the essential port of import, the delivery dock where substances may be drawn through, processed, or chewed through and over, before moving into further unseen chambers. Chains of small muscles operate, in cahoots with sinal and olfactory systems, to process incoming substances. The administration of chemotherapy distorts the experience of ingestion: temporal obligations are enforced, tastes are altered by toxicities, and the cavity itself may be obstructed by the wearing of a mask to avoid infection or prevent its transmission. In the pursuit of prevention of iatrogenesis, the mouth must accept a variety of chemicals, medications, pills, and solutions, from analgesic mouthwash to soothe ulcers, to painkillers to ease rheumatic pain.

In considering what exits, our moisture-laden respirative exhalations and our adaptive voice are the objects which become emancipated at the point of the mouth; once passed the lips, their contactual link to the corporeal host is broken. However, it is the lingering possibility and anticipation of what *may* leave the body through the mouth, after the administration of chemotherapy, that looms large in the mind of the cancer patient (Lorusso et al, 2016). Despite antiemetic pre-medications, vomiting is a common side effect of a TCH-P protocol and the prospect of vomitus travelling through the mouth, which may already be suffering a variety of iatrogenic issues, carrying with it its distinct flavour, arouses fear, disgust, shame, or dread.

Processes of ingestion, incorporation, emanation, and expulsion relate to permissions and agencies. This sensitive, intricate, intimate cavity has sets of rules by which it must abide and customs which it must respect, in a chemotherapy-related context especially. Oral behaviours deemed safe and reasonable include breathing, yawning, drinking, eating, and talking (be that friendly conversing or the formal delivery of consent to intravenously accept modifying and toxifying solutions). Behaviours relating to fundamental drives such as sex and musical or non-lexical expression are forbidden. The recipient of a TCH-P intravenous regime is deemed to be a hazardously toxic entity for a minimum of 48 hours and therefore kissing or oral sexual activity must be refrained from in order to protect the other(s). Bodily fluids including saliva are regarded as problematically toxic in the early stages of the 21 day chemotherapy cycle. In hospital, vocal musical expression is unheard of: to sing, or to recite *konnakol* would be an act of transgression, a potential irritant to others.<sup>52</sup> The mouth may not behave as a musical instrument.

In considering the permissible and forbidden behaviours of the mouth, questions of the mouth's modalities and methodologies arise: what may the mouth behave as, what may it present, and what may it represent or symbolise? The productive oral factory must perform all its common multidirectional functions, crafting and shaping phonic substances, breaking down and processing foreign matter, separating, concealing, and articulating. All of this must take place at the same time as the mouth is being poisoned, its cells dying in their millions each day (Henson, 2005; Nagata et al, 2010; Ravichandran, 2011; Han & Ravichandran, 2011). The mouth becomes a chaotic and unpredictable place that hosts varieties of sufferances and displays iatrogenic maladies which may include mucositis, infection, loss of taste, swelling, burning throat, pain, altered tastes, dryness, or overproduction of saliva following steroidal ingestion.

The mouth in chemotherapy treatment becomes a vestibular chamber of liminality and site of intersection of substance and processes. In its display of iatrogenesis and sufferance, during the in-betweenness of pre-treatment life and post-treatment recovery, or pre-diagnosed life and post-management death, it reveals the profound damage caused by chemotherapy. Moreover, the mouth exhibits cellular damage which inspires hope for the destruction of the internal, unseen cancer; it puts "one's body where one's mouth is" (Shusterman, 2012, p.4). In this sense it is a conduit, carrying or hosting hopeful information about the invisible

<sup>&</sup>lt;sup>52</sup> See Gunaratnam (2009) for a discussion of auditory space, noise, and alterity in care at the end of life.

inside, and a conduit in its moving of information, transmitting speech and sound. Put simply, the more cellular damage the mouth exhibits, the more likely the damage to the tumour in the breast.

## CONCLUDING REMARKS

TCH-P prizes the positive value of imperfection inherent in Karnatak music, embracing inaccuracy, as explicated by Pearson (2021). In deviating from aesthetic norms of virtuosity, articulation, intonation, and presentation, this research disrupts standardised ableist performance; it exposes elementary fundamental building blocks which underpin the metric systems involved in complex Karnatak music, and offers one example of an expressive alternative in the form of a work of sonic life writing. As a performance-autoethnographic and illness-acoustemological video, experiences of chemotherapy treatment are shared and integrated with paraverbal features which communicate the effects of a toxic intravenous regime. Despite TCH-P being a work exploring knowledge with voice and hands (Voegelin, 2023), it is the mouth that is the primary site of autoethnography; this toxic and in some ways forbidden orifice becomes an adept, injured workplace of movements and mechanisms, a contradictory first and last point of the body.

# <u>ADDENDUM</u>



These images display the metadata for the home filming and audio recording of TCH-

P on 15th April 2023, three years after my final chemotherapy session.

>>KRANKENHAUSFUNK and the extrinsic death receptor pathway<<

A masked nurse covered in plastic appears from their station. It's time to remove the cannula from the hand of the old woman in the far corner: she's ready to go home. I listen to the sound of Boby trolley wheels and sticky trainer soles crossing the thick Lino floor, in polyrhythmic dialogue with the dependable whirr of my own infusion pump. All movement is now so audible in this quiet ward which used to brim with chatter; a very different acoustic territory. Where is everyone? Have they been sent home? Surely everyone still needs their chemotherapy? It can't just be cancelled, can it? Did they really need it in the first place then?

There are almost no patients here, and definitely no visitors. No conversations to have and no conversations to eavesdrop. I sit alone, cannulated and connected again, in receipt of the usual drugs, their pattern now familiar and slightly less appalling. This strange place is no longer a daunting hubbub - in fact, there's hardly anyone here. The chairs around me are taped off; strictly no companions allowed. In fact, besides the nurses, no one's allowed near me at all, companions or otherwise. I am a lone striving wannabe going-on-being (I won't use the "s" word), no longer a member of the burgeoning and diverse tribe. With no conversation there's just the occasional meeting of hopeful smiling eyes, above a mask, across this clandestine and risky room. Where has everyone gone? Too drugged up to read, I put my headphones on and listen to the musical offerings sent to me by absent friends.

\*

"Your body must be heard"

Hélène Cixous, The Laugh of the Medusa, 1976

>>KRANKENHAUSFUNK and the extrinsic death receptor<< began as a seed of an idea, inspired by the 2022 open call for CTM Festival in Berlin and its theme of "Contact." Dr Scott McLaughlin, Associate Professor in Composition and Music Technology at the University of Leeds, suggested I might propose an idea for CTM's Radio Lab programme which commissions experimental works in the field of what Magz Hall (2015) describes as "expanded radio arts." My initial thought was a playful one: what if hospital radio was technologically reimagined so as to be broadcast not through ward speakers or bedside entertainment systems but through the medical machines used for patients' treatment? Given that so many items of electronic medical equipment contain speakers in order to provide sonic alerts or physiological information — intravenous infusion pumps and beeping heart monitors spring first to my mind — I thought this idea could potentially make for an interesting installation. Unfortunately, my proposal was not accepted. This original seed, however, grew from this small and playful idea into the more substantial work of practice research that constitutes this chapter and corresponding video.

\*

The title of this chapter denotes its two principal themes of research: hospital radio and the biological process of cellular apoptosis. Whilst hospital radio is a fairly well-known phenomenon, at least to people in the UK, apoptosis is a process unfamiliar to many and therefore requires explanation. It is, along with necrosis, one of the two main mechanisms of human cell death (Lekshmi et al, 2017) and as adults, billions of our cells die each day via these two mechanisms. For adult humans, estimates range from 60 billion cell deaths daily (Cotter, 2009), roughly 694,000 per second, to 86.4 billion cell deaths per day, equating to 1 million cell deaths per second (Henson, 2005; Nagata et al, 2010; Ravichandran, 2011; Han and Ravichandran, 2011). This normal physiological process of programmed cell death occurs in almost all animals on earth, from the reticulated giraffe of Somalia to the nematode worm *Caenorhabditis elegans* (Alberts et al, 2002; Elmore, 2007; Liu et al, 2013; Kaczanowski, 2016). I shall further expound this

process of apoptotic cell death later in this chapter but suffice to say, at this introductory stage, that apoptosis is central to cell life and death, and to our life and death as a whole. Our cells die so that we can go on living, or rather we are programmed to die in order to go on living through billions of daily micro-reincarnations.

I re-applied to participate in CTM Festival, following further study of hospital radio, and was invited to present as part of the international Research Networking Day.<sup>53</sup> I was unsure what to call my festival presentation until I discovered that the German term for hospital radio is the very pleasing compound word "krankenhausfunk," literally meaning sick-house-radio. I combined "krankenhausfunk" with the term for a particular type of apoptosis called "the extrinsic death receptor pathway." As I will fully explicate later in this chapter, I have transducted this extrinsic death receptor pathway of apoptosis into a compositional process and applied it to three pieces of musical and sonic material in a work of sonic life (and death) writing. In essence, >>KRANKENHAUSFUNK and the extrinsic death receptor pathway

Notions of, and relating to, broadcasting are important to this research. I note here, as somewhat of an aside, that running through this chapter is an elusive linguistic and conceptual connection between "seed" and "broadcast," relating to cyclicality, which I am not able, currently, to fully articulate to my satisfaction but nonetheless optatively desire to be able to express artfully in time. I consider the associative relationship between the seed and its method of sowing in agriculture known as broadcasting. A crop may be sown using the broadcast method — a

<sup>&</sup>lt;sup>53</sup> I presented my research at CTM Festival in early 2022 and was then commissioned by Huddersfield Contemporary Music Festival hcmf//2022 to create a live performance of the work which was premiered in the CREATE Lab of the Barbara Hepworth Building in Huddersfield in November 2022.

scattering by human or machine — its seeds growing and developing over months into fully matured plants before being orderly harvested. The process of broadcasting may take place again the following year; an early stage in the regulated cycle of regeneration and renewal. Such a systematic and cyclical process bears similarities with biological processes of cell regeneration and renewal, a dis-regulation of such processes often being a sign of cancer when proliferative cellular behaviours usurp regenerative patterning (Cooper, 2000; Hanahan and Weinberg, 2011; Feitelson et al, 2015; Northcott et al, 2018).

Radio broadcasting takes its name from the agricultural method, not scattering seeds but audible information, be that musical, sonic, or speech-based. Like patterns of agricultural production, radio schedules have a cyclical nature of repetition, regeneration, and renewal. As I will explain further, hospital radio is very much in decline at this time in the UK, the numbers of stations and shows waning, with existential concern over its future. The hospital radio network has not been regenerating and renewing but gradually petering out, falling silent for longer and longer periods, as if its apoptotic systems have been running in overdrive. It is this decline, in part, which has contributed to my idea for a radical reimagining of hospital radio: I believe there is scope for progressive, artistic, transformative renewal and regeneration in this field.

One of the principal aforementioned pieces of musical and sonic material used in K+EDRP is the Hindu Gāyatri mantra. Unlike single-syllable "seed" mantras, known as *bīja* mantras and associated with Hindu Tantrism,<sup>54</sup> the *Gāyatri Mantra* is a most prestigious and auspicious verse. Alper (1989, p.354) describes the *Gāyatri* as "exemplary among mantras as, let us say, the Ganges is exemplary among rivers." So

<sup>&</sup>lt;sup>54</sup> See White (2000), Flood (2005), and Padoux ([2010] 2017, 2011) for discussion of Tantric mantra use, recitation, and vibration.

revered is this great mantra that it is broadcast around the world on a variety of radio stations, repeated daily at set times in a dependable cycle. For example, Radio Paramaribo in Surinam broadcasts the Gāyatri every single day at 19:00 for 15 minutes, and Radio Ananda from Nevada City, California plays the Gāyatri mantra on constant repeat.<sup>55</sup> Just as mantras are repeated (or vibrated), cyclically, so the time cycles of Indian musics (as described in the previous chapter) return, looping. The cycle is never far from Indian music; nor is it from cancer treatment with its plotted cycles of chemotherapy and immunotherapy; nor the cellular micro-reincarnations of the human body; nor the vibrated repetitions of mantra recitation; nor the broadcasting of seeds in the agricultural calendar. It is this connected periodic circularity that I wish to draw attention to and illuminate here.

Returning now to the core research issues of this chapter, K+EDRP disrupts and transgresses the specifics of contemporary hospital radio and its consumption, taking it beyond the hospital walls, and into new radio territories and bodily sonic geographies (Gallagher and Prior, 2013; Doughty et al, 2016; Gallagher, 2016). Asking how and why hospital radio may be radically re-imagined as a broadcast of patient experience — and why a reimagining may be beneficially disruptive — is the primary path of inquiry in this practice-based research project.

I will briefly describe a short history and key features of hospital radio in the UK, with special focus on Radio Marsden, before examining the specific characteristics of the contemporary hospital radio system. I will discuss the impact of hospital radio in relation to Wilson's principles of aesthetic realism (2020) and apply Gregory Whitehead's notion of radio "triangulation" (2003) to both the contemporary hospital radio situation and then to radio art, with reference to works relating to the body by

<sup>&</sup>lt;sup>55</sup> Radio Ananda offers a variety of listening options — the repeated, looping Gāyatri mantra being one of them —but its main focus is the 400 pieces of music written by American Hindu religious leader Swami Kriyananda, a disciple of Paramahansa Yogananda (author of the cult classic book, *Autobiography for Yogi* (1946).

Whitehead and Anna Friz. In my analysis, I aim to realistically acknowledge the practical limitations involved in both broadcast forms because theory cannot entirely address financial and infrastructural realities. In this examination of radiophonic spaces, I turn again to Wilson's theory of critical realism in art (2019) and its various stages of relation to understand how "we both make connections, and come to know ourselves as connected" (2019, p.ix).

Wilson's examination of ways of connecting through the arts is also pertinent to the second research question for this project: how might Eve Kosofsky Sedgwick's theory of reparative reading be applied to listening? With particular attention to the reparative potential of radio, I will develop the term 'reparative listening,' taking my lead from Sedgwick's theory of reparative reading from her brilliantly titled essay, *Paranoid Reading and Reparative Reading, Or, You're So Paranoid, You Probably Think This Introduction is About You* (1997). In pursuit of acoustic justice, K+EDRP articulates the intimate testimonial potential of radio (arts), and its scope for reparation, in both an expressive and transmissive way, as opposed to the Sedgewickian idea of paranoid reception so prevalent in textual illness narrative criticism.

As with all chapters of this research portfolio, K+EDRP holds dear the aim to make the "inaudible audible" (Vickers et al, 2017), and, in this particular case, seeks to explore how apoptosis may be understood through or with sound, and to what end or value. I will discuss sonification of biological and medical information and develop the term "artistic sonation" to better describe the methodology developed and adopted in this practice research inquiry. The chapter concludes with a full commentary of the work.

Before exploring issues concerning hospital radio, I include the brief description of K+EDRP from both the abstract of my CTM Festival presentation from

2022 and subsequent live performance premiere at Huddersfield Contemporary Music Festival (hcmf//):

>>KRANKENHAUSFUNK and the extrinsic death receptor pathway<<

is

- 1. an installation or live performance
- 2. a re-imagining of hospital radio as a broadcast of patient experience through reclaimed, repurposed, and rewired chemotherapy infusion pumps
- 3. a self-reflexive interpretation of the artist's personal experience of illness during the Covid-19 pandemic
- 4. an invitation to make contact with the kingdom of the sick: to encounter a localised radiophonic space derived from extraordinary and extreme experience. It is both hopeful and confronting. Mantras, musical gifts, and the sounds of machines delivering chemotherapeutic and immunomodulatory solutions, drop by drop, are blended in a process of sonic cell apoptosis.

