# The Ambivalence of Radiotherapy: Re-framing effects and their temporalities in treatment for gynaecological cancer

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## Abstract

Within the biomedical paradigm, treatment effects are typically split into primary and secondary effects with temporality playing a key role in this separation. Yet, this kind of ordering of effects with some effects understood as happening on the ‘side’, secondary and temporary, does not fit with how they are experienced by many patients who undergo treatment for cancer. Drawing on empirical data from a research project that gathered narratives of women’s experiences of radiotherapy for gynaecological cancer, we observe radiotherapeutic effects that are experienced as ambivalent and temporally diverse and as overlapping demands that the women endure and manage. We propose Derrida’s concept of pharmakon as a relevant and useful analytic for understanding radiotherapy treatment, thus bringing into focus the ambivalent effects of radiotherapy - it is both therapeutic and toxic. Pharmakon, we argue, offers a way of disrupting the logics that govern current practices of therapeutic radiotherapy, and provides a way to re-negotiate the ordering and temporal understandings and practices of therapeutic efficacy, outcome and accountability of radiotherapy treatment - away from a temporal fragmentation of treatment effects and patients’ bodily experiences to a focus on how best to support the whole patient in living with the ambivalent, temporally diverse and overlapping effects and demands of treatment.

## Introduction

Within the biomedical paradigm, treatment effects are typically split into primary and secondary effects; a categorisation and discourse that are argued to be informed by the scientific methodology that informs biomedicine, where specific diseases are seen and understood to require specific medical treatment (Etkin, 1992). The primary treatment effect of chemo-or radiotherapy for cancer is cancer cell death, yet the same treatment also leaves secondary effects that are known and managed differently to the primary effects. However, as DiGiacomo (1989: 61) observed in her work on the cancer clinic, ‘[b]iologically, there is no difference between the tumoricidal effects of anticancer drugs and hair loss, nausea and other consequences of taking them. It is all the same effect, but biomedical discourse separates them through the language of “side effects”’. Temporality plays a key role in this separation and ordering of effects. The primary effect is often represented as urgent (therapeutic) and long-lasting (curative), while secondary effects are often represented as temporary, non-urgent and deserving of less attention because they will go away in time: hair grows back, blood counts stabilise, soreness goes away, bladder and bowel function return to normal, energy levels go up, skin returns to normal, etc. Such hierarchy of effects is underpinned by a temporal conception of time that focuses on effects as medical events happening in clock-time (Ihlebæk, 2021).

The biomedical discourse of treatment effects as happening on the ‘side’, secondary and temporary, however, does not fit with how they are experienced by many patients who undergo treatment for cancer. Drawing on empirical data exploring women’s experiences of radiotherapy for gynaecological cancer, we observe radiotherapeutic effects that are experienced as ambivalent and temporally diverse and as overlapping demands that the women endure and manage.

We argue that the current biomedical understandings of temporality embedded within ideas about radiotherapy treatment and its effects have profound implications for medical care and what gets attended to during treatment and in understandings of living with and beyond cancer. Our data shows that the focus given to the urgent and therapeutic effects is at the expense of adequate attention to demands and ‘life effects’ of treatment (Ruckenstein, 2019), as they are framed as secondary and temporary. Consequently, we argue, the women were encouraged to endure life in the present as if the future is what matters most (Adams et al., 2009). Struggles and difficulties (even temporary ones) are overlooked and opportunities to understand and care for patients living with radiotherapy and its demands are missed.

The paper contributes to recent scholarly debates on the collateral effects of medicine that shed light on their ‘immediate and lingering presences in sociality and structures within and beyond medicine’ (Varley and Varma, 2021: 141). This includes the ‘life effects’ of pharmaceuticals (Ballantyne and Ryan, 2021; Chua, 2016; Martin, 2006; Persson, 2008; Ruckenstein, 2019), the iatrogenic effects of medical errors, negligence and malpractice (Shapiro, 2018; Smith-Oka, 2022; Varley and Varma, 2021), and the ‘polyiatrogenic’ effects of uncoordinated treatments (Ecks, 2021). Together, the papers share a focus on locating effects beyond ‘singular points in time’ and as more than their clinical presence (Varley and Varma, 2021: 141), as well as a focus on analysing the structures, systems and infrastructures through which treatment effects become known and acted upon, or not. We contribute with an analysis of the hierarchy and temporality of treatment effects, focusing specifically on the ambivalence of radiotherapy, and how it is possible to conceptualise ambivalence as a productive force that challenges prevailing biomedical logics of treatment effects.