# HOSPITAL RADIO

Hospitals can be noisy places. Scores of people in close proximity to each other, sounds of medical equipment, and spaces designed without consideration of their acoustic profile all contribute to the sonic hubbub of hospital life (Grumet, 1993; Bharathan et al, 2007; Rice, 2003, 2013). Noise pollution and excessive sound are known to cause "deleterious effects" on human health in healthcare settings (Bharathan et al, 2007, p.31); some of what one might hear whilst in the wards, what Gunaratnam<sup>56</sup> describes as the "sonics of suffering" (2009, p.3), such as the sounds accompanying the fatal heart attack of a fellow in-patient, may be very distressing (Rice, 2003). It is no wonder that the invention of hospital radio proved popular in the

<sup>&</sup>lt;sup>56</sup> See Gunaratanam (2009) for a discussion of "noisy others" and "control over acoustic space" in multicultural hospice settings.

twentieth century, providing distraction and entertainment for patients, staff, and visitors. This section aims to explore some of the many purposes, functions, and fundamental features of hospital radio: some tangible, practical, and historic; others performative, qualitative, and futural. Beginning with a short history of hospital radio, with a special focus on Radio Marsden, I will examine the changes from the twentieth century broadcast model to the contemporary online streaming paradigm, the decrease in listenership brought about by this advancement in broadcast technology, and the resultant transformation of the hospital radio territory. I shall examine the British Hospital Broadcast Association's latest report findings using Wilson's principles of aesthetic critical realism (2020) and apply Whitehead's notion of triangulation (2003) to the hospital radio model. Following an explanation of how K+EDRP fulfils Whitehead's qualifying requirements of radio art, I will discuss other corporeal, medical, and hospital-related radio and sound works, including Whitehead's collection *The Respirator and other outcasts* (1989) and Anna Friz's *Respire* (2009) and *Revenant* (2023).

The first hospital radio service in the world started over a century ago in May 1919 at the Walter Reed General Hospital in Washington DC, United States (Rice, 2003).<sup>57</sup> Six years later, the York County Hospital, United Kingdom installed its radio system, the first in the UK, with headphones provided next to 200 of its hospital beds and 70 speakers located in communal areas, "fed by a wireless receiver located in a small alcove" (Crow, 2005, p.6). Early transmissions included speech-based items such as sports commentaries, poetry readings, and church services, as well as musical offerings. By the 1970s and 80s, UK hospital radio stations were an integral and ubiquitous part of the hospital experience, offering a varied listening service for

<sup>&</sup>lt;sup>57</sup> Much of the early use of radio was in contexts of war (Burrows, 1962) and I note here a speculative connection between the relationship between war and radio and the use of warfare-based metaphor in the treatment and experience of cancer, not least expressed in standardised cancer narratives.

in-patients, and providing a training ground for budding DJs; many well-known British broadcasters, including Ken Bruce and Simon Mayo, began their careers in hospital radio (Crossan, 2012). Pop music and pop music request shows dominated these radio services across the country, and still continue to. There are, however, some shows dedicated to less mainstream genres such as country music and jazz, for example, on the 2023 Sunday schedule of the Birmingham Hospital Broadcast Network, BHBN.

One of the pioneering stations in the UK was Radio Marsden, serving the Royal Marsden cancer hospitals in London and Surrey, led by David Peschier from 1969. Peschier developed a programme schedule that was both thoughtful and varied, involving participation from patients *and* staff. The station's schedule included regular classical music shows curated by local music experts; evening shows that blended poetry and relaxing music to fall asleep to; there were competition shows with prizes on offer and invitations for patients to share their best jokes; the *Marsden People* show featured hospital consultants and staff talking about their life and work; and *Once Upon A Chula* featured stories and jokes for youngsters in the children's ward (Peschier, 2021). Since the departure of Peschier, Radio Marsden has slimmed down the variety of its offerings, in line with many other UK hospital stations.

Hospital radio stations have traditionally been amateur operations providing training for people interested in careers in broadcasting, guided by more experienced, and often retired, volunteers. Historically, these well and well-meaning volunteer presenters and producers were powerful intermediaries between the kingdoms of the well and the sick, providing information from the outside world — such as news and sports updates — to the confined, temporary, transient residents of the hospital in the pre-smartphone age. In the twentieth century, the musical, sonic, and speech-based information selected by well volunteers was transmitted to sick residents via closed, in-house, low-powered broadcast systems (Crow, 2005).

Therefore, hospital radio broadcasts were inaccessible to residents of the kingdom of the well beyond the hospital walls.

Not only would the volunteers select and supply information from the outside kingdom of the well to the contained kingdom of the sick, but information, and what would now be described as content, would also be generated from within the contained kingdom of the sick itself. Broadcasts sometimes took place from inside the wards<sup>58</sup> and there was much integration of patients, staff, and radio volunteers, such as the aforementioned *Marsden People* show. This blend of information and content was hermetically contained within the locality of the hospital, not shared back out into the world outside the hospital boundaries due to the aforementioned closed broadcast networks. It is important to note this vectoral flow of information and content in order to appreciate the radical disparity between the hospital radiophonic spaces of the twentieth and twenty-first centuries.

Modern broadcast systems used in hospital radio are primarily dependent on internet streaming which has bust open these previously sealed, covert networks and territories. The selection and flow of content and information in the contemporary setting is consistent with its ancestor in that volunteers choose what to broadcast and share with the audience, but, there has been a radical transformation in the potential listenership as hospital radio can now be listened to by anyone who chooses via internet streaming. Covert containment no longer exists and the audience is now, at least potentially, dispersed across the globe. For example, a person recovering from a hip replacement in a Welsh hospital can simultaneously listen to the same show, broadcast from that same hospital in which they are temporarily

<sup>&</sup>lt;sup>58</sup> Peschier describes guest appearances in the Pinkham Ward for Christmas shows in the 1970s involving Sandra and Janet, two bunny girls from London's Playboy Club who "stunned their audience," and entertainer Nadine Dubarry who, as part of her act, went around "pinning French things on the men in the audience" (2021 : 86-7). Peschier notes "it was different times back then" (ibid., p.87).
residing, as their family member in, say, New Zealand. Despite this opening up of the hospital radio territory, listenership is dwindling with far fewer patients tuning in. What accounts for this decline in listenership?

The contemporary reputation of hospital radio in the UK is certainly not as high as it could be, and, in fact, the medium has become a subject of ridicule. Tom Binns, a former breakfast radio show host on British commercial station XFM,59 created a popular comic character in the 2010s called Ivan Brackenbury: an inept and dorkish hospital radio DJ. Brackenbury, appearing on television shows including 8 out of 10 Cats Does Countdown on Channel 4 (ABC TV, 2018), chooses amusingly inappropriate and lyrically insensitive songs to dedicate to in-patient listeners during his Disease Hour show. One of Brackenbury's comic tricks is the use of well-meaning but blundering catchphrases such as "if you're at death's door, I'll pull you through" (ABC TV & view, 2010). Although this is simply a knowing comedy act where everyone is in on the joke, the humour owes a lot to the fact that it is not difficult for the audience to imagine that a blundering hospital radio volunteer would make such insensitive comments, such is the poor reputation of hospital radio and its predilection for a hackneyed and cheesy presenting style. This old-fashioned style of radio delivery is one of the reasons for its decline, I believe, alongside other important factors including lack of funds, lack of interest compared with the popularity of streaming services and social media, and increased hygiene and infection control protocols (especially following UK hospital superbug issues<sup>60</sup> and the Covid-19 outbreak).

The number of hospital radio stations in the UK has more than halved in the last

<sup>&</sup>lt;sup>59</sup> XFM is a national station, owned by Global Media, focused on indie rock and guitar-based music.

<sup>&</sup>lt;sup>60</sup> Twenty-first century trends in methicillin-resistant Staphylococcus aureus (MRSA) infections in UK hospitals are discussed by Edgeworth et al (2019)

30 years (Crossan, 2012). This once thriving network of British hospital stations is on the wane with the number of stations in operation decreasing year on year and the operating hours of these remaining stations being regularly reduced. The general decline in radio listening and the rise of streaming services and social media are not the focus of my research and discourse on the changes in media consumption and technological advancement is well explicated by Albarran et al (2007), Ruggiero (2000), Mooney (2010), Bolin (2016), and Chan-Olmsted et al (2022). I am, however, interested in appreciating the potential effects of the decline in hospital radio, drawing on Wilson's developments in "realising aesthetic experience" (2020, p.67), before turning to Whitehead's notion of the triangulation of radio (2003).

The purposes and functions of hospital radio, since its inception to the modern day, are manifold. Hospital stations have and continue to provide distraction and entertainment for patients, diverting their attention from the general hospital acoustic environment, as described in the introduction to this chapter. Most pertinently to hospital networks, Busemann and Engel (2012; cited in Chan-Olmsted et al, 2021 : 3) recognised specific affective needs, such as "relaxing and avoiding loneliness," as the main motivators behind radio consumption. More generally, Chan-Olmsted et al (2020, 2022) identified six reasons for radio listening: entertainment, socialisation, pastime, habit, escapism, and information. Pastime and longstanding habit are not likely motivators for patients and visitors but certainly could be for members of staff. Entertainment, socialisation, escapism, and information, however, are core tenets of hospital radio, particularly for patients, and Peschier's Radio Marsden was a prime example of such values. Whilst entertainment and escapism are arguably achievable from a wide variety of sources (streaming services, television, and social media), community-based socialisation and information are not. Might the decline in hospital radio listenership therefore negatively affect patient experience?

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# HOSPITAL RADIO AND AESTHETIC CRITICAL REALISM

The British Hospital Broadcasting Association (BHBA) reported "evidence of hospital radio stations having impact on psychosocial health outcomes" (Thomas and Coles, 2016, p.3) in a variety of ways which relate to Wilson's categories of aesthetic, axiological, and cultural experience (2020). The BHBA's findings relating to hospital radio listenership are:

- 1. Boredom reduced by entertainment
- 2. Loneliness reduced by social interaction
- 3. Anxiousness/frustration reduced by being calming and reassuring
- 4. Disorientation reduced by creating a sense of belonging
- 5. Depersonalisation reduced by making one feel like an individual
- 6. Health and wellbeing awareness increased by providing information (Thomas and Coles, 2016, p.3)

Whilst some of these positive outcomes are achievable, to a greater or lesser degree, through the consumption of alternative media such as television, hospital radio is uniquely placed to beneficially influence patient experience as evidenced by the BHBA report. Aesthetic critical realism is not concerned only with lofty and fetishised conceptions of art but with everyday and ordinary experience (Danto, 1981; Carlson, 2000; Brady, 2006; Wilson, 2020), therefore it provides a suitable framework with which to assess community hospital radio and its influence on patient experience. As Dewey sought to establish, "to understand the [a]esthetic in its ultimate and approved forms, one must begin with it in the raw; in the events and scenes that hold the attentive eye and ear of man, arousing his interest and affording him enjoyment as he looks and listens" ([1934] 2005, p.3). Moreover, Wilson's principles of aesthetic critical realism (see introduction) pertain to relational properties, being-in-relation, values, and (emotional) valency motivated by aesthetic experience, all of which speak

to the BHBA report. I shall now address the BHBA report findings in connection with some of Wilson's categories of experience.

Aesthetic experience is concerned with being-in-relation and with phenomenological specialness and specificity. Enabled by a realist ontology, Wilson argues that aesthetic experience is "emergent from, comprised by, but irreducible to, three central modes of relationality" (2020, p.83). The first of these three central modes is perception: perception of colours, pitches, timbres, pulses, patterns, etc. Without wanting to enter into a discussion here regarding the many interesting issues concerning perception from philosophical or neuroscientific perspectives,<sup>61</sup> suffice to say that we have a "relational encounter" (ibid.) with perceptible features, separate from and independent of ourselves, when we listen to a song, or a story, or we look at a painting. This first mode of aesthetic experience describes the perception of exclusive phenomenological specificities such as music (or musical elements) played on hospital radio or speech-based items such as interviews or stories.

The second mode of relationality in aesthetic experience is responsive, moving from the perception of external stimuli in the first mode, to the "internal" (ibid.) effect of the encounter with the external. This second mode is where we begin to meet the BHBA report findings: the reduction in anxiety and frustration experienced by hospital radio listeners brought about by calming or familiar music and reassuring content is a second mode of relationality response involving entangled meta-processes of "cognition, memory, and reflexivity" (ibid.). It is in this second mode that we "discern," "deliberate," and "dedicate" (Archer, 2007): we discern what matters to us through our emotional, somatic, or cognitive responses; we deliberate the intensity of our discernments; and we then choose whether or not to dedicate our attention to the "unfolding experience" (Wilson, 2020, p.84). The choice whether or not to dedicate

<sup>&</sup>lt;sup>61</sup> See Crane (2005) and Hirst (2014) for discussions on the problem of perception

attention, or course, is based not solely on, or reducible to, unconscious decisions and responses in the moment but is inextricably bound with formative experiences relating to taste and class (Bourdieu, 1987, 1994; Prior, 2013; Deeming, 2014). As radio is a temporal medium, this choice whether or not to dedicate attention is crucial as, patently, beneficial effects of hospital radio, as set out in the BHBA report findings, cannot be achieved if hospital radio is not chosen as an object of attention. Whitehead acknowledges this choice and describes the relationship the broadcaster or artist has as a "fragile, weird complicity with a listener, who is always just one twitch away from tuning you out" (2003, p.2).

This second mode not only puts us in relation with separate, independent, perceivable, external stimuli, but also in relation with ourselves, connecting with our constantly reshaping and remodelling sense of self: our own sense of who we are, as shaped by our responses. Just as the body is in a constant state of renewal and regeneration through the cellular processes of apoptosis and necrosis, so our sense of self, our identity, is refashioned on an ongoing basis, not least at times of serious illness. Change in personal identity is a common theme in illness narratives and health humanities research (Sontag, 1978; Lorde, 1980; Frank, 1995; Kayser and Sormanti, 2002; Major, 2002; Bellizzi and Blank, 2007; Galgut, 2010) and hospital radio must undoubtedly reinforce the sick status or identity of an individual listening whilst staying in hospital. The BHBA report findings, however, state a positive impact of this reinforced sick identity by an increased feeling of belonging; perhaps a communal socialisation and collective identity in radiophonic space brings solace, creating solidarity within the kingdom of the sick, therefore reducing feelings of isolation and loneliness, sadness, guilt, or shame.<sup>62</sup> This level of relational

<sup>&</sup>lt;sup>62</sup> Shame and guilt are commonly reported psychological experiences with cancer, as reported by Arian et al 2021, with lung cancer patients reporting the highest distress levels of all cancer groups (Dirkse et al, 2014)

experience of hospital radio therefore draws on the "when" and "where" of experience, as well as the "what." I shall return to these specificities of hospital radio in the subsequent discussion of Whitehead's notion of triangulation.

The third level of relationality concerns a constellational experience not only of the specifics of the radio broadcast (or elements of) and the empirical effects and responses they engender, but of a potential<sup>63</sup> and possibility (radiophonic and, perhaps, reparative), and an engagement with more than just subject and object: a connection with both positive and present, *and* "that which is absent" (Wilson, 2020, p.84). This level of relationality speaks to Voegelin's (2023) process of listening, as discussed in the literature review, that

performs entanglements, through which contingent subjectivities and plural realities are revealed that are not representational but are a matter of relationality and of experience. It aims to narrate this entangled subjectivity not as an anthropology of the other but as a sonic anthropology of the in- between and of interdependencies; of my listening now as an ethical and response-able hearing of how I and you and more than human bodies are together and with each other. Such a relational listening unsettles singular actualities in favour of plural fictions that are not untrue but reveal the possibilities of the world and of how else we could think it. (2023, p.66)

This concatenated engagement of potential — involving values, ideas, memories, desires, and absences — may be better understood through Wilson's subsequent category of experience, that of the axiological.

From the Greek *axia*, meaning value or worth, axiology is a branch of practical philosophy investigating the nature of value and processes of valuation (Smith and Thomas, 1998). Wilson's explication of axiological experience moves us from individual to collective – from lone sick person to member of a community – based on the values derived, perhaps primitively or unconsciously, from approach- avoidance

<sup>&</sup>lt;sup>63</sup> After D W Winnicott's "potential space" in *Playing and Reality* (1971)

responses to stimuli (Elliott, 2008). Positive second-level emotional, somatic, and cognitive responses to hospital radio develop, through third level relationality and axiological experience, into the impacts reported by Thomas and Coles (2016) including the reductions in boredom, anxiety, and frustration: values and valency manifesting in terms of forces or potentials that motivate us to move or be moved. The aforementioned deliberation of our discernments and responses elicits emotional valence and arousal, where emotional valence describes the degree to which an emotion is positive or negative, favourable or unfavourable, and arousal refers to the strength or intensity of the emotional state (Barrett and Russell, 1999; Citron et al, 2014). For Wilson, valency describes the energisation of behaviour and impact describes, and depends on, value.

Wilson affords primacy to the idea that experience can be theorised as "a distinctive emergent form of energy" (Wilson, 2020, p.90) which motivates or stimulates our behaviours "towards or away from a given artwork" (ibid., p.93), or, in this case, a radio broadcast, simultaneously engendering value as "a type of force or power" (ibid., p.99). Furthermore, Wilson also argues for

experience [to] be treated as a particular type of energy in its own right, rather than simply a "response" to external energy (light, sound, chemical or electrical energies, for example), hinges on an emergent property of such an energy system (comprising force, energy and work), which is *not* present in any other context. This is its being contingent upon our *knowledge* of being-in-relation with the forces involved, i.e., that which we call "value(s)" (ibid.).

The focus of impact measurement is axiocentric and valent. The BHBA report shares qualitative findings based on questionnaire responses and interviews. Raw et al (2014) have discussed the difficulties of value and evaluation in arts and health research and practice, a problem which "contributes to the sector's vulnerability" (ibid., p.97). There simply are not available funds or resources to evaluate hospital radio using biomedical metrics or quantitative data (Dileo and Bradt, 2009; Stuckey and Nobel,

2010) and so findings rely on qualitative data (White, 2009) which in itself is founded on value and valency.

For Grünberg, "any value implies the transcendent" (2000, p.7) and, without wanting to be reductionist, but in the interest of brevity, transcendence is a primary goal of hospital radio.<sup>64</sup> Examples from a great variety of potential experiences of transcendence include the distraction from "sonics of suffering" (Gunaratnam, 2009, p.3) or the transcendence of awareness of pain or discomfort through entertainment and laughter. Like hospital radio, transcendence is an important part of critical realism and has been addressed by Archer, Collier, and Porpora (2004).

The final category of Wilson's aesthetic critical realism applicable here to hospital radio and the BHBA report is that of cultural experience, determined by our "collective system(s) of value recognition" (Wilson, 2020, p.129). Whilst our personal perceptions, responses, and experiences are unique, as is their value, they are contingent upon "collective societal choices and actions, they *are* to a greater or lesser extent shared" (ibid).<sup>65</sup> Wilson goes on to say:

we often assemble in the same space and time to participate in a common experience — an experience of being-in-relation; we laugh and cry together; we discuss the "highs" and the "lows" of the experience afterwards often for days or months, sometimes these experiences stay with us for a lifetime" (ibid.).

Although Wilson is describing experiences such as concerts, film screenings, and exhibitions here, his description of cultural experience is nonetheless pertinent to hospital radio, not least due to the specificity of the location, content, and

<sup>&</sup>lt;sup>64</sup> For discussions of senses of transcendence — inwards, outwards, on, and with — see Bhaskar (2002), also Collier (1999).

<sup>&</sup>lt;sup>65</sup> Connecting back to Bourdieu's work on taste and class (1987, 1994)

radiophonic space. There is a coming-together of listenership (hence the report's noting the reduction of disorientation by "creating a sense of belonging"), of radiophonic space shared, of potential communal transcendence, be that through laughter, tears, or otherwise. This coming together, in relation, leads to Whitehead's somewhat more practical and empirical notion of the triangulation of radio.

#### TRIANGULATION OF HOSPITAL RADIO

Radio is mostly a set of relationships, an intricate triangulation of listener, "player" and system. Gregory Whitehead, Drone Tones and Radiobodies, 2003

Is Whitehead's notion of the intricate triangulation of *listener-player-system* in radio art applicable to hospital radio? I shall address each of these three categories of listener, player, and system in turn.

Waterman (2007, p.119) describes how listening can be "passive or active, collective or solitary, face to face or schizophonic" and these qualities are particularly interesting when considering the specificities of hospital radio, especially given the (power) imbalances in the health status of the community. In pre-internet hospital radio, the listenership was transient yet static in its radio territory. Of course, patients came and went with considerable and constant turnover but the listenership was focused and contained, steady in number, albeit with different bodies. With pre-digital/internet broadcast systems, there was a semi-secretive exclusivity to hospital radiophonic space: no necessity for what Rudolf Arnheim (1936) described as one of the facets of the miracle of the wireless, the overcoming of spatial isolation. Rather, the listeners to hospital radio were confined, together, within the walls of the hospital, a place where no one really wants to be, and all were members of a captive and diverse community of temporary residents. Hospital radio, unlike general FM and

DAB stations, is not listened to "in the background" while doing other things such as driving to work or cooking dinner, what Whitehead describes as "listening with only half an ear" (2003). When staying in hospital, there is little activity and often nothing to do besides lie in bed and tend to the business of illness and recuperation, experiencing a variety of suspensions of time as explicated in chapter three. This discrete listenership was also more regularly involved with the radio: be that in the form of requests, quizzes, or storytelling/sharing. These characteristics are still true for the contemporary hospital radio audience within hospital but this audience is, as I have outlined, no longer an exclusive and covert cohort with a boundaried geography.

The passivity/activity of hospital listenership is spectral and mutable: one patient may be gravely ill, barely able to move or communicate, strongly medicated, but still able to listen to the radio; another may be keen to send a music request or play along with quizzes whilst waiting to go into theatre for surgery. Of course, there is much consensus in the idea that all listening is active or engaged (Nancy, 2007; Wilson, 2020; Robinson, 2020; LaBelle, 2021; Voegelin, 2023) but the levels of experience, as explicated by Wilson, will vary according to the health status of the inpatient and the drugs which have been administered to them.

Hospital radio listenership, discounting the contemporary potential audience outside the hospital, is overwhelmingly collective, as the BHBA report finds (Thomas and Coles, 2016). Although one could argue that listening through headphones (which are provided with each bedside entertainment system) makes for a solitary or isolated experience, the fact that patients are listening live together within a ward, within a building, within the boundaries of a hospital campus, undoubtedly makes for a collective radio territory or radiophonic space even when they are unable to identify who is also listening along with them. The listenership is also, clearly, schizophonic – i.e. separated from the sound source, studio and volunteers – and

generally listening via individual bendy bedside entertainment units.

Who are the "*players*" in hospital radio? For Whitehead, radio art must be "some kind of event or performance or presentation — a "play" in the broadest sense — that deals with the fundamentals of radio, and the material of radio is not just amorphous sound" (2003, p.1). In relation to hospital radio, the notion of "play" suggests creativity and a sense of fun. Huizinga suggests play as a mechanism of social group formation which holds true in the case of hospital radio, especially in the pre-internet broadcast era, as the groupings "tend to surround themselves with secrecy and to stress their difference from the common world" ([1938] 1998, p.13). The exclusivity and specificity of a hospital radio schedule, involving dedicated request shows and hospital specific information, qualifies it as a community network.<sup>66</sup>

Hospital radio's "players" must be active, with the agency to control the transmission of information and content, and the ability to plan, produce, and schedule broadcasts. These players are volunteers about which one could speculate regarding their interest and experience in radio generally, degrees of altruism and self-interest, and their interest in the wellbeing and enjoyment of the patient listenership. The listener, however, may adopt the occasional, temporary role of player if they choose to make a request, take part in a quiz on air, or agree to be interviewed.

The "system" of hospital radio is a complex network of communication, distribution, and reception: an operation of relation. The system involves many parties and bodies with little or no connection to the players or listeners and primarily

<sup>&</sup>lt;sup>66</sup> ""A voice for the voiceless" — that is how community radio has often been described" (Lewis & Jones, 2006). With dwindling patient and staff participation, besides music requests, must naturally come a reduction in the community component of hospital radio and, therefore, the famous observation by Zane Ibrahim, the founder of Bush Radio in Cape Town, no longer rings true in relation to hospital radio: "a community radio is 90% community and 10% radio" (ibid.)." The current situation, at least on some British hospital stations, may now reflect the inverse of this equation.

pertaining to the broadcast method and mechanism. The system encompasses all those involved in funding and fundraising, from a single donor giving a few pounds at a community event, to teams of specialists working for the National Lottery Community Fund (who provide funding to hospital radio stations). These agents are connected to accountants who, in turn, are connected to both hospital managers and administrators and those working for service providers such as Hospedia and Patientlink.<sup>67</sup> Then there are legal advisors looking after licensing matters and technicians ensuring the functioning of those broadcast methods. There are designers and technicians involved in the invention and maintenance of technologies integral to hospital radio, and more designers involved in streaming service interfaces and web pages. The system is a diffuse conglomeration, with myriad financial priorities and concerns, and its actors have little to no connection to the listening bodies in receipt of the radio "play." The following section examines how K+EDRP disrupts the model of triangulation through "an intricate play of position" (Whitehead, 1993, p.2), inspired by the works of Gregory Whitehead and Anna Friz.

## RADIO, ART, BODIES

I strongly believe that radiomakers must find ways to disrupt the boundaries of "sound art," most of which sounds very tired and familiar anyway. Radio happens in sound, but I don't believe that sound is what matters about radio, or any of the acoustic media. What does matter is the play among relationships between bodies and antibodies, hosts and parasites, noise and irresistible facts in a strange parade destination unknown, fragile, uncertain... Each broadcast takes place inside an echo chamber of information, stories, biographies, life stories — inside the echo chamber sounds the most unnerving question of all, the ghost question: who's there? (Whitehead, 1996, p.96)

<sup>&</sup>lt;sup>67</sup> Two of the main UK providers of hospital bedside entertainment systems

K+EDRP disrupts Whitehead's model of triangulation, as applied to hospital radio, by subverting and, to a degree, amalgamating the roles of (sick) listener and (well) player; the work also reimagines the system as an independent enterprise, free from the infrastructural and financial restraints of the conventional model. In K+EDRP, it is the person in the standard role of listener - me, as cancer hospital in-patient - who becomes the player, all be it after the fact of my hospital stay(s). I have created what Whitehead defines as the qualifying feature of radio art, a "kind of event or performance or presentation - a "play" in the broadest sense" (2003, p.1), a work which is "an intricate play of position" (ibid., p.2). I present a complete reimagining of hospital radio as broadcast of patient experience, both biological and biographical, using a system of my own, independent invention. By purchasing and recycling old Baxter Colleague intravenous infusion pumps - rethinking and rewiring them through experimentation and "play" - the standard system is bypassed completely in favour of an innovative method of sounding which gives the sick player full autonomy and control. As discussed in the introduction and literature review (Mesley, 2006; Sontag in Rieff, 2009; Ehrenreich, 2001, 2010), women undergoing cancer treatment can feel, and be made to feel, infantilised and without agency. In K+EDRP, I, the person undergoing cancer treatment, have control of the machines with which I was treated and agency regarding the sounding and communication of my biomedical process. I, as the player and controller of the "system," have jurisdiction over the information and content broadcast. The established vectoral flow of information and content comes not from the kingdom of the well to the sick, but quite the inverse. Artistic information about the experience is/ has been transmitted, via medical machines, in locations beyond the hospital walls, such as the Barbara Hepworth CREATE Lab in Huddersfield (in November 2022), and Cafe OTO in London (in April 2023). I will provide a detailed commentary of the work later in this chapter but wish, at this point, to connect it with Gregory Whitehead's work and the work of Anna Friz, whose chapter title Becoming Radio (2008), neatly encapsulates my feelings about K+EDRP.

Gregory Whitehead is a prolific writer, radio programme maker, and sound artist who has made over one hundred "radio adventures" (as described by NTS Radio) for networks including the BBC, NPR, Radio France, and Deutschland Radio. Some key works include Radio Unbroken, a songspiel made for Radio Revolten festival, and Display Wounds, a fascinating short radio play about the study of wounds, a discipline known as vulnerology. Although not exclusively a collection of expanded radio art, Whitehead's The Respirator and other outcasts<sup>68</sup> (1989), released on cassette by Minerva Editions, has provided inspiration for K+EDRP with its blend of storytelling; sonic, compositional treatment processes with a focus on "entropy and eruption" (Whitehead, 2012); material "recyclings" (ibid., 1996); sampling and musique concrète techniques;<sup>69</sup> and corporeal and illness-related subject matter. Whitehead's work tends to be very repetitive and cyclical, giving insights into the subject matter with each new repetition as sonic treatments of the original material are applied and developed. Drawn "in spirit" (ibid.) from Whitehead's own experience of a near fatal car crash when he was sixteen years old, this collection of work brings together themes of traumatic brain injury and respiratory struggle with minimalist compositional processes (especially clear on the track Totenklage/ Lacrymosa with its dirge-like repetitions entropically losing sung syllables, and superseded by the spoken word "death" and disturbing electrical medical sounds emerging and dominating the musical texture) and sound modifications and superpositions (Teruggi, 2015).

<sup>69</sup> Teruggi describes musique concrète as music involving "any kind of sound from any origin" blended "together in a musical structure" through "sound modifications and sound superposition" (2015, p.52). Musique concrète is more commonly referred to as acousmatic music in contemporary discourse but I have opted for the older descriptor as it more accurately describes Whitehead's compositional technique for the works comprising *The Respirator and other outcasts* (1989). As Andean notes, "acousmatic music is a culture and a practice first, and a theory after; as a result its boundaries, if they exist at all, are fluid and only vaguely discernible at best, making an accurate definition close to impossible. Also, it could be argued that the 'acousmatic' is a creative act of *listening* rather than of composing; to some extent, any electroacoustic work – or, indeed, any musical work whatsoever – could in theory be successfully listened to from the acousmatic perspective, and thereby considered an acousmatic work" (2010, p.107).

<sup>&</sup>lt;sup>68</sup> All tracks on *The Respirator and other outcasts* are included on the album *The Pleasure of Ruins and other castaways* released in 1993

A later work, *The Problem with Bodies*, shows Whitehead "is as much [an] elaborate prankster as impassioned explorer" (Margasak, 1994). This humorous work repeats the phrase "the problem with bodies is the reason for antibodies, and the problem with antibodies is nobody at all" as a vocal exercise with Whitehead droningly instructing himself to repeat the phrase firstly without using his tongue, then with his mouth closed, and finally without using his larynx so that only exaggeratedly articulated consonants are sounded. This work shares commonalities with *TCH-P* (chapter one) with its exploration of the physicality of language and the change of sounds produced when elements of the productive, sounding mechanism are challenged, inhibited, or disconnected.

Like Whitehead, Friz is concerned for the health of both experimental radio art and community and campus based radio stations (Friz, 2008). Friz advocates for a development of a transceptive radio ecosystem — a meeting of transmission and reception — in both radio art and community radio contexts:

community radio provokes the audience into listening for the unexpected while encouraging them to come to the station and become programmers, thus beginning a kind of circle of transception between the listening community and the radio station. Radio art in this context is not necessarily the purview of <<experts>> or <<pre>community of listeners and creators in shared radio space — where space is something actively produced rather than a vacancy waiting to be filled. (2008b, p.92)

This renewing and regeneratively inclusive proposal for the dynamic health and strength of micro, mobile, or non-mainstream radio, such as hospital radio or expanded radio art events and festivals, is a principle engaged by K+EDRP with its transgression and transformation of the standard triangulation of radio outlined by Whitehead (2003); the oscillating potential of transition from listener to player, player to listener-player, listener-player to system component, and degrees thereof, encourages a "do-it-yourself ethic and aesthetic" (Friz, 2008b, p.92) which enacts and

embodies an open access community that values "dynamic heterogeneity and experimentation" (ibid., p.90).

Friz's work frequently examines the interplay between public and private spaces, seeking "a poetics of radio, made of intimate sounds revealed" (ibid., p.99). A relative of Whitehead's *The Respirator*, Friz's *Respire* (2009b), a multi-channel transmission performance and/or installation, presents oft-neglected and regularly dismissed sounds of the body. Not by making the inaudible audible as K+EDRP seeks to do, but by amplifying the subtle, undesirable, and taken-for-granted, Friz propounds the human sounds of respiration (with "other bodily exclamations typically absent from regular radio programming" (Friz, 2009b)) in undulating combination with signals and frequencies to reveal "the invisible contours of the radio landscape that surrounds us" (ibid.). Like K+EDRP, there is a spatial element to the work which includes a multitude of hanging speakers.

Exploring "mortality, decay, and regeneration" (ibid., 2023), *Revenant* is a new two part radio work about storm and drought, above and below ground, seen and unseen, heard and unheard. Although not a strictly a humanly corporeal work unlike others discussed in this section, the themes of mortality, decay, and regeneration are extremely pertinent to this chapter; the subject of the earth relates back to my introductory remarks regarding the origin of the word 'broadcast' and its agricultural roots, and the renewal and regeneration of the earth, fomented by floods and fire echo the process of apoptosis which K+EDRP sets out to express.