We draw on the case of radiotherapy treatment, whose effects are inherently ambivalent. While radiation, in carefully prescribed doses, is used to kill cancer cells, it always carries with it the risk of significant damage to surrounding tissue. Despite efforts to minimise the risk of radiation toxicity to surrounding organs or tissue, many patients will suffer acute and long-term physical, emotional and psychological effects that significantly impact their quality of life (QOL) (Macmillan, 2013; Miller et al., 2019). Radiation damage to surrounding tissue can lead to bowel and bladder problems, fatigue and pain, sore skin, changes to sexual function, early menopause, lymphoedema, and bone problems, amongst others (Jo’s Trust, 2020). They can be acute and/or present themselves late, months or years after treatment has ended (Adams et al., 2014; Fernandes and Andreyev, 2021; Lind et al., 2011) to the extent that patients can develop pelvic radiation disease (Andreyev et al., 2011). While radiation damage is common (Andreyev, 2007; Faithfull, 1995; Hofsjo et al., 2018; Kuku et al., 2013Theis et al., 2010;), the effects are often underestimated and underreported by clinicians (Yeung et al., 2020), despite clinician reporting systems being in place (Oliver et al., 2022; SCoR, 2020).

Despite medicine’s best attempts to quantify and minimise the toxicity of radiation, we will arguably always to some extent be blind to the scope and significance of radiation on the individual. Yet, such ambivalence of radiotherapy treatment tends to be side-lined, as its therapeutic effects take priority. The ultimate aim of radiotherapy treatment for cancer is to rid the body of the cancer or to alleviate symptoms from malignancy. Yet, it is also important to acknowledge that by privileging the therapeutic effects, we may fail to engage adequately with its collateral effects. Such effects can be unpredictable, uncertain and multiple, and not necessarily reflected in how patients are supported in consent for radiotherapy and their experiences during and after treatment.

We propose engaging with the concept of ambivalence to explore radiotherapy as simultaneously therapeutic and toxic. This tension underpins radiotherapy treatment, and we explore how it is felt and experienced by patients. Drawing on the work of the philosopher Derrida (1981), we suggest the concept of pharmakon as a relevant and useful analytic for understanding radiotherapy treatment as a ‘benevolent adversary’ (Singleton, 1992). Pharmakon is an ancient Greek word that means both remedy and poison. Derrida famously discussed pharmakon in his work on speech and writing to exemplify the contradictions, as he argued, that condition all language and all meaning (Stocker, 2007). Writing, for example, can be a way of remembering but also of forgetting. Writing is both. Ambivalence, Derrida argued, is therefore not necessarily something to do away with; rather it can be a strength, as Derrida (1981: 127) points to here:

If the pharmakon is ‘ambivalent’, it is because it constitutes the medium in which opposites are opposed, the movement and play that links them among themselves, reverses them or makes one side cross over into the other […] The *pharmakon* is the movement, the locus, and the play: (the production of) difference (Derrida, 1981: 127).

Being critical of the idea that problems have good or bad solutions, Derrida argued for the importance of being comfortable with permanent oscillation and being able to live with conflicts between seeming opposites. Ambivalence, as Derrida saw it, holds a power to disrupt the competing discourses of therapy and toxicity upon which the pharmakon depends, and to see how things could be different. By analysing radiotherapy treatment as pharmakon we focus on the ambivalent effects of radiation as treatment that is at once therapeutic *and* toxic. At the same time, the concept also provides ways of disrupting the logics that govern current practices of therapeutic radiotherapy.

We start with a discussion of existing research on ambivalence, before providing a description of our method. We then move on to the empirical section that details women’s experiences of radiotherapy treatment for gynaecological cancer and its effects, and in the discussion, we pose the question of what would happen if we take seriously radiotherapy treatment as a pharmakon, therapeutic and toxic, *at the same time*.