#### REPARATIVE LISTENING

Drawing on the work of queer feminist theorist Eve Kosofsky Sedgwick (1987, 1990, 1993, 1996, 1997, 2000, 2003) and the subsequent "reparative turn" involving work by Butler (2002, 2018, 2021), Hanson (2007, 2011), Love (2010), Hawthorne (2018),

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Moreno-Gabriel & Johnson (2020), and Edelman (2023), I will attempt to examine how reparative reading of illness narratives relates to the potentialities for a reparative listening to works of sonic life writing. I will first explore Sedgwick's reparative legacy and connect the affective enablement (Love, 2010) which she gave rise to with notions of acoustic justice (LaBelle, 2021; DeNora, 2006). This section concludes with a consideration of the reparative potential of radio and radiophonic space, drawing on object relations psychoanalysis (Winnicott, 1953) which connects back to principles of aesthetic critical realism by Wilson (2020), as outlined above.

Perhaps the most common description of Eve Kosofsky Sedgwick's work is *enabling* - I have used it myself many times to describe her effect on me. (Love, 2010, p.235)

Espousing a shift away from the position and techniques of paranoid reading i.e. of literary criticism and re-framed authorship through theoretical, critical discourse - to a reparative position, which encourages and enables intimate knowledge of experience in favour of "multiplicity, surprise, rich divergence, consolation, creativity, and love" (ibid., 2010, p.237), has been Sedgwick's powerful and impactful legacy over the last several decades. The work of pioneering psychoanalyst Melanie Klein has been highly influential in Sedgwick's thinking (Sedgwick, 2003, p.128) and the word "reparative" is itself a psychoanalytic term, pertaining to Kleinian concepts of positions. Hinshelwood writes, "the term 'position' describes the characteristic posture that the ego takes up with respect to its object" (Hinshelwood cited in Sedgwick, 2003, p.128). In an artistic academic context, this equates to the paranoid position exhibiting egoistic ideals and behaviours including the holding dear of egomaniacal critical discourse, the exchange of strong opinions, and the imperative resistance to, and refusal of, surprise. Love goes further by describing paranoid reading as a practice which encompasses traditional and "familiar academic protocols like maintaining critical distance, outsmarting (and other

forms of one-upmanship), refusing to be surprised (or if you are, then not letting on), believing the hierarchy, becoming boss" (2010, p.23). The metric of success in paranoid reading is the reframing of authorship through the application of theory and disavowal of affect.<sup>70</sup> Conversely, the reparative position favours affect; affords primacy to attentiveness (of the other) rather than hyper vigilance; subjugates the ego in favour of non-monopolistic openness to love; and "stays local" with its resistance to the conflation and application of swathes of theory and telling of "big truths," instead preferring pleasure in the descriptive richness of the object at hand (Love, 2010). In the reparative position, the hermeneutics of success is the virtuosity of description and the intensity of affect.

Sedgwick compares the oscillating flexibility of psychological *positions*, such as depressive or schizoid, with critical practices of the reparative and paranoid: neither of these being fixed "theoretical ideologies" but rather heterogenous and fluctuating "relational stances" (2003, p.128).<sup>71</sup> The notion of the "reparative" as a relational stance is quintessentially Kleinian in its integral hope to 'make good again.'

Reparation is integral to the depressive position. It is grounded in love and respect for the separate other, and involves facing loss and damage and making efforts to repair and restore one's objects. Effective reparation involves a type and degree of guilt that is not so overwhelming as to induce despair, but can engender hope and concern. Reparation itself provides a way out of despair, by promoting virtuous cycles rather than vicious cycles in states of depression. It is a significant root in all creative activity and indeed a central part of development. (Spillius et al, 2011, p.470)

Relating the Kleinian psychoanalytical notion of reparation to reparative reading practice, as influenced by Sedgwick, Hanson notes that it "begins from a position of

<sup>&</sup>lt;sup>70</sup> See Frank and Wilson (2020) for discussions of Affect Theory as developed by psychologist Silvan Tomkins.

<sup>&</sup>lt;sup>71</sup> Similar fluctuations are examined in chapter three with an exploration of psychoanalyst Michael Balint's theory of ocnophilia and philobatism ([1959] 2018), expressed through rhythm.

psychic damage... that bears within it the possibility of a "reparative position" that picks up the fragments to construct a sustainable life... the reparative is not just a critical mode but more generally a life skill." (2011, p.102). Therefore, to adopt a reparative stance or practice is to reject the hermeneutics of suspicion (a dispassionate, critical, skeptical, analytical distanciation from the artistic object), and reap the enabled dividends of a more surprising, consoling, enabling, and loving position that recognises the "damage" manifest in all adult psychic life. The reparative stance or practice is dependent on attentiveness and respect for the separate other, principles which share parallels with acoustic justice and testimony.

Before exploring issues of acoustic justice further, I wish to close this section with a statement from Sedgwick which echoes the ideas of Anna Friz in the context of radio:

Part of the motivation behind my work... has been a fantasy that readers or hearers would be variously — in anger, identification, pleasure, envy, "permission," exclusion — stimulated to write accounts "like" this one (whatever that means) of their own, and share those. (Sedgwick, 1987, p.137)

As renewal and regeneration is a cardinal theme of this chapter, the desire to influence, "stimulate," and inspire — *through* the reparative and the affectual — is reestablished here as a mode for promoting the ongoing health of an artistic practice, be that writing (in the case of Sedgwick), or community and campus-based non- commercial radio practices (as in the work of Friz). Replacements and reincarnations — be they artistic, cellular, biological, or theoretical — are essential for any network, practice, or organism to healthily continue "going-on-being" (Winnicott, [1960] 2016, p.587).

What might a reparative listening practice offer in relation to sonic life writing and how is reparative listening practiced in other contexts? In engaging with the dynamics of listening involved in situations of reparation, justice, and recognition, I connect Sedgwick's reparative mode with a new condition of reparative listening in the context of sonic life writing. The notion of acoustic justice aims at highlighting practices or actions that re-work the distribution of the heard, detuning or retuning tonality of a place, and a given acoustic norm, so as to support the movements of bodies and voices, especially those put at risk by appearing or sounding otherwise. Central is a concern to frame the deeply human necessity *to be heard* and how this comes to be enacted across a range of settings; whether within local scenes of discussion and debate to greater institutional arenas where having a say and being heard support processes of justice and recognition, the imperative of being heard calls out for a particular critical framework. (LaBelle, 2022, p.138)

LaBelle's framework of acoustic justice is an expansive promulgation championing listening as a "deeply transformative capacity" (ibid., p.139), enabling not only (re)orientation with struggles, belonging, and the constant remodelling of our senses of self and other (Wilson 2020), but cooperatively fostering opportunities to "attune and attend, to hold and nurture, defend and debate, and which supports reflection and sympathy, compassion and care, for oneself and for others, and that greatly assists in contending with dominant and prevailing systems that make and unmake bodies" (LaBelle, 2022, p.139). This transformative capacity incorporates all of the aforementioned relational stages of Wilson's aesthetic critical realism (2020), discussed in this chapter, and consolidates them in a listening-based understanding of "well-being," not from the perspective of the individual but in a development and respect for collective rights. As established in the introduction to this thesis, the need to be heard is ubiquitous and universal (Stauffer, 2015), individually and collectively, with repair being an integral component of this need, along with the desires for the capacities which LaBelle expounds above. Justice, through sounding and listening, is a reparative mechanism to heal oppression, violence, or neglect (ibid.)

In relating acoustic justice to my own experiences of oppression, violence, and neglect during cancer treatment, I regard the unfolding of the Covid-19 pandemic as one of the main causes of injustice I perceived and experienced (along with dissatisfaction with aspects of breast cancer culture discussed in the introduction, financial difficulties, and personal and social relationship issues). The panoply of absences engendered by the pandemic — absences of care, company, support, time, due diligence, and best treatment — are conflated, represented by, encapsulated in, but not irreducible to the collection of compositions which comprise this portfolio. As Covid-19 presented a very serious threat to my life, (due to chemotherapy-induced, life-threatening neutropenia,<sup>72</sup> a condition of dangerously low white blood cell count), I was encouraged to shield, alone, for as long as I could possibly manage. By retrospectively sonating and sounding out my experience, I hope, more unconsciously than consciously, to redress harm caused by my silent isolation and provoke a reparative response which involves LaBelle's qualities of transformative listening in contexts of acoustic justice. In doing so, I present a possibility akin to Sedgwick's and Friz's stimulating calls for others to follow in the footsteps laid down in these early experiments in the nascent field of sonic life writing about illness.

In discourse on reparation in social and judicial contexts, themes of retribution and punishment can often feature. I wish to make clear that retribution and punishment are of no interest to me in my research and creative output; I believe that the injustices I deem myself to have suffered were not caused by any malicious intent or any form of my victimisation but, instead, were unfortunate and unintentionally harmful consequences of many people doing their best at an extremely challenging and panicked time in modern history. The search for acoustic justice in these works of sonic life writing is connected not to retribution but to restoration and recovery: recovery of time spent in the company of others whose elected position it was to

<sup>&</sup>lt;sup>72</sup> Boxer and Dale (2002) describe the causes and consequences of neutropenia while Crawford et al (2004) focus on how cytotoxic chemotherapy suppresses the hematopoetic system, presenting fatal risks.

listen to my experience, and restoration of the unfilled need to be heard that was left unsatisfied and unmet during the period from March 2020 to July 2022.

Recovery and restoration speak to ideas about healing. Here, I wish to remain focused on notions of the reparative rather than explore the expansive field of research on healing (Bonny, 1986; Moreno, 1995; Koen, 2011; Toop, 2018) but I do refer to Federici's radical, feminist, politic plea to "listen to the body" (2020) in order to advance our understanding of health and healing, as understood through the lens of justice and reparation, and as means of benevolently disruptive intervention in normative breast cancer culture. LaBelle (2022) picks up on Federici's call and asks how we might listen to the body. By understanding the body as an acoustic chamber, as "something that resounds," LaBelle asks how we might tend, accommodate, or resist a corporeal listening, and what ways such listening may be challenged or impaired by cultural and educational factors (Bourdieu, 1987, 1994). If conditions that shape and define our circumstances of "hearing and being heard, voicing and being responsive, sounding and listening, which regulate or inform one's attention and orientation with respect to oneself and others" (LaBelle, 2022, p.141) can be met then acoustic justice and bodily knowings can be achieved. Through encouraging and enabling opportunities for people to engage with reparative listening (to the body) under suitable conditions (such as hospital radio), we may create a "holding environment" (Griffin, 2016 (after Winnicott, 1953, 1971)) which allows for and supports the sharing of life (and death) stories (King, 2017).

Radio itself has a reparative dimension. Object relations psychoanalysis (Klein, 1986; Fairbairn, 1952; Winnicott, 1964, 1971) — "a school of thought in which there is a great deal of emphasis on experience, process, matters of relatedness and our sense of significant connections between the external world around us and our internal, psychological experience of it" (Bainbridge and Yeats, 2013, p.8) — has influenced

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contemporary discourse on radio studies, especially the output of the Media and the Inner World Research Network.73 With its exploration of the reparative spaces of radio, the Media and the Inner World Research Network (funded by the UK Arts and Humanities Research Council (2009-2013)) investigated psycho-cultural understandings of relationships between artistic and media objects and processes of perception, relation, and responsive experience (Bainbridge and Yates, 2014b). The findings of this multi-faceted research project revealed the "importance of the reparative, emotional work of radio past and present" (ibid., 2013, p.7). In an "increasingly therapeutic culture" (ibid., 2013, p.8), radio is a medium of great reparative potential, uniting internal and external worlds (Wilson, 2020), and holding space for "multiplicity, surprise, rich divergence, consolation, creativity, and love" (Love, 2010, p.237). Bainbridge and Yates (2013, p.7) regard reparation, as Sedgwick did, as a tolerance of, and attendance to, the "complexities of lived experience" and the varied nature of radio output allows for the expression of these complexities through speech, sound, and music. This variety gives space for the forging of identities and imagined communities, Balick (2018) argues, which are independent of our close network of friends, family, and colleagues, helping us to feel a broader relationship, through attentive listening, that may not be immediately modelled for us in everyday life. It is therefore a medium of tremendous scope and potential in its ability to connect and relate. For Karpf (1980), radio, and especially the regular radio voice, creates an anchorage or a homely point of return which may offer comfort,

<sup>&</sup>lt;sup>73</sup> Media and the Inner World (MiW) research network, led by Caroline Bainbridge and Candida Yates, focuses on the place and role of emotion and therapy in the media and in popular culture. The AHRC-funded network (2009–2013), whose members included Valerie Walkerdine, Robert Young, Michael Rustin, Margaret Walters, David Aaronovitch and Brett Kahr (Yates, 2011), "held a number of public roundtable discussions, seminars and conferences on various themes. These were framed by a concern to develop a psycho- cultural understanding of the relationships between objects of the media and popular culture and the processes of emotional experience and its role in shaping notions of identity and relatedness in the contemporary age" (Bainbridge and Yates, 2014b).

reassurance, and containment, and support an appreciable and appreciative sense of "going-on-being" (Winnicott, 1960, p.587). Just as Bainbridge and Yates (2013, p.8) have emphasised the importance of attending to the "complexities of lived experience" in media and culture, K+EDRP attempts to explore not only cultural, emotional, and therapeutic complexities, but biological and medical complexities too. The following sections discuss how the process of apoptosis can be expressed through music using a new methodology of artistic sonation.

## SONATION, APOPTOSIS, AND MUSICAL COMMENTARY

K+EDRP, a re-imagining of hospital radio, is a reparative work of expanded radio art which repurposes and recycles artefacts, physical and sonic, in the sharing of a biological and biographical narrative. I regard this project as a work of 'artistic sonation,' not merely transducting medical data into sound through standard sonification methods (as discussed in the introduction and literature review), but combining an intimate testimony of cancer treatment in conjunction with a sonic transduction of the biological process of apoptosis. Before explaining apoptosis, in particular the extrinsic death receptor pathway, and how I have artistically sonated the process, I will endeavour to develop the idea of artistic sonation and distinguish it from general sonification.

Sonification is a family of representational techniques under the umbrella of the more general term 'auditory display' for revealing information in data and communicating it in a non-speech aural form - sonification makes the inaudible audible. (Vickers, Hogg & Worrall, 2016, p.89)

All the works in this practice-research portfolio hold dear the aim of making the inaudible audible. However, all three works go beyond auditory display revealing quantitative information in data and fervently seek to reveal qualitative information as their primary methodology. It is the quantitative bias of sonification that makes it an

unfit term for these works of sonic life writing and so I am adopting the term "artistic sonation" as a next best descriptor; a term which envelops unconventional mechanisms of sound production incorporating performance autoethnographic elements of cancer experience.

Sonation is the bringing forth of sound; to sonate is to sound. Often associated with birds, sonation typically involves mechanisms of sound production unconnected to the larynx or syrinx. The rubbing together of legs, the aeroelastic flutter of feathers, or the hitting of tools or beaks on rocks or trees are all forms of sonation in the natural world (Clark and Prum, 2015; Rico-Guevara et al, 2022). I am describing K+EDRP as a work of "artistic sonation" as I am bringing forth sound not vocally but from the tools used in my cancer treatment (i.e. the Baxter Colleague infusion pumps) and sounding my internal biological process using a compositional process which mirrors the apoptosis brought about by the intravenously administered drugs I received while in the chemotherapy ward of the Sussex Cancer Centre in 2020. To be clear, what distinguishes this experiment in artistic sonation from a work of sonification is the incorporation of repurposed machines, the radiophonic dimension, the non-expression of numerical data, the audio processing and mixing representing and inducing nausea, and the sharing of musical gifts sent to me by absent friends. The incorporation of strong qualitative information communication also distinguishes artistic sonation from sonification; going beyond data to a richer level of performative expression and representation. Before returning to artistic sonation in the commentary section, I turn to pathologist Dr Susan Elmore to introduce the process of apoptosis.

## <u>APOPTOSIS</u>

The process of programmed cell death, or apoptosis, is generally characterized by distinct morphological characteristics and energydependent biochemical mechanisms. Apoptosis is considered a vital component of various processes including normal cell turnover, proper development and functioning of the immune system, hormone-dependent atrophy, embryonic development and chemical-induced cell death. Inappropriate apoptosis (either too little or too much) is a factor in many human conditions including neurodegenerative diseases, ischemic damage, autoimmune disorders and many types of cancer. The ability to modulate the life or death of a cell is recognized for its immense therapeutic potential. (Elmore, 2007, p.495)

Apoptosis and necrosis are the two main overlapping groups of naturally occurring cell death processes in multicellular organisms (Formigli et al, 2004; Elmore, 2007). Apoptosis occurs in both developmental and adult homeostatic stages of life in all metazoans (Doonan and Cotter, 2008) and can be triggered by the activation of one of two pathways: these are the intrinsic and extrinsic apoptotic pathways (Lossi, 2022). Apoptosis generally happens in cells that have fulfilled their purpose and their useful lifespan, making way for new cells by eliminating the injured, infected, superfluous, and aged cells from the body (Logue and Martin, 2008). In very simple and flagrantly reductive terms, too much apoptosis can cause degenerative diseases including Parkinson's and Alzheimer's (Dickson, 2004) whilst too little apoptosis can cause cancers (Farghadani and Naidu, 2021). Treatments for cancer therefore involve cell death-inducing therapies. As described in chapter one, my treatment plan involved the intravenous administration of the chemotherapeutic and immunotherapeutic drug regime abbreviated to TCH-P. To recap, T and C refer to the chemotherapy drugs Docetaxel (brand name Taxotere) and Carboplatin; H and P stand for the immunotherapy drugs Trastuzumab (brand name Herceptin) and Pertuzumab (Perjeta). Docetaxel and Carboplatin are pro-necrotic agents whereas

Trastuzumab and Pertuzumab are pro-apoptotic; therefore, it is the cellular process of apoptosis, engendered by the immunomodulatory agents Trastuzumab and Pertuzumab, that this work expresses and sonates.

I have chosen to artistically sonate the *extrinsic* death receptor pathway of apoptosis: a highly controlled, relay race-esque sequence of signals that brings about an "ordered dismantling" (Logue and Martin, 2008) of the cell through the "binding of ligands to cell surface 'death receptors' which in turn initiates the caspase cascade" (Kumar et al, 2005 p.1). A simplistic explanation of the extrinsic pathway begins with the understanding that many cells have surface receptors that contain intracellular regions called death domains (Danial and Hockenbery, 2018): within these death domains, located in the fluid inside a cell but outside of its nucleus, are the death receptors. Guicciardi and Gores describe the death receptors as being part of the "tumour necrosis receptor superfamily characterised by a cytoplasmic region known as the "death domain" (2009, p.1).

Death receptors are also to be found on a cell's surface (Leonard and Johnson, 2017) and in order for a cell to be "orderly dismantled" (Logue and Martin, 2008) via the extrinsic pathway, a death ligand must bond to a death receptor on the cell's surface. A ligand may be thought of as a key and the surface death receptor as a lock. When the ligand and receptor connect, a dismantling process ensues involving the poetically named caspase cascade. Caspases are signalling proteins which are the effectors of cell death: they are the demolition crew in this operation (Arney, 2020). Their enzyme-cutting cascade of activity begins with the initiator caspases and ends with the executioner caspases (Ha et al, 2021). This chain of caspase activity leads to blebbing of the plasma membrane, as seen here in a diagram from William Stillwell's *An Introduction To Biological Membranes* (2016, p.118):

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This image clearly shows the formation of irregular bulges, called blebs, on the cell surface, which then break away in the later stages of the apoptotic process. These breakaways relate to the derivation of the word apoptosis: from Greek, meaning to "fall away (from)", or "falling leaves" (Watson et al, p.2022). I note this word derivation in order to connect back with the theme of regeneration and renewal, and the agricultural term 'broadcast.' Watson et al (2022) explain that Andrew Wyllie, a pioneer in the discovery of programmed cell death, developed the term "apoptosis:"

after consultation with a colleague at Aberdeen, Professor James Cormack of the Department of Classics, a word that encompasses the process of leaves falling from trees in autumn or petals falling from flowers, which perfectly encapsulates a process where cells melt away from tissues as part of the natural turnover of the tissue, rather than due to a pathological process. (2022, p,4333)

These morphological changes and fragmentations are succeeded by the resolution stage, phagocytosis. During blebbing and fragmentation, the cell exposes "find me"<sup>74</sup> and "eat me"<sup>75</sup> signals which attract cells called phagocytes (Chekeni et al, 2010). These phagocytes engulf and clear away the fragments (Ren and Savill, 1998) in an "active and highly regulated process that not only serves to remove potentially histotoxic cells from the inflammatory milieu, but also directs the phenotype of the phagocytic cell to be anti-inflammatory" (Hart et al, 2008, p.280).

<sup>75</sup> such as phosphatidylserine

<sup>&</sup>lt;sup>74</sup> e.g. nucleotides ATP and UTP, chemokine CX3CL1 (Chekeni & Ravichandran 2010)

#### **COMMENTARY**

In brief summary, the apoptotic "headlines," from the process explained above, which I have transducted in deconstructive compositional process are i) the binding of ligands to receptors, ii) the caspase cascade, iii) blebbing of the plasma membrane, iv) fragmentation, and v) phagocytosis. To what material is this process applied?

The day before receiving my second course of TCH-P I asked friends, via social media, to send me music, playlists, or podcasts to listen to whilst in hospital; I note here that this scenario is rather an inverse of the standard music request procedure in hospital radio. The two most outstanding musical "gifts" I received were Jagjit Singh's recording of the *Gāyatrī Mantra* (2010) (sent by neuroscientist Professor Anil Seth) and Farida Khanum's recording of the ghazal *Aaj Jane Ki Zid Na Karo* (Shemaroo, 2014) (sent by artist and musician Dara Okat Godzuki). These two recordings, plus a home-recorded reproduction of a hospital field recording, are the material to which the transducted extrinsic pathway compositional process has been applied. Before detailing the compositional process, sound design, and the repurposing of Baxter Colleague infusion pumps, I will describe the features of these three pieces of material which act as sonic cells, beginning with the *Gāyatrī Mantra*.

Mantras are central to the ritual traditions of Hinduism and, indeed, Hindu traditions can sometimes be defined or delineated by the mantras they use: mantras for Visnu or his incarnations will be repeated by Vaisnavas, mantras for Śiva will be repeated by Śaivas and so on. The most famous Vedic mantra is the Gāyatrī: 'om bhūr, bhuvaḥ, sva,/tat savitur vareṇyaṃ/bhargo devasya dhīmahi/dhiyo yo naḥ pracodayāt' which can be loosely translated as (Om, earth, atmosphere, and sky. May we contemplate the desirable radiance of the god Savitr; may he impel our thoughts.'<sup>76</sup> This is taught to young Brahmans during their sacred thread ceremony (upanayana) and is thereafter uttered

<sup>&</sup>lt;sup>76</sup> from Rigveda 3.62.10

### every morning at sunrise by orthodox Brahmans. (Flood, 1996, p.222)

The *Gāyatrī mantra* has many modern connections to health, hospitals, and healthcare settings. A variety of trials and studies (of varying and questionable credibility) have been conducted in recent years on the effectiveness of Gāyatrī mantra recitation for reducing the severity of symptoms and suffering caused by stroke (Dewi et al, 2020), psychotic disorders (Porandla et al, 2021), diabetes (Rastogi et al, 2020), and ADHD (VK and Chaube, 2021). The Jagjit Singh recording of the *Gāyatrī mantra*, performed in Raag Yaman Kalyan, was released in 2010, one year before Singh's death. The mantra is repeated twelve times over the course of the recording, significantly fewer times than the sacred and auspicious number of 108 so commonly associated with cyclical mantra recitation, especially in connection to the use of *malas* (rosaries) and their related *japa* (recitation of mantras).

The second sonic cell is Farida Khanum's recording of the ghazal *Aaj Jane Ki Zid Na Karo* (Shemaroo, 2014). Known as Malika-e-Ghazal, Queen of the ghazal, Khanum is most closely associated with this particular ghazal, written by Fayyaz Hashmi (1920-2011). The poem, so pertinent to the fear of isolation and the challenges of time experienced during cancer treatment, is as follows:

aaj jaane ki zid na karo yoon hi pehloo mein baiThe raho aaj jaane ki zid na karo haay mar jaayenge, hum to luT jaayenge aisi baatein kiya na karo aaj jaane ki zid na karo

tonight, don't insist on leaving. keep on sitting close to me like you are. tonight, don't insist on leaving. oh I will die, I will be lost, don't say such things. tonight, don't insist on leaving.

tum hi socho zara, kyun na rokein tumhein

jaan jaati hai jab uTh ke jaate ho tum tumko apni kasam jaan-e-jaan baat itni meri maan lo aaj jaane ki zid na karo

just think for a moment, why should I not stop you. my life seems to leave my body when you get up and go, I swear to you, my beloved just agree to this request of mine tonight, don't insist on leaving.

waqt ki qaid mein zindagi hai magar chand ghadiyaan yehi hain jo aazaad hain inko kho kar mere jaan-e-jaan umr bhar na taraste raho aaj jaane ki zid na karo

life is trapped in the prison of time but these are the few moments that are free by losing them, my beloved let's not have a life of regret tonight, don't insist on leaving

haaye mar jaayenge, hum to lut jaayenge aisi baatein kiya na karo aaj jaane ki zid na karo

kitna maasoom rangeen hai ye samaa husn aur ishq ki aaj meraaj hai kal ki kisko khabar jaan-e-jaan rok lo aaj ki raat ko aaj jaane ki zid na karo

what an innocent, colorful weather it is. it is the peak of beauty and love today. who knows what will happen tomorrow, let's stop this night, tonight, tonight, don't insist on leaving. (BollyMeaning, 2024)

The third sonic "cell" which is orderly dismantled, in apoptotic fashion, is a home recorded audio replica of sounds I heard whilst in hospital. These recordings

were also featured in TCH-P, and were made using the Baxter Colleague infusion pumps which I purchased from Ebay. For understandable ethical reasons regarding (data) privacy in healthcare settings, I have consciously reproduced hospital field recordings (in my home studio) for use in this portfolio of work.

There is one further element of sonic material that is present almost all the way through this work but does not undergo the apoptotic compositional process: it is a microelectrical recording taken from the ancient Yew tree, taxus baccata, in the churchyard in Stanmer village, near Brighton. The chemotherapeutic agent Docetaxel is a semi-synthetic drug originally derived from the European Yew tree, taxus baccata (Alken and Kelly, 2013). Although Docetaxel is pro-necrotic, not pro-apoptotic, I wanted to include sonic material which derives from at least one source of my combined drug regime. As Herceptin and Perjeta, the two apoptosis-inducing drugs, are laboratory-produced monoclonal antibodies generated with "recombinant DNA technology in a mammalian cell (Chinese Hamster Ovary) culture" (Komarova et al, 2011), I opted for the easier recording of the Yew tree. Using a patented sonification technology called a PlantWave device, I recorded measurements of the electrical variations caused by physiological activity in the needles of the Yew and then, using PlantWave premium software, converted these measurements to MIDI. An acronym for "musical instrument digital interface," MIDI is a protocol, or message system, which connects devices such as synthesisers and computers. Having imported this MIDI transduction of the Yew tree, I assigned the sample named Geheimnis (meaning "secret") in the digital audio workstation Ableton Live Suite 11, the software I regularly use for composing and performing.

In the recording and composition of K+EDRP, equipment and software used includes the VoiceMemo app on my phone, AppleMusic for the purchase and download of the mantra and ghazal sonic cells, the PlantWave device for recording

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the Yew, my MacBook Pro to host the digital audio workstation Ableton Live Suite 11, and two AKAI MPK Mini Mk3s for performing, controlling, and recording further MIDI tracks beyond the Yew-based Geheimnis track.

The piece begins with a 2 minute sample of the opening two cycles of Singh's Gāyatri Mantra recording. At 00:55, the Yew tree Geheimnis track is faded into the mix, representing the start of the cyclical intravenous treatment regime, the track remains as a fluctuating and undulating ostinato for the subsequent 17 mins, almost to the end of the piece. Here, the term "track" refers not to a complete work, as is used in reference to tracks on an album, but to a single element of a complete work: when working with a digital audio workstation (DAW), such as Ableton Live 11, a track is one single element of a work which can host clips, recordings, and flows of signals including effects and mixing. For perspective, there are 20 tracks active within K+EDRP.

As the Gāyatrī mantra fades out at 01:50, a sine wave on C# (the tonal centre of Singh's rendition of the mantra) emerges, in a neutral, bridging role, representative of the bags of saline fluid which were intravenously administered between each drug during the days spent on the drip. The C# sine is then joined by another sine wave on A, the tonal centre of the next musical cell, *Aaj Jane Ki Zid Na Karo*. From 02:25 to 04:25, the beginning of the ghazal is sampled with the Yew tree ostinato audible in the background texture. Another sine wave on A enters at 04:20, another neutral device employed to transition to the next cell, the first of the home-produced hospital sounds recordings. A saline sine wave on C# re-enters at 05:10 which marks the end of the first treatment cycle and a transition to the next.

Due to the Covid-19 pandemic, my prescribed chemotherapy treatment of 6 cycles (each cycle 21 days long) was reduced by half.<sup>77</sup> Fortunately, the scan following

<sup>&</sup>lt;sup>77</sup> My immunotherapy treatment was unaffected by the pandemic and I received all 18 doses, administered either intravenously or subcutaneously, in 21 day cycles.

my third cycle of chemotherapy showed that the cancer had almost completely gone and, therefore, surgery could take place to remove the tumour bed, the first lymph node, and surrounding clear margins to ensure risk of spread or recurrence was reduced to its minimum. Therefore, K+EDRP is in three parts, or cycles.

The second cycle of TCH-P as expressed in K+EDRP begins at 05:43 when the Gāyatrī mantra returns. This time, the sample is reduced in duration, as the tumour would be reduced in size following one cycle of TCH-P, due to the pro-necrotic and pro-apoptotic action of the previous treatment cycle. This second cycle implements the first three of the five aforementioned deconstructive stages of apoptosis as transducted into compositional musical process, namely the binding of death ligands to death receptors, the resultant caspase cascade, and the blebbing of the plasma membrane. Once I had imported the audio of the three sonic cells (mantra, ghazal, and hospital sounds) into Ableton, I was able to observe the waveform of each audio track. The lowest points on the schematic suggested potential credible areas for the location of sonic death receptors. Therefore, in these quieter areas of the waveform, I superposed sonic death ligands using the Pitched Ambience sound from Ableton's Ambient and Evolving collection within the Instrument Rack. To the Pitched Ambience death ligand track I applied a Stereo Flyby effect in mid resolution to represent the caspase cascade initiated by the binding of the ligands to the receptors; Stereo Flyby adds a spacious, descending pitch echo, or shadow, to the death ligand cluster chords played with Pitched Ambience. At 06:45, the blebbing of plasma membrane is represented by fast-paced stereo panning. This uneven and unsettling stereo panning can, for some listeners, induce a slight feeling of nausea, a feeling common to the experience of receiving TCH-P.

The death ligands continue through the subsequent transitional sine waves and into the second cycle's occurrence of Khanum's *ghazal*. As with the mantra, the

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duration of the ghazal sample is reduced in this second cycle. Considerable blebbing occurs at the end of the sample through the use of fast-paced stereo panning. The re-produced hospital sounds in the second cycle enter at 09:10 with both very slow and very fast stereo panning applied. This unpredictable unevenness marks the later stages of apoptosis beginning. Another sine wave, still accompanied by the Yew ostinato, provide a transition to the final cycle which begins at 10:40.

The mantra returns for the final time at 10:40 but with small sections of the reduced sample omitted, cut out in caesura, representing the fragmentation of the cell. I isolated the Stereo Flyby effect from the ligand track and re-doubled the effect to mark the exposure of the 'find me' and 'eat me' signals which invite and attract the phagocytes to clear away the fragmented cell debris. Long, distanciated and arpeggiated reverb effects are once more applied in conjunction with extended periods of inactivity (such as 14:10 to 14:50) representing the clearance process of phagocytosis, leaving the tumour bed unoccupied by its previously deadly cancer. The tinkling, breathy Yew tree ostinato remains prominent during these inactive periods of relative stasis.

The piece concludes with a re-production of the sounds of my chemotherapy pump, beginning at 17:40. This recording represents the beeps I heard marking the end of my final day of the TCH-P protocol. I watched the timer on my Baxter Colleague pump screen count down the drips remaining and made sure to listen very fully and intently to those final sounds. Those final beeps carried/carry an ineffable meaning for me as the experience and effects of receiving three cycles of the TCH-P protocol was, without any doubt, the greatest challenge I have faced in my life and, at times, was so difficult that I came very close to stopping treatment and opting for palliative care. I do not think I would have been physically or psychologically able to cope with another cycle of the treatment and so, in this respect, the Covid-19 pandemic saved me from

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further unbearable experience.