## Ambivalence as an Analytic Lens and Productive Force

There is an essentially ambivalent quality to artefacts (Woolgar and Cooper, 1999), meaning that we can never really know them for sure. Not only are our experiences of technologies complex and multiple, they are also immersed in competing discourses that can lead to tensions and conflicting demands as well as personal and political dilemmas. ‘The most important task is [then] to engage the essential ambivalence of artefacts in general’, Woolgar and Cooper (1999: 443) write. Yet, how can this be done?

Turning to Derrida (1981) and his writings on the pharmakon, he conceptualises the relations and movements between opposites (or competing discourses) as ambivalence that is characterised by an ‘undecidability’. Such ‘undecidability’ is what precedes and makes possible the production of opposing meanings, he argued, and at the same time, is that which makes it impossible to decide, because pharmakon is both remedy *and* poison, an undecidable (Bates, 2005). Derrida’s notion of ambivalence then specifically engages with the opposing discourses that underpins ambivalence, exploring ‘the movement and play that links them among themselves, reverses them or makes one side cross over into the other’ (Derrida, 1981: 127). Importantly, the notion of ‘undecidability’ is not a synonym for mere indeterminacy (Bates, 2005), because ‘undecidability is always a *determinate* oscillation between possibilities […]. These possibilities are themselves highly *determined* in strictly *defined* situations (for example, discursive […] but also political, ethical etc.)’ (Derrida in Bates, 2005: 5).

In the case of the pharmakon, there is a permanent oscillation between the possibilities of remedy and poison, which are defined, discursively, politically, and ethically, in specific situations. In the case of pharmaceuticals, for example, Persson (2004) describes the unique history of HIV drugs, and their introduction into an AIDS crisis, where concerns about adverse effects were largely mitigated by a sense of urgency to treat HIV-infected individuals. Since their introduction in the 1980s, and despite improvements in drug design since, the adverse effects of HIV drugs remain ‘an unequivocal part of HIV health management’ (Persson, 2004: 48). Yet, despite of their co-existence, it is pharmakon as ‘remedy’, Persson (2004: 49) comments, that has been considered the most reassuring of its poles, with the poisonous pole having been ‘largely obscured by the scientific achievements and restorative paradigm of modern medicine’. Although, as Persson’s (2004: 53-54) work shows, this triumph of biomedicine ‘is complicated by its manifold transformative potential, the unpredictable and indelible imprints it may leave on bodies and selves’. What the concept of pharmakon then offers, Persson writes, is a way to disrupt the logic of biomedicine and its notions of therapeutic causality and efficacy or ‘disease-therapy-outcome’. She is thus critical of the seemingly fixed relation between therapeutic and adverse effects, arguing instead for the multiple and unpredictable capacity of pharmakon.

Further describing the relation between the two poles of pharmakon, we can draw on Singleton’s (1992; 1998) work on the UK cervical cancer screening programme. Her work points to ambivalence as a productive force in making technology work. While ambivalence in social theory has been viewed and conceptualised in mostly negative terms, most notably as ‘the new disorder of risk civilisation’ (Beck, 1994: 12) and thus as ‘an inevitable but undesirable state of modern being that we must all learn to bear’ (Widger, 2018: 406), Singleton (1992) shows how ambivalence can play an important part in making relations amongst entities durable and workable (see also Singleton and Michael, 1993). In her analysis of the UK cervical screening programme (CSP), Singleton observes how ambivalence can reinforce and sustain the CSP actor-network by addressing divergent elements within it, through which the CSP becomes the ‘benevolent adversary’ to the general practitioner (GP).

Similarly, by drawing on the concept of the pharmakon, we may conceptualise radiotherapy treatment as a ‘benevolent adversary’, meaning that its seemingly contrary values constitute its relation. On the one side, radiotherapy treatment is known and organised as a hierarchy of effects, yet a simplified representation that our empirical data problematises. Drawing on the insights from Singleton (1992), if we are to make radiotherapy treatment work for the individual patient, ambivalence must be recognised as part of constituting radiotherapy treatment, and thus both sides of pharmakon must be given equal priority. Despite of the uncertainty and instability that this may cause, ambivalence is not to be feared but must be seen as part of what makes radiotherapy work for the individual.