I conclude this commentary with some memories of and remarks about the Baxter Colleague infusion pumps used in this work. Whilst in receipt of TCH-P in hospital, I would be connected to the Baxter Colleague via a chain of components including a cannula (usually going into a vein in my hand but sometimes into my wrist or inner elbow depending on how many of my veins had blown), tubing, drip bag, pump channels, and ports. If I wanted to move around during my treatment — step out of the ward to make a cup of tea or visit the bathroom, for example — I would take the Baxter Colleague with me, mounted as it was to a drip stand with a ring of castors at its base and capable of maintaining function on battery power once unplugged from a mains socket. Being connected to this machine was terrifying, at first, but by my third experience in the chemotherapy ward, I had become strangely used to this machine and curious about it and its capabilities. I liked its blue and orange screen options, the green LED light behind the power symbol, and its repertoire of rhythmic sounds so specific to this seemingly strange location and the unexpected and unwelcome procedures and behaviours I was enduring there.

On deciding to make this work, I investigated the purchase of these machines and discovered many available to buy on eBay for around £55 each. My original, and somewhat naïve, plan was to use the speaker already inside the Baxter pumps to broadcast the piece. Of course, the speaker inside the pump is very small and not suitable for any low frequencies or high quality sound. With the help and advice of an engineer, Samuele Matteucci, I built on some homemade, larger speakers which were attached via the handle of the Baxter Colleague. These worked fairly satisfactorily in a small gallery installation context but when it came to performing the work live at the Barbara Hepworth CREATE Lab, at hcmf//2022, I soon realised I would need significantly more capable (and therefore expensive) speakers in order for the
audience to hear the full audio spectrum of the work. I opted for a Cambridge Audio home cinema system comprising 4 Min22 speakers and an X301 subwoofer. The 4 Min22 speakers are an almost identical colour to the Baxter Colleagues and, for the performances at hcmf//2022 and Cafe OTO, I attached them to the infusion pumps and drip stands using medical cable ties. I also bought drip bags, labels, tubing and drip chambers and set these up to recreate, as best I affordably could, the infusion apparatus as I remembered it. The X301 subwoofer was placed in the centre of the stage/performance space, next to the amp, under the desk at which I sat with my laptop and AKAI MPK mini MK3s.

The decision to make this work and to spend large periods of time sitting and working with six Baxter Colleague chemotherapy machines in my home has engendered mixed feelings ranging from post-traumatic fear to confident pleasure. The challenge of yielding to the cancer treatment has been, to some degree, counterbalanced by the reparative agency I have chosen, post-treatment, to take control of the machines and adapt them for my own practice research and artistic experimental purposes. These re-purposed, re-wired machines now travel around the UK, sounding out my body at various events and performances, and offering listeners the opportunity to engage in conversations about cancer and its treatment from unorthodox and creative perspectives.

#### CONCLUDING REMARKS

K+EDRP is the most substantial work in this doctoral research portfolio of compositions. Drawing together scholarship in literary theory, scientific and medical research, psychoanalysis and affect, sound studies and radio arts, and aesthetic critical realism, with experiments in audio engineering, artistic sonation, and new compositional methods, this work attempts to benevolently disrupt the hospital radio model, offering an opportunity for reparative listening. This radical re-imagining of hospital radio, beyond the hospital walls, explores new bodily sonic geographies, making the inaudible biological process of apoptosis audible. Ultimately, this work, imbued with connections to seeds and broadcasting, offers a unique sounding of a body — my body — and "an experience of being-in-relation" (Wilson, 2020, p.129).

# CHAPTER THREE

Anuvāram Jugalbandī (for the time beings)

To have one's plans ruined with just hours' notice was an extra cruel arrow, especially as I'd just bought that hairdryer. Instead of travelling, touring, learning, researching, playing, I am laid out on my bed — sick and tired, not to mention scared — comparing this cycle to the last in my miserable diary of unwanted bodily happenings.

[Day 3 - feeling seasick, hallucinating, nonstop spitting in a bucket. Day 9 - sight in my right eye packs up again (can't even watch Frasier anymore), and my face blows up with freakish pockets of fluid. I no longer recognise myself.]

What followed the immense explosive disruption was an obligation to act temporally and be temporal, for the 'time being.' Constantly numbers. A series of rhythmic, temporary existences roll and cycle, prone to interruption at any moment; all frightening and all hosting the battering pulls of dread and anticipation; frustrated desires and wailing losses; feelings of desperate isolation and bonded community; intimate dependance and steely aloneness. That linear course I so precisely and confidently plotted has been obliterated and replaced with rimless spheres of bearing and unbearable times; somewhere between action and passivity are these periods of cellular morbidity, sad perseverance, spurned disbelief, earthly determination. Lists. Thank God for that money. Seems I am impossible to care for more than a segment. Why do I seem to respond and perceive this differently? It's too difficult to land any care packages or buoyancy aids over my defences and I reckon it's just easier if I do this alone; remote voices down the line at my choosing. And I suspect everyone's time is about to change anyway...

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"Instead of the old line of forward time, now something like a globe holds you. You live inside a great circle with no rim"

Denise Riley Time Lived, Without Its Flow, 2012

"We are not diagnosed with a deadly disease, we are merely interrupted"

Rebecca Housel, 750 Words About Cancer, 2019

"Time does not always flow according to a line [...] nor according to a plan but, rather, according to an extraordinarily complex mixture"

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Michel Serres and Bruno Latour, Conversations on Science, Culture and Time, 1995

Major diagnoses of serious illness interrupt lived and felt time, bringing about new and previously unrealised temporalities which fall outside the conventional structures of academic, industrial, social, and economic schedules. For both the sick person and the caregiver, time changes its velocity and mass, revealing covert subtleties, throwing up interruptions, and needily demanding altered horizons. A forward, futural, linear sense of time is impeded by the processes of diagnosis and treatment, and by acts of caregiving. Although the felt sense of time for the sick person and the carer may differ greatly, both are encouraged by the system and culture of healthcare to dwell in the temporal short-term — the present tense; for the time being; becoming "time beings" — acting out behaviours and patterns of waiting, repeating, and persevering. Riley (2012) and Baraitser (2017) describe a suspension of time in relation to bereavement and to care, a sense of lived time viscously collecting

and pooling, obdurately preventing its flow. Rasmussen's and Elverdam's (2006) findings, as published in the *Journal for Advanced Nursing*, describe the experience of time by participants cured of cancer with regard to time's "handling," its appropriation, and an increased awareness of time's intensity and its disruptions. Time experienced by the sick person and the caregiver (to whom I shall refer collectively as "time beings" throughout this chapter) is manifestly rhythmic, with shades of intensity.

In this chapter I offer a creative, autoethnographic, musical *rhythmanalysis* of a period of time during cancer treatment experienced by a sick person and their unpaid, familial carer: this takes the form of a *jugalbandi* (duo) performance, recorded live at Cafe OTO in London in April 2023. A *rhythmanalysis* — or examination of spatiotemporal practices — is usually associated with understanding social processes in non-practice-based scholarship;<sup>78</sup> for this chapter, however, the *rhythmanalysis* manifests as musical, sonic entity. *Anuvāram Jugalbandī* uses the following research question as its primary enquiry: how might music explicate the qualities and intensities of time experienced during treatment for cancer? This chapter also investigates how rhythm may express the fluctuating dependancy of sick person upon carer, and how the musical concept of *jugalbandi* might be applicable to the relationship between these time beings.

Following a discussion about the concept of *jugalbandi*, I will explain how it is applicable to non-musical contexts and particularly to the relationship of sick person

<sup>&</sup>lt;sup>78</sup> The term *rhythmanalysis* was first coined in 1931 by Portuguese philosopher, Lúcio Alberto Pinheiro dos Santos, in his work examining the physiological dimensions of rhythm (. The term was then adopted by Gaston Bachelard in *La dialectique de la durée* (The Dialectic of Duration), originally published in 1936 (2000), and is now mostly commonly associated with Henri Lefebvre's collection of essays regarding the relationship between space, time and everyday life, titled *Rhythmanalysis*, published posthumously in 1992 (2013). Emile Durkheim ([1912] 2008), Rudolf Laban ([1921] 2014), Roland Barthes ([1977] 2012), and Georges Perec ([1974] 1997), among others, have also notably considered rhythm in their work relating to subjects including social processes, effort and movement theory, monasticism, and the "infra- ordinary" of the everyday and the domestic, respectively.

and caregiver.<sup>79</sup> Then, exploring the various qualities of time experienced by this duo, I will show how these qualities may be categorised as suspended and repeated times, and how they may be reflexively communicated in a *jugalbandi* performance incorporating both freely improvised and fully composed music.

#### MUSICAL JUGALBANDI

The Hindustani word *jugalbandi* means "entwined twins" or a "conjoint bond" (Krishna 2013, p.246). Pesch states the literal derivation/translation as "pair, to bind" and describes *jugalbandi* as "an interaction between musicians having different backgrounds or specializations (e.g.instruments)" or "a joint performance of North and South Indian musicians" (1999, p.432). *Jugalbandi* performances have long been popular with notable examples including *The Valley Recalls* performance in 1995 at the Nehru Centre, Mumbai by groundbreaking santoor player Shivkumar Sharma and bansuri virtuoso Hariprasad Chaurasia,<sup>80</sup> and the famed 1972 concert at Philharmonic Hall, New York City given by Ravi Shankar on sitar and Ali Akbar Khan on sarod (Shankar and Khan, 2023). It is important to note that *jugalbandi* is not simply a duet performance: a concert given by dhrupad singers the Gundecha Brothers, or the Dagar Brothers, would not qualify as a *jugalbandi* because these pairings are performances between

<sup>&</sup>lt;sup>79</sup> I use the terms 'carer' and 'caregiver' interchangeably throughout this chapter and recognise that they are more associated with British and American use respectively.

<sup>&</sup>lt;sup>80</sup> The Valley Recalls performance of 1995 reunited Pt. Shivkumar Sharma with Pt. Hariprasad Chaurasia and references their 1968 album, *The Call of the Valley*. According to Peter Lavezzoli, in his book *The Dawn of Indian Music in the West, Call of the Valley* is one of the highest-selling Indian albums of all time and is an important marker in the establishment of the santoor as a classical instrument, as well as a folk instrument (2006, p.33). The duo, under the name Shiv + Hari, also released an album titled *Yugal Bandi* in 1974 on His Master's Voice.

musicians of the same gharana, of the same Guru or Ustad<sup>81</sup> — such as Shankar and Khan who were both disciples of Ustad Allauddin Khan — do however qualify for *jugalbandi* status as they are performing with different instruments. Same instrumental pairings would generally only be regarded as a *jugalbandi* if the performers were from different musical traditions: for example, a Karnatak vocalist such as Bombay Jayashri from Chennai, in the South, performing with a Hindusthani khyal singer such as Manjusha Kulkarni-Patil of the northern Gwalior gharana.

The combination of melodic instrumentalist or vocalist with a percussionist also does not immediately qualify for *jugalbandi* status despite the different instrumental disciplines.<sup>82</sup> Even though percussionists in South Asian classical musics have prominent and virtuosic roles, their status rarely affords them equality with their melodic performing partner, as is demonstrated by their smaller pay packets (Neuman, 1990). Aneesh Pradhan (2014), a regular arts contributor to the independent Indian digital news publication, *Scroll*, notes that the term *jugalbandi* is oft-misused, particularly in relation to well-known, accompanying percussionists. Whilst Pradhan believes that a melodic instrumentalist or vocalist can never truly play in *jugalbandi* with a percussionist, this view is contested in the field of music programming in South Asia and beyond with an abundance of concerts of such mixed performances being afforded that descriptor, as well as a host of percussion-

<sup>&</sup>lt;sup>81</sup> "*Guru*" and "*Ustad*" are the reverential names in Hindustani music given, as a rule, to teachers of Hindu and Muslim faiths respectively. "Pandit" may also be used as an honorific title for an expert Hindu musician (Sorrell and Narayan, 1980).

<sup>&</sup>lt;sup>82</sup> See Clayton (2013) for discussion of musical interaction between different instrumental disciplines using a dynamical systems approach in dialogue with with an "ethnographic and interpretative framework attentive to local contexts and meanings" (ibid., p.17).

only *jugalbandis*.<sup>83</sup> It seems, however, that few percussionists are of high enough status to be regarded as worthy *jugalbandi* participants with a melodic performer; an equal status of performers being an important qualifier of the *jugalbandi* label.<sup>84</sup> The clearest example of a percussionist achieving equal billing is tabla player, Zakir Hussain, whose many noteworthy *jugalbandis* include performances with santoor player, Rahul Sharma, and veena player, Jayanthi Kumaresh.<sup>85</sup> If the role of the percussionist is not simply to accompany and imitate but to perform on a more equal musical footing with the instrumentalist or vocalist, and, crucially, with some degree of musical autonomy, then such a pairing may be afforded the term *jugalbandi*. It is with this understanding of the term that I title this chapter and performance, and with the obvious caveat of the piano not being a traditional South Asian classical instrument and therefore not being bound by the same rules and conventions.

# JUGALBANDI IN NON-MUSICAL CONTEXTS

Just as a *jugalbandi* is an intimately bound and often intense musical pairing in performance, the term can be used more widely and in non-musical contexts. For instance, Indian celebrity chef, Sanjeev Kapoor, created the recipe, "prune and

<sup>&</sup>lt;sup>83</sup> One particularly impressive example of an all-tabla *jugalbandi* is a performance by Zakir Hussain and Yogesh Samsi, with lehra accompaniment by an anonymous sarangi player (Raghbir Singh, 2022). This is a spirited duo performance with intricate, musical dialogue between the instruments; it exudes a collegiate and intertwined relationship, unlike the more formulaic and game-playing/playful percussion solos of Karnatak music, known as the *tani avartanam*, which have a hierarchy of status intrinsically built in to their structure (Pearson, 2021).

Yogesh Samsi's first teacher, Taranath Rao (1915-1991), is credited with promoting *jugalbandi* performances by tabla players (Ganesan, 2020).

<sup>&</sup>lt;sup>84</sup> Anuvāram Jugalbandī affords equal status to percussionist and pianist.

<sup>&</sup>lt;sup>85</sup> Hussain's jugalbandi with Jayanthi Kumaresh shows that he is not simply an accompanying percussionist but also a melodic instrumentalist as he repeats the pitches of the melodic phrases on the bayan tabla played by Kumaresh's veena. See Reddy (2018) from 01:26.

almond *jugalbandi;*"<sup>86</sup> the cricketing partnership of Sachin Tendulkar and Ricky Ponting in the 2013 Indian Premier League Mumbai Indians team was described as the Sachin-Ponting *jugalbandi* (Doraiswamy, 2018); and political scientist, lawyer, and journalist Vinay Sitapati's 2020 book examining the entangled lives of BJP politicians, Atal Bihari Vajpayee and Lal Krishna Advani, over the course of seventy years is titled, *Jugalbandi: the BJP before Modi*.

In this chapter, I consider the bonded *jugalbandi* of sick person and caregiver through a musical performance on piano and miniature mridangam.<sup>87</sup> The sick person is represented by the piano, and the caregiver, the mridangam. The title, *Anuvāram Jugalbandi*, describes the variety of repetitious rhythms and rhythmic qualities experienced by this bonded duo. As I will explore below, *anuvāram* is a Sanskrit word meaning "time after time." In this case, the word *jugalbandi* not only describes the musical interaction of the pairing — an interaction which does not place the percussionist in a purely accompanying role but in one with independent agency and without the obligation to imitate — but also neatly evokes the intimate, entangled, and corporeal connection between ill person and carer, as stated in Pesch's aforementioned definition.

Like attachment, the term affectional bonds is metaphorical (there being no literal, physical "bond"). It refers to the fact that two individuals are "tied" or "bound" to each other in a relationship. When two people are bound into an attachment relationship, they recognize each other as uniquely important; monitor each other's whereabouts; have some understanding of each other's goals, intentions, and desires (with sufficient age or cognitive development); have experienced strong emotions in relation to each other; and would be extremely upset and, at least for a time, lost without each other. This complex situation is summarized, for convenience, by the term *bond*.

(Shaver & Fraley, 2000, p.111)

The notion of *jugalbandi* pairing, or binding, correlates with studies in the <sup>86</sup> For this very simple recipe, see Kapoor (2024)

<sup>87</sup> This chapter examines the bond between two performers; see Pais (2017) for discussion of the elastic, affective bond between performer and audience.

fields of nursing (Williams, 2021; Alselami and Butcher, 2022), medicine (May et al, 2014), philosophy (Adams, 2017) and psychology (Blaffer Hrdy, 2011), as illustrated in the above passage by Shaver and Fraley. Their critique (2000) of Bell's and Richard's *Caregiving: The Forgotten Element in Attachment* (2000) illuminates the notion of *jugalbandi* in its explication of the understanding of the positions and intentions of the bonded persons in the relationship. Just as the monitoring of each other's whereabouts and understanding of desires is key to the affectional bond between sick person and familial carer, it is also essential between musicians in performance. For example, musicians must keep track of where their duo partner is within a time cycle or within a structural component of the performance (e.g. *pallavi, anupallavi*, etc),<sup>88</sup> and must understanding and of skill to be shared and communicated, with affectional bonds of appreciation often manifestly clear in the eye contact and shared enjoyment between the musicians on stage.

For a *jugalbandi* in a situation of care, an efficacious bond requires the time beings to understand each other's needs, desires, and intentions. Such relationships are frequently discussed in illness narratives. Butler's and Rosenblum's landmark feminist illness narrative *Cancer in Two Voices* ([1991] 1994) tells of the close, loving bond between them. Sociologist, Barbara Rosenblum, describes the uncertain, variable, interruption-prone experience of her treatment for terminal breast cancer in an alternating dyadic *jugalbandi* diary exchange with her partner, Sandra Butler. The affectional bond of Shaver's and Fraley's theory (2000) is evident with Butler's steadfastness and commitment, and her monitoring and understanding of Rosenblum's needs and desires:<sup>89</sup>

<sup>&</sup>lt;sup>88</sup> *Pallavi* and *anupallavi* are sections of Karnatak compositions such as songs called *kritis* (Sathyanarayana 2004, Krishna 2013).

<sup>&</sup>lt;sup>89</sup> Rosenblum writes particularly movingly about her lack of sexual desire on p.132, describing how the bond between her and Butler changed to one of profound intimacy once she could no longer feel any kind of erotic charge during her chemotherapy treatment.

I'm very lucky. Sandy has been exceptionally steadfast and easy about the changes in my body. She did not compel me to pay attention to her needs, her anxieties, her worries... During vomiting bouts she simply got the bucket, never cringing or complaining. She was always softly, gently there, through everything. (1994, p.134)

Whilst Butler's caregiving was dependable and foreseen, Rosenblum's challenging experience was one of unpredictable physical, emotional, and temporal disruption:

What is it like to live in a body that keeps on changing? It's frightening, terrifying, and confusing. It generates a feeling of helplessness. It produces a slavish attention to the body... One loses one's sense of stability and predictability, as well as one's sense of control of the body... Predictability ends... Time becomes shortened and is marked by the space between symptoms. (1994, p.136)

These two contrasting positions of Butler's steadfastness and Rosenblum's uncertain variability lend themselves easily to expression through music, especially through rhythm: regular, repetitive, dependable phrases counter the unpredictable, unstable, and offbeat.

# **ILLNESS AND TIME**

As with music, rhythm, time, and duration are central to the experience of serious illness. O'Brien notes that the word 'chronic,' as in chronic illness,<sup>90</sup> derives from the Greek god *Chronos*, the personification of time (2014, p.57) and medical sociologist David Morris goes as far as to say that chronic illness is in fact defined by time. To live with chronic illness is to live life "clocked" (Morris, 2008; Saleh, 2010; O'Brien,

<sup>&</sup>lt;sup>90</sup> There is great disparity in the definitions of the term "chronic illness" but I refer here to the World Health Organisation's statement from 2016 describing how chronic illnesses "are of long duration and generally slow progression. The four main types... are cardiovascular diseases (like heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructed pulmonary disease and asthma) and diabetes."

One issue with the WHO's definition of chronic illness is its connection only to noncommunicable illnesses, therefore excluding diseases such as AIDS which, undeniably, has a decades long history of chronic sufferance.

2014; Jowsey, 2016), just as Rosenblum described her experience in *Cancer in Two Voices* (1994). During cancer treatments, time may be clustered, periodic, inescapable, and, ultimately, provisional:

common to all chronic disease, is the way that death, not as the limit of one's possibility, but as biological demise, becomes thematic as a matter of time (rather than temporality), something to be clocked, something to which and against which all other clocks are clocked and measured. (Morris, 2008, p.417)

Being confronted with one's own corporeal impermanence by a cancer diagnosis, and undergoing treatments and procedures to delay or avert that particular impending cause of death, make mortality thematic of one's experience of time. Awareness of the enforced regularities of treatments and behaviours countered by the disturbed temporalities of the unstable body engenders myriad questions — how many cycles of this treatment must be administered? At what time of day are these pills taken? How much time do I have left?

Physician and pioneer of narrative medicine, Rita Charon, precisely describes the disparity of lived time in the kingdoms of the sick and the well:<sup>91</sup>

When the doctor or nurse enters the room to do something — to palpate, to cut, to medicate, to stitch — he or she remains within vectored time, that is, a state of time in which one event leads to another and can even be conceptualized as having caused it while the patient inhabits a timeless enduring. This is not just the difference between passivity and activity but the more unfathomable distinction between living within and outside of time, between diachrony and synchrony....

Not only does the nature of the actions accomplished by the sick and the well differ but also their temporal states of being differ according to their tempo, durability, evanescence, and stillness. T S Eliot's "still point of the turning world" indeed refers to the timelessness within the shell of time that, perhaps, best explains the sick person's dwelling in temporality. (Charon, 2006, p.44)

<sup>&</sup>lt;sup>91</sup> I again reference Sontag's opening paragraph of *Illness as Metaphor* regarding the kingdoms of the sick and the well (1977, p.3)

The disparate qualities of time outlined here by Charon chime with the findings of a panoply of writers on time and care (Butler and Rosenblum, 1994; Morris, 2008; Saleh, 2010; O'Brien, 2014; Jowsey, 2016; Baraitser, 2017, 2022; Jagoe and Kivland, 2020) and suggest parallels with musical features such as tempo, harmonic stasis, or the pulseless improvisation of an *alap*. An *alap* is the opening section of a Hindustani musical presentation in which there is an "absence of pulse" and therefore an unpredictability to the improvisation (Sorrell and Narayan, 1980, p.92).

Baraitser, too, profoundly investigates the qualities of time associated with illness and care, many of which share musical equivalents that I have attempted to express in this chapter's accompanying *jugalbandi* recording. In an extended meditation on the more unappealing, or at least uncelebrated qualities of time — qualities that are not flashy or exciting — Baraitser calls for a new appreciation of time in relation to care.

My suggestion is that we engage instead with an 'unbecoming' time — time that is lived as radically immoveable, experiences of time that are not just slow, sluggish, or even interminable in the sense of Heidegger's account of boredom, but are radically suspended, 'a great circle with no rim.' To live this time may turn out to be a question of ethics, inserted within a question of ontology — the arduous temporal practice of maintaining ongoing relations with others and the world which I will come to name as care. (2017, p.4)

Two categories of time are mentioned here by Baraitser which are common to practices of care and to the experience of illness: these mutually inclusive categories are repeated times and suspended times. Repeated and suspended times also feature in the works of Butler and Rosenblum (1994), Riley (2012), Jowsey (2016), Baraitser (2017, 2022), Salisbury (2020) and Salisbury et al (2023) and have easily expressed musical equivalents.

#### REPEATED AND SUSPENDED TIMES

Before a detailed commentary of the repeated and suspended times explored in the performance of *Anuvāram Jugalbandī*, I will explain their properties and incidence for both sick person and carer and ask in what ways may time be suspended or repeated? Whilst repeated times are fairly easily understood in the context of cancer treatment — the repeated cycles of chemotherapy and their iatrogenic consequences being one example — the idea of suspended times requires a little more unpicking. The Oxford English Dictionary offers multiple related definitions of the word 'suspend,' most of which relate to time, and include:

to debar, postpone, delay;

to put a stop to;

to put in a state of abeyance;

to stop or check the action or movement of (something) temporarily; to

hold in suspense;

to hold back from;

to abrogate or make inoperative temporarily;

to refrain from forming (an opinion) or giving (assent)

decisively; to come to a stop for the time;

to keep in a state of mental fixity, attention, or contemplation;

to rivet the attention of;

to cause to depend;

to regard as dependent;

to prolong (a note of a chord) into the following chord; to

hang from a support;

#### and also

to defer dealing with; (obsolete)

to put off consideration of;

(obsolete) to pass over for the time;

(obsolete) to profane; (obsolete) to be in doubt; (obsolete) to disregard. (obsolete) (Oxford English Dictionary, 2023)

For the sake of brevity, I shall not examine each of these definitions in relation to sick person and carer as many of them are self-evident and will inevitably share commonalities with the lived experience of the reader. However, I do wish to draw attention to a few of the above definitions, beginning with the obsolete ones.

On reading the OED's list of obsolete and rarely used definitions, I was struck by how pertinent the definitions are to the contemporary experience of cancer treatment. At the time of writing, the UK faces a "shocking gap in cancer care" according to The Guardian newspaper (Ungoed-Thomas and Das, 2023) with only 2.4% of NHS England trusts hitting their target of beginning cancer treatment within two months of referral. Cancer patients are passed over for a time, their dealing with deferred to such an extent that The Guardian reports one unnamed leading cancer charity describing the NHS cancer care system as unfit for purpose and "leaving lives" hanging in the balance" (ibid). These lives are in suspension, being suspended, dangerously hanging, with long waits proving detrimental to survival. Cancer Research UK points out that quantifying the impact of these suspensions, these long waits and missed targets, is difficult due to the varying growth rates of different types of cancers but, overall, the effect is negative (ibid.). Hanna et al (2020), in the British Medical Journal, show that delays in treatment cause significant harm with a four week delay of the commencement of cancer treatment causing a 6-8% increased risk of death and being "associated with increased mortality across surgical, systemic treatment, and radiotherapy indications for seven cancers" (2020, p.1).

Also pertinent to contemporary cancer experience is the definition of

"suspend" as the verb "to profane." With connections to the desecration of sacrality, synonyms for the verb "to suspend" (in relation to the act of profanation) include "to violate," "to contaminate," "to damage," and "to pollute." Treatments of cytotoxic nature, of radiation, and of surgery all meet this obsolete definition of "suspend" with their poisonous, deadly, and disfiguring modi operandi. Furthermore, cancer diagnosis can be met with moralistic judgements from others, somewhat akin to a loss of sacred status or to a state of self-desecration: if the body is a temple then what have you done to profane it? I was asked numerous questions along these lines following my diagnosis. Opinions regarding so-called bad karma or the hypothesising over past actions as cause of cancer (Galgut, 2010) lead to stigma, to changed identity, and to social discreditation (Goffman, [1963] 1990). In contrast, illness as spiritual experience has become a somewhat commonplace theme in illness narratives: Rose's *Love's Work* (1995) and Kushner's *Angels in America* (1991) being important examples.

I now return to the contemporary definitions of "suspend" and offer Jowsey's review of the "interconnected temporal structures that significantly contribute to our understanding of how chronic illnesses are experienced" (2016, p.1094) as a framework through which to assess the ways in which time may be suspended during treatment for cancer. Jowsey's four overlapping structures are:

- 1. Calendar and clocked time (socially understood construct);
- 2. biographical time (individually held temporal construct, understood more completely as the individual ages and in relation to society);
- 3. past-present-future time (socially understood temporal construct); and
- 4. inner time and rhythms (individually held temporal construct, uniquely tied to inner rhythms and processes).

Time may be suspended from these four temporal structures in myriad ways. For

Western societies, calendar and clocked time operates in a linear fashion and can be used to measure how long one works, how long a medical procedure takes to complete, or the duration of a friendship (Postill, 2002; Jowsey, 2016). Suspensions from this time are easily understood with time off work being one of the most obvious examples (and possibly a secondary gain also). The notion of "time off" applies to both the time beings and generally means time that is not economically or industrially/productively active; that time may be "busy," however, spent with the arduous and often repetitive activity of health-related behaviours and care.

Biographical time references the "summative period of time allotted to an individual during the course of their life" (Jowsey, 2016, p.1095) with an example of suspension being the interruption of expectation of established phases of life: childhood, adolescence, adulthood, old age (Bury, 1982). These phases of life set out by Bury (1982) and others are categories of heteronormative time, not accounting for experiences of queer time (regarding issues such as reproductive futurism, new temporal logics, and the AIDS crisis of the 1980s and 90s) as detailed by Edelman (2004), Halberstam (2005), Taylor (2010), and Madden (2023). The premature cessation of biographical time, or even possibility of cessation, of whatever (phenomenological) perception of biographical time one holds, painfully disrupts the expected patterns of life. For the cancer patient, their lifespan may be significantly curtailed; for the carer, if they are young, their adolescence may be cut short as they take on the adult responsibilities of caregiving.

Paterson (2001) describes the development of bodily, experiential knowledge over time by those with chronic illness to form a past-present-future temporal understanding incorporating interruption, intrusion, and immersion in illness (Jowsey, 2016). Morris (2008, p.4) describes the individual's requirement to be "improvisational" when it comes to identity and behaviour in past-present-future

orientations in relation to chronic illness.<sup>92</sup> That improvisational flexibility applies to both the time beings, given the unpredictability of the unstable body undergoing cancer treatment; however, in the performance of *Anuvāram Jugalbandī*, only the piano adopts an improvisational methodology. I will return to the improvisational experience of cancer in the compositional methodology section of this chapter.

The final temporal structure is that of inner time and rhythms. One clear suspension of these personal times may be the disruption of the circadian rhythms of the time beings. For example, during chemotherapy, the sick person must take steroids (and anti-emetics) over a period of days in order to better withstand the cytotoxic treatment. These steroids, such as dexamethasone, can cause significant insomnia and psychoactive side effects which, coupled with the iatrogenic nausea of chemotherapy, may disrupt the natural circadian rhythms of the body. The caregiver may also have their circadian clock suspended if they provide care during the night, as in Rosenblum's and Butler's case (1994), with Butler holding the bucket during Rosenblum's unpredictable vomiting bouts.

Whilst these suspended times connect with Jowsey's macro temporal structures (2016), and Hutchings' interpretations of world-political time and the personal 'our' time (2008, p.157), repeated times are considerably more challenging to measure in terms of their duration and their interplay. I regard the repeated times and behaviours of the time beings as dependable rhythmic series which include events such as radiotherapy appointments (usually scheduled on a daily basis for periods of one to seven weeks (Cancer Research UK, 2024)), the regular preparation of meals, and the administering of medications such as daily Filgrastim injections to treat iatrogenic neutropenia caused by chemotherapy.

<sup>&</sup>lt;sup>92</sup> Morris (2008) writes specifically about diabetes in this article but his theories of improvisational and provisional time, drawing on the work of Merleau-Ponty and Heidegger, are more widely applicable to a variety of chronic illnesses.

To further examine the broad and interconnected categories of suspended and repeated times, I have turned to the work of Lisa Baraitser to explicate their varieties and explore their musical expressions. The suspended times are described by Baraitser as including "pause, hiatus, interval, ellipsis, hesitation, intermission, break and gap" (2022, p.1). I add destruction, interruption, and loss to this list. The repeated times include "waiting, delaying... impeding, persevering, enduring, preserving, returning, staying and ending" (ibid., p.2). From Baraitser's *Enduring Time* (2017) I add maintaining, recalling, and remaining to this list. For clarity:

Suspended Times	Repeated Times
pause	waiting
hiatus	delaying
interval	impeding
ellipsis	persevering
hesitation	enduring
intermission	preserving
break	repeating
gap	maintaining
destruction	recalling
interruption	remaining
loss	staying
	ending

Before moving on to discuss the qualities of time in performance, I wish to close this section with an acknowledgement of the work of Nancy Munn (1992) and Georgina Born (2015). Munn's (1992, p.93) explanation of "time's pervasiveness as an inescapable dimension of all aspects of social experience and practice" speaks to the rhythmic research of this chapter and underpins Born's criticism of Bourdieu's social and cultural theory which concerns itself with stasis and social reproduction, rather than change (over time) (Adkins (2011) in Born (2015)). [The following outlines] the bidirectional mediation of music and time: how music produces time through the contingent articulation of its several temporalities, while in turn the variant temporalities immanent in social, cultural, political, and technological change mediate the evolution of music and musical genres. (Born, 2015, p.372)

Born's examination of layered temporalities of various musical objects (notably the making of "digital-musical times" (ibid., p.375) and "temporal ontologies" (ibid., p.381), relating to Wilson's aesthetic critical realism (2020), is offered in prospect of "contributing back to social theory more adequate theorisation's of time" (ibid.). In its own way, this chapter and composition are offered in prospect of contributing back not to social theory, but to medical and health humanities, providing a sounding out of the temporal complexities experienced by sick person and carer, in the form of repeated and suspended times.