Taking the position of ambivalence is then an opportunity to explore possibilities for doing better. Tom Widger (2018), in his work on suicide and magic-bullet interventions in global health, is also arguing for the possibilities of ambivalence, especially as a way to explore ‘ethical possibilities’ rather than ‘ethical shortcomings’ of global health interventions. Attending to ambivalence, he concludes, might be ‘precisely what allows change to occur: ambivalence leads to critique, the development of alternative perspectives and ways of reimagining debates’ (Widger, 2018: 407).

## Methodology

Our research adopted the narrative correspondence method (Thomas, 1998) to capture patient experiences of radiotherapy. The research involved two UK-based studies collecting narratives from people relating to their experiences of radiotherapy treatment for cervical, endometrial, vulval or ovarian cancer. The first study invited participants to submit narratives from the start of their treatment and up to six months after ending treatment. They were recruited from a cancer treatment centre in the North-West of England over a period of 12 months. Criteria for eligibility included: diagnosis of gynaecological cancer and scheduled to receive radiotherapy treatment for gynaecological cancer (including brachytherapy, adjuvant and new-adjuvant chemotherapy), capacity to independently consent to involvement in the study, and able to demonstrate understanding and respond to verbal and written material in English. Exclusion criteria included: under 18 years of age and unable to communicate in spoken and written English. Potentially eligible participants were identified by the hospital and approached with an invitation to take part. They received a Participant Information Sheet and invited to ask questions. Following consent, a researcher from the university got in touch with each participant to introduce themselves and provide further information about participation in the study. Prior to data collection, the study had gained approved by the Health Research Authority (HRA) that assesses research projects in the NHS in England.

The second study invited participants, who have had gynaecological cancer at any point in time, to submit narratives about their experiences of radiotherapy treatment for gynaecological cancer. They were recruited online via social media and through gynae cancer charities and support groups. Criteria for eligibility included: anyone who has had radiotherapy treatment for gynae cancer at any point in time, carers and/or significant others of someone who has had radiotherapy treatment for gynae cancer, capacity to independently consent to involvement in the study, and able to demonstrate understanding and respond to written material in English. Exclusion criteria included: under 18 years of age and unable to communicate in spoken and written English. Potential participants were invited to contact the research team, whereafter they were provided with a Participant Information Sheet. They were invited to ask questions before they consented to take part, which took place through an online form. Ethical approval prior to data collection was approved by the Faculty of Health and Medicine’s Research Ethics Committee at [anonymous].

We asked all participants to keep a journal of their experiences and to submit one or more narrative entries using either written, voice and/or video recording methods. They were all provided with a participant guide to support them in making entries. We invited participants to structure their narratives around key moments of their experiences and provided prompts to get them started, such as ‘what is going on for you today?’ and ‘what are you thinking and feeling about having radiotherapy treatment?’. We would regularly check-in with the participants to hear how they were getting on with their narratives.

From the first study, we received 46 narrative entries from 16 women, who were undergoing radiotherapy treatment for cervical cancer (n = 9), endometrial cancer (n= 6) and vulva cancer (n= 1). From the second study, we received 32 narrative entries from 18 women, who have had radiotherapy treatment for cervical cancer (n =4), endometrial cancer (n= 9), vulva cancer (n=3), and endocervical (n=1) ranging from less than a year and up to 25 years ago (at the time of data collection). 1 participant did not provide details of their diagnosis. All participants identified as heterosexual and white females and ranged in age groups from 25-34 to 65 and over, with the majority being 55 and older. Most participants were employed (n =16) or retired (n =13) with the remaining self-employed (n =3) or unemployed (n =3). All participants had radiotherapy treatment in the UK. Narrative entries varied in length, content and format. From the first study, we received both short daily entries as well as longer monthly narrative entries. Most participants from the second study submitted one longer narrative entry covering multiple topics related to their experiences. Most narrative entries were typed or handwritten, with only 3 audio entries and 1 video entry. The audio and video entries were transcribed verbatim by a member of the research team.

The datasets gave us a rich set of narratives on women’s experiences of undergoing radiotherapy treatment for gynaecological cancer. While experiences varied to some degree, most participants shared accounts of difficulties and challenges, with a significant number describing those as life-changing and/or traumatic. Combined, the narratives provide breadth and depth in relation to the many demands of being a patient (practical, physical, personal and social), the range of factors that shape experiences and when, how and why difficulties arise.

The narrative entries were analysed using the cross-sectional thematical analysis technique (Charmaz, 2006), where sections of text were broken up into themes and subthemes that could be grouped together across the whole dataset. The qualitative data analysis software Nvivo was used to support analysis. We identified several broader themes, including ‘treatment’, ‘life’, ‘sexual selves’, ‘late effects’, ‘dignity’, ‘communication’ and ‘trauma’ that we write about elsewhere [Author]. For this paper, we report on findings related to the theme and subthemes related to the demands of treatment, hereunder experiences of treatment effects, as situated in specific arrangements and lived experiences of radiotherapy treatment. We used an abductive approach in thinking through this dataset (Tavory and Timmermans, 2014), reading the empirical dataset iteratively in light of our conceptual proposition on ambivalence. Four analytical themes emerged from this process that each address how the women in our study experienced their treatment and its effect.

## Experiences of Radiotherapy Treatment and Its Effects and Demands

### ‘Worse Before Better’

*Bowel movements manageable. I have been given Loperamide Hydrochloride capsules if required but not needed. Am I supposed to feel this good? I am hopeful that the side effects don’t worsen even though I have been told things will get worse before they get better*. Andrea

The phrase ‘worse before better’, as captured in Andrea’s narrative above, exemplifies the virtue of pharmakon as ‘remedy’. While Andrea has been informed about possible acute effects of her treatment for endometrial cancer, she is also reassured of the therapeutic effects of radiation and that these are the primary effects of her treatment. Any other effects are secondary and temporary. A hierarchical taxonomy of effects has thereby been introduced, also an order embedded within biomedical discourse, as Etkin (1992) observes. Writing on pharmacotherapeutic side effects, Etkin (1992: 100) comments how in biomedical discourse, it is usually understood that ‘in order to conform to the biomedical paradigm, there must be a ‘primary’ effect to which all others are subordinated’. This is not to say, however, that biomedicine is not interested in these other effects; yet conforming to the biomedical paradigm nonetheless means that the primary and intended effects of treatment are always understood as therapeutic with any other effect categorised as unintended ‘side’ effects.

These secondary effects of treatment are thus less than their therapeutic counterparts (Etkin, 1992), a kind of ordering and valuing of effects also evident in Polly’s account below. Polly had radiotherapy treatment for endometrial cancer more than 10 years ago, yet she continues to experience dark vaginal discharge from time to time. Although she has raised concern about the discharge, she is reassured that this is not evidence of recurrence, but instead of radiation damage to her vagina. Here, in the way she narrates her experience, the therapeutic effects of her treatment are considered more significant than the radiation damage to her vagina.

*I have dark vaginal discharge from time to time which has been checked out by the surgical team twice. No evidence of recurrence of the cancer but evidence of radiation damage to the upper third of the vagina so I came away reassured.* Polly.

That the ‘better’ therapeutic effects are given priority over the ‘worse’ effects of treatment is also evident during consent. While many of the women in our study were informed about the possible acute and late effects of treatment, some also shared their experiences of not giving those effects much consideration at the time of consent.

*You’re not really listening because all you think about is ‘you want the cancer gone’*. Anna.

For Anna, the mixture of emotions at the time of consent meant that she did not ask further questions about the possible acute and late effects of her treatment, while for Kathleen, the focus on treatment and recovery in the accompanying information leaflet meant that she did not feel nervous about her treatment, but on reflection, she wished that she had been told more about what can happen mentally and physically.

*I recently re-read the one about radiotherapy while doing this and I commented to a friend that I think it was the Disney version I read…. I really wasn’t scared or nervous of the treatment, but I think I should have been more aware of it. I think the information you get should be more realistic and be told what can happen mentally and physically.* Kathleen.

Temporality plays a critical part in the valuing of effects that is going on here, as patients are often advised that ‘side’ effects are typically temporary and that they will ‘settle’ or that ‘worse’ will become ‘better’ with time. The primary effects of treatment take priority, while their opposite and collateral effects are downplayed.

### ‘Just getting on with it’

Many of the effects of treatment are, for a lot of the women in our study, responded to by carrying on, managing and enduring the many physical, emotional and social demands and effects of treatment. Those include, amongst others, the worry that comes with a cancer diagnosis, concerns about how to get to/from treatment, the stress of undergoing treatment itself, the uncertainty of the physical effects and how to deal with them, the normalisation of adverse effects and finding ways of managing, bearing and enduring the changes, discomfort and pain of treatment. For many of the women, this has meant responding with protective and/or preventive measures, such as listening to music to keep themselves distracted during treatment, wearing sanitary towels or incontinence pads to protect against discharge or leaks, making changes to their diet to prevent or manage diarrhoea, trying out different creams to soothe the skin, or never being too far away from home, in case of fecal urgency.

Sarah, a single mum of two who underwent radiotherapy for cervical cancer, writes about how she is being careful about what and when she eats, trying to avoid the high in fibre foods and only eating after the school run. For Donna, who had diarrhoea for six months after ending treatment for endometrial cancer, the loose bowel effect of treatment means always taking a bucket and wipes with her in the car when going out, and for Kathleen who had treatment for endometrial cancer, it means always thinking of where the nearest toilet is, and never going too far for a walk.

*I have to say it’s not a pleasant feeling, having to go out, go to appointments, school run etc., and wonder if you do actually need to poo or if it’s just gonna be a constant feeling*. Sarah.

*Tired of always having to think about where will the nearest toilet will be when I go out or if there is a toilet. I can’t go too far for a walk in case there is no loo.* Kathleen.

For many of the women, the effects of their treatment have become normalised. Maggie, for example, who suffered with pain and diarrhoea for several weeks during and after treatment for cervical cancer still found a form of normality in her new routine, on and off the toilet, and Christine, who continues to suffer from bowel incontinence months after ending treatment for vulva cancer, accepts this condition as her ‘new normal’.

*Today still running the toilet. Spoke to the nurse. She told me it could be this way for about six weeks. Normal day on + off the toilet. But in myself, I feel fine.* Maggie.

*I suffered from bowel leakage incontinence for most of the treatment and still do. I have accepted this as part of my “new normal”.* Christine.

The understanding and framing of their effects and experiences of treatment as normal and secondary arguably contribute to the lack of priority given to their concerns and issues, making them feel that they must ‘grin and bear it’ and ‘just get on with it’, as described by some of the women. This is also evident in Jane’s account below, whose experience of having radiotherapy treatment has largely gone unheard in the clinical context. After seeing a privately paid physiotherapist, however, she realises that her felt lack of interest in her wellbeing, beyond her clinical recovery, made her feel obliged to manage on her own and say: ‘it is all fine’.

*It made me realise what I’ve been missing all these months in my treatment and the approach of the team. […] I realised that no-one had spoken to me about any of these things, and that I’d just accepted that I needed just to get on with it. I’ve honestly come away from this 1 hr session feeling that I have the right to feel better about everything and that I have a right to look after myself too and that for the first time, someone has actually asked the right questions and given me permission to do something about it – up until now, I’ve felt obliged to say ‘it’s all ok really – I’ll manage and have swept under the carpet all of the resulting issues that I didn’t feel I had a right to do something about (sex, bloating, menopause symptoms, thoughts about a cancer diagnosis, coping and caring’).* Jane.

Jane’s narrative tells a story of a patient who feels left alone to figure out how to manage the effects of treatment. The focus on her clinical recovery made her feel obliged to bear the discomfort and not draw attention to her struggles. When she did raise concerns, she was given a leaflet with general advice. However, despite such efforts to provide care and support, Jane did not feel cared for. Others share similar experiences of speaking up, but not feeling cared for.

*The other thing that I’ve really struggled with is roundabout the same time as my back became very painful, um, I also started suffering from really quite bad bladder and bowel inflammation. Um, I’ve, yeah, I’ve had several episodes of real urgency and when I’ve needed to go, I’ve really needed to go. […] at a surgical appointment I explained this to the, erm, consultant who just shrugged his shoulders and said, “Um, and you can always wear incontinence pads, can’t you Well, you’ve had radiotherapy, what do you expect??” So, that was, that was really upsetting.* Anita.

Yet, the problem that arises when patients, like Jane and Anita, are left to ‘get on with it’, is not only that they may not recognise those as effects for which support is or should be available, as Schultze et al. (2020) argue, but that the biomedical ordering and valuing of treatment effects undermine effects as personal experiences and do not recognise treatment effects as ‘life effects’ (Ruckenstein, 2019) with the consequence that the patients are denied agency and the power to demand (better) attention and treatment.

The framing and expectation that some treatment effects are temporary also plays a role in how such denial of agency operates. This is evident in Elizabeth’s account.

In her 80s, Elizabeth is undergoing radiotherapy for cervical cancer, and during treatment and for some time after, she experiences diarrhoea and pain that comes and goes, especially when showering. She describes the pain as ‘traumatic’. Yet, when two district nurses learn that she can shower okay, they tell her to carry on as before.

*Had diarrhoea all night. Feeling week at the knees. Managed to shower at 12 mid-day. Felt better for it. Good start to the day. But deteriorated as the day went on. Rather a yucky day. Got up at 9am. Went back to bed at 11am. Didn’t shower until 3pm. Feel good today. Didn’t last. Went down like a flat tyre. Energy levels nil. Having a shower is quite traumatic but I feel so much better afterwards. I make myself shower every day. […]. When they [the two district nurses] heard I could shower ok, they just examined me to make sure I had no infection and told me to carry on as I have been doing. They wouldn’t be coming again*. Elizabeth.

The two nurses’ assessment of how Elizabeth is doing is framed by a priority given to her functional capacity (that she can shower ok) with an understanding of her pain as temporary (the two nurses will not come again). It is expected that any pain or discomfort will settle in time. Yet, not only do such expectations inform how clinical assessments are concluded and acted on or not, they also shape how patients, like Elizabeth, are made to feel about their effects, and whether or not they feel that they can speak up and be heard. This resonates with existing research on pain and suffering that shows how a wider context of legitimacy and recognition of a person’s illness affects the extent to which a person bears the pain and suffering (Broom et al., 2014; Morris, 2014). It is evident from the women’s narratives that the framing of treatment effects as secondary and temporary shapes their worthiness for care, making them feel that they must ‘get on with it’.

### A Whole Body Denied

The biomedical discourse that separates the pharmakon as remedy from pharmakon as toxicity works to temporally fragment the effects of treatment *and* the patient’s bodily experience. The urgent focus is on the patient’s clinical recovery with any other effect attended to in time, if at all and in some situations, as if these were unrelated to the treatment itself. ‘The fragmentation of time and the fragmentation of the body [then] reproduce each other’, (DiGiacomo, 1989: 62). A result of this, however, is that a temporal discontinuity in clinical discourse is created that has the consequence that the whole physical body is denied (DiGiacomo, 1989). When effects of treatment are ordered and further split into categories such as bowel effects, bladder effects, fertility effects, etc, and if any of these are interpreted as medically significant, patients may be referred to a variety of health care professionals, who will offer care and support for those effects. With this kind of breakdown, however, the patient experience becomes fragmented in time and space, and any links between treatment effects may be missed (DiGiacomo, 1989; Ecks, 2021). This is evident in many of the women’s accounts.

Donna describes how she felt that her difficulty with resuming full vaginal intercourse and with using the dilators were unacknowledged as an effect of her treatment, and Polly describes her experiences of late bowel effects that were dismissed as unrelated to her treatment because she had been discharged as ‘cured’.

*The effect of losing my cervix, and a reduced vaginal vault is that I have never, not even with dilators, been able to resume full vaginal intercourse. I believe the radiotherapy has probably also had an effect on the tissue in that area. That has been very hard, and pretty much unacknowledged by oncology the whole time I was attending (despite my mentioning it). It was made quite clear that the only purpose of the dilators supplied was to prevent adhesions and facilitate internal exams.* Donna.

*Late side effects became noticeable in 2015. I was suffering from abdominal colic, constipation and bloating. My consultant surgeon did a triple scan with contrast before discharging me from his care as “cured”. The scan revealed no metastases but a “loaded colon” and degenerative changes in my lumbar spine. It took me some months of visits