#### REPEATED AND SUSPENDED TIMES IN PERFORMANCE

The repeated and suspended groupings of time, as shown in the table above (p. ), are explored by the musical *jugalbandi* of piano and miniature mridangam. The piano, played by me, represents the sick person and performs mostly suspended times; the half-size mridangam, played by Stan Talman (himself a familial carer for someone undergoing cancer treatment), plays the part of the carer and performs repeated times or rhythms. As with previous chapters, testimony informs *Anuvāram Jugalbandī*, using materials and ideas that were present or manifest at the time of my cancer treatment to explore my research questions: these materials are the piano and miniature mridangam, and two konnakol *korvais* given to me by Prathap Ramachandra that I was learning at the time of my treatment. Here are the *korvais* written in standard Western notation, without *solkattu*:

Korvai A (excerpt) - Piano





The performance begins with a solo chordal piano introduction using *Korvai A* as its rhythmic foundation. *Korvai A* is in fact only the beginning of a much longer korvai, shown in full here below:



The listener may note that *korvai* A is not performed exactly as notated: it is unstable to a small degree with rests sometimes cut (e.g. bar 8 is omitted) and short semiquaver patterns repeated (e.g. bar 15 hosts this first rhythmic deviation from the original korvai), signalling far greater instability to come. This minor instability combined with clipped, unpedalled, biting, improvised chords represent the lived time before diagnosis: a period of stress, anxiety, and trepidation waiting for the results of scans and biopsies (Hislop et al, 2002; Galgut, 2010; Kovar et al, 2020). It is impossible to know when a cancer begins to manifest and therefore I have focused on the temporally bracketed periods of diagnostics/diagnosis (00:01 - 02:01), primary treatment (02:02 - 04:04), and early stage recovery in this performance (04:05 - 05:20).

The point of diagnosis arrives at 00:47 and marks the most major example of suspension. Here the interruption, disruption, and loss of *korvai A* represent the suspension of three of four of Jowsey's temporal structures: calendar and clocked time, biographical time, and past-present-future time. At this point it is unknown whether *korvai A*'s abeyance is temporary or permanent; one enters a time of pooling liminality, a hiatus, separate from the expected and projected temporal structures, and one knows not if one will be cured and therefore able to resume one's 'old' life. This pooling quality, as described by Riley (2012) and Baraitser (2017), is expressed musically through the use of the piano's sustain pedal. Until this point, all chords are short, defined, and with agitated movement. The use of the sustain pedal, also known as the damper pedal, allows for the now slow-moving chords to pool in sustained resonance, their ambiguous harmonies reverberating in unresolved suspension. This period of time between diagnosis and the start of treatment continues until 02:02 and features many of the suspended times in the chart above: pause, hiatus, interval, hesitation, break, gap, destruction, interruption, and loss.

The mridangam first enters at 01:14 with three simple and gentle phrases of five

beats, as notated in *korvai B*. Groups of three repeated rhythmic phrases are essential to both Hindustani and Karnatak musics, mostly commonly described as *tihai* in the North and as a key component of *korvais* in the South (Clayton, 2008). These three tentative opening phrases mark the beginning of caring activities; repetitive but tentative, without confident insistence. At this point, treatment has not yet started and so caring takes the form of emotional support and of preparatory acts such as shopping for balms and potions to relieve potential side effects or trying on wigs ahead of imminent hair loss. Caregiving is often unexpected, with family members being drawn in gradually and being active as carers before they define themselves in that role (Seltzer and Li, 2000).

This gradual drawing in is represented in the structure of *Korvai B*: it loosely takes the form of a shape known in Karnatak music as a *mridangam yathi*. Rhythmic phrases and compositions in Karnatak music are often conceived as geometric shapes, called *yathis*. There are six main types of *yathi*, one of which being the *mridamgam yathi*, characterised by its drum-like shape: narrower at the ends (where the drum skins are stretched) and broader in the centre. *Korvai B* adheres to this palindromic structure in a textural sense with the outer sections being thinner in their activity (rhythmically sparse with long rests) and the central section being considerably more dense with its demisemiquaver and semiquaver groupings. As Gopal (2004, p.101) shows:

**Mridanga Yathi**—In this Yathi, the arrangement of the constituent angas and the rhythmic pattern is broad at the centre and narrows towards the ends like the shape of a mridangam. This is the opposite of Damaru Yathi.

$$\begin{vmatrix} & & & & & \\ 0 & 0 & 1 & 8 & 8 & 8 & 1 & 0 & 0 \\ 1 & 2 & 4 & 8 & 12 & 8 & 4 & 2 & 1 \\ & & & & & & & \\ & & & & & & \\$$

In Anuvāram Jugalbandī, the active central section (bars 41-70) on mridangam represents the carer at their most busy and active whilst the sick person is at their most ill during primary treatment comprising chemotherapy, surgery, and radiotherapy. This central section ranges from 02:02 to 04:04 in the recording and features rhythms of persevering, enduring, recalling, maintaining, and remaining qualities. The outer sections of korvai B (bars 1-40 on the above score and heard at 01:14 to 02:02 in the recording, and bars 71-111 heard at 04:04 to 04:44) feature rhythms of waiting, delaying, impeding, staying, and ending, therefore conveying all of the repetitive qualities in the above list at some point in the mridangam's korvai. Whilst these repetitions have many easily understood correlations with aspects of care - such as driving the sick person to and from appointments or, as Butler did (1991), holding the sick bucket every time it is needed — they also pertain to a sense of hope. For it is with hope that acts of repetition, pragmatic routines of returning and going over the same ground, "may allow a small degree of difference, an opening for something new to emerge" (Baraitser, 2022, p.17). This hope for something new to emerge is a hope for positive change for the unstable sick person and, in turn, therefore a hope for the need for care to subside.

Just as important as the need for care, and perhaps more interesting, is the desire for it. Once the familial carer has assumed and defined their role, the relationship between them and the person for whom they care can be fraught with tensions. It is this shifting dynamic which provides the motivating force for the piano's improvisation. Before exploring further this oscillating attachment to care and to independence, I shall set out my reasons for the mixed compositional methodology I have chosen.

#### COMPOSITIONAL METHODOLOGY, OCNOPHILIA, AND PHILOBATISM

Anuvāram Jugalbandī uses a combined mixed compositional methodology of free improvisation and fully determined composition in order to best explicate, sonically, the groups of suspended and repeated times set out above. Free improvisation is not the optimal methodology for performing repeated rhythms and phrases: its free nature is too unpredictable to make repeated times meaningfully communicable. This is why the mridangam plays a fully fixed rhythmic composition (*Korvai B*). In order to maintain a clear contrast, appreciable by the listener, it is essential for the piano to have freedom, to improvise, to explore the qualities of suspension, for improvisation, as a phenomenological process, does not suppose one fixed truth but "embraces a myriad of possibilities" (Dowler, 2019, p.445). It is this embrace that makes free improvisation the best methodology for exploring the position of the sick person within the complex, bonded situation of illness and care.

I have turned to the work of Hungarian psychoanalyst, Michael Balint ([1959] 2018), to investigate the relational dynamic (perhaps a "position," to use a Kleinian term, as discussed in chapter two) between the *jugalbandi* time beings, from the autoethnographic perspective of the sick person. Raluca Soreanu (2019) beautifully sets out the creative dyadic correspondence between Michael Balint and classical

scholar David Eichholz from August 1953 to February 1954. This fascinating exchange of multiple letters, itself a *jugalbandi* of correspondence, discusses matters of psychoanalysis, ancient languages (mostly Greek), and creative etymology. Following many witty and associative plays on words — not unlike the inventive musical play between Shankar and Khan in the *jhala* climax of their 1972 *jugalbandi* concert — Eichholz and Balint together arrive at the terms "ocnophil" and "philobat" to express relational positions. Balint later explicates these terms in his 1959 publication, *Thrills and Regressions*.

As Sedgwick distinguished the reparative and paranoid relational positions to the literary object (as discussed in chapter two), Balint articulated the object relations concerning the "leaving and rejoining of security" ([1959] 2008, p.26) using the two positions of ocnophilia and philobatism. These two positions, as I will show, are applicable to challenging times and experiences, such as chronic illnesses like breast cancer. For the ocnophil, reliance and attachment to objects and people transpires in unfamiliar, dangerous, or threatening situations. This is a drive or desire for security, with the obvious involvement of fear: a desire for, or attachment to, a protective object or person. The philobat, on the other hand, prefers to face challenges alone and unaided, with a kind of heroic thrill in operation. As with paranoid and reparative positions, I argue that ocnophilic and philobatic positions are not fixed and mutually exclusive but instead the experience of serious illness can inspire oscillations between these two positions throughout the course of treatment and recovery. Philobatic tendencies may dominate in some areas of the experience and oncophilic drives in others. Put simply, sometimes the sick person feels the ocnophilic drive to rely on their carer for security, help, and protection, and at other times they experience the philobatic desire for independence.

I have chosen to play with these shifting ocnophilic and philobatic positions,

which I like to think of as drives, in the psychological sense of the word regarding motivation,<sup>93</sup> to explore personal dynamics between the time beings, sounded by the *jugalbandi* of piano and mridangam. In the early stages of research for this chapter/ performance, I quickly realised I needed to employ this relational layer, expressed through free improvisation, otherwise the piano and mridangam parts would be separate and unrelated: an unengaged and unengaging *jugalbandi*. I shall now highlight some of the piano's ocnophilic and philobatic moments in performance.

Ocnophilic and philobatic musical expressions may only commence once the mridangam enters at 01:14: the mridangam/carer being the object with which the piano is in relation and therefore experiencing the shifting dynamic of the "leaving" and rejoining of security" (Balint, [1959] 2008, p.26). Being a single, independent person at the time of my treatment, living alone, I was keen to maintain my independence and reluctant to accept help. I felt like a philobat most of the time. For the three chemotherapy cycles I went through (cut short from six cycles due to the Covid-19 situation in March 2020), my mother would stay with me in my flat for a few nights at the start of each cycle. She would take over the living room with her belongings and so I felt constrained to my bedroom and my kitchen. This feeling of being constrained relates to the word jugalbandi with the Sanskrit word bandi having one particular translation as "prisoner" (Sanskrit Dictionary, 2024). As the pandemic progressed, I became more and more constrained, increasingly imprisoned in my flat. I was told by one of my chemotherapy nurses that Covid would likely kill me as my immune system was so low due to the cytotoxic chemicals administered to me. I had to be exceptionally careful regarding contact with others and her advice was to start shielding.

<sup>&</sup>lt;sup>93</sup> Drive motivation theory being created by behaviourist Clark Hull in the 1940s and 50s and developed by his collaborator, Kenneth Spence. See Spence (1958).

My reluctance to be cared for was motivated by my desire for continued independence and my fear of contracting Covid. The philobatic drive rarely abated in those first few months of treatment except for days when I had to inject myself with a drug called Filgrastim and felt too anxious to put the needle into my own stomach. These philobatic expressions are evident from 01:14 to 02:08 when the piano and mridangam play in turn, completely separately from each other, in a very simple, paired down, exploratory *jugalbandi* exchange. This period covers the first 40 bars of *korvai B*.

The first ocnophilic passage in the performance occurs at 2:34, the start of the second repetition of bars 41-70 of Korvai B by the mridangam. At this point, the piano gradually connects with the percussion, sometimes playing exactly together, and by 02:52 the piano is echoing the repeated 5 beat mridangam phrases of bars 67-70 of korvai B. A swing back to philobatism happens at 02:56 with suspended, irregular chords reoccurring in the piano part. This continues until 03:14 when the piano adopts the repeated demisemiquavers of korvai B, attempting to sync in with the mridangam but not managing to. These fast repeated notes in the piano are uneven and unstable to represent the negative impact of treatment and iatrogenesis; fingers unable to reliably execute phrases with the accuracy and strength they used to. At 03:31, a harmonious passage ensues with both time beings playing exactly together in bonded union. Philobatic playing returns at 03:41 whilst the mridangam remains steady, dependable, and repetitive. The shifting relation of piano to mridangam continues until the mridangam stops playing at 04:44; the piano is then solo once more, representing the early stages of recovery and shielding. It is responsible and independent but echoing the caring rhythms of the mridangam.

#### CONCLUDING REMARKS

The use of improvisation and fully-determined composition in this performance to

express not only the qualities of suspended and repeated times of the sick person and caregiver but also the relational position between them chimes with Born's (2015, p.381) "experimental article" on temporality and the cultural object and LaBelle's work on sonic agency:

Sound and sounding practices may therefore function as the basis for creating and occupying a highly malleable and charged relational arena, modulating the social coordinates and territorial boundaries by which contact and conversation may unfold. (2018, p.8)

The sounding of autoethnographic experience, combined with temporal analysis and psychoanalytic theory, makes for a malleable, charged, modulating performance that sounds out the inner relational experience of the attachment bond of care. The identity and experience of the "time beings" is not static but is in temporal process and relational process. The exploration of movement and stagnation, musically, brings concepts of time and texture into conversation with medical humanities discourse and Indian rhythm. By exploring the concept of *jugalbandi* in musical and non-musical contexts, I hope to have shown the suitability of music to communicate complex bonded relationships. *Anuvāram Jugalbandī* attempts to offer a reflexive contribution to medical and health humanities through creative practice, drawing attention to the temporal nature of illness, for both sick person and carer, as being manifestly rhythmic.

#### **CONCLUSION**

These transdisciplinary experiments in sonic life writing form a performance autoethnographic otobiography of the experience of HER2+ breast cancer and are offered in the hopeful pursuit of countering agnotology by sounding a non-lexical, sonic testimony. Bypassing the problems of warfare-related metaphor and resisting conventional cultural representations, this portfolio proposes a new, innovative potential for exploring the experience of breast cancer through transdisciplinary composition and reparative listening. Rejections, reflections, and re-imaginings, with a spirit of benevolent disruption, underpin this musical practice-based doctoral research.

In Chapter One, TCH-P investigated how iatrogenesis, and illness more generally, can inform and transform an ableist artform, namely the South Indian musical practice of *konnakol*. Foregrounding disruption, process, and energy (or lack of) over formal perfection (Hamilton and Pearson, 2020), TCH-P rejects the traditional tendency towards virtuosity and, instead, proposes the integration of iatrogenic experience not just as a compositional device but as a new means of expressive, sonic life writing. In >>KRANKENHAUSFUNK and the extrinsic death pathway<<, a radical re-imagining of hospital radio explored the possibilities for artistically sonating the biological process of apoptosis in transdisciplinary composition. Connecting literary theory, affect, aesthetics, and medical research, with modes of listening, sounding, and experiments in mechanical repurposing, K+EDRP provides a retrospective, reparative opportunity to make contact with "the kingdom of the sick" (Sontag, [1978] 2013, p.3) and disrupt the diminishing contemporary hospital radio model. Reflecting on the complex and fluctuating relationship between sick person and carer, Anuvāram Jugalbandī (for the time beings), examined how major diagnoses of serious illness interrupt lived and felt time, bringing about new and previously unrealised temporalities which fall outside the conventional structures of academic, industrial, social, and economic schedules. In a recorded duo performance for piano and percussion, this work explores how the South Asian musical concept of *jugalbandi* — an intricate and entangled form of duo performance — may be applicable to non-musical contexts and particularly to the relationship between ill person and caregiver.

I hope that this body of research may offer a basis for future significant and engaging work. Being a transdisciplinary project, multiple ways forward are possible with potential scope for a variety of public-facing engagement. Some examples of future routes include live events sharing further works of sonic life writing, audio and video recordings, the development of corporeal acoustemology as a manifesto and practice, and the further exploration of musical and sonic works made with medicinal plants.

Whilst the scope of this thesis is broad — my research has explored key themes in many capacious fields including medical humanities, life writing, sound studies, and ethnomusicology — the defiant intent of this research is clear and focused. This otobiography strives to make the inaudible audible through a transdisciplinary compositional practice committed to corporeal acoustemology, sonic agency, and acoustic justice. Holding Sontag's insistence most dearly — that the healthiest way to be ill is to be truthful (ibid.) — this thesis and portfolio are comprised of my best, and most honest, reparative musical efforts.

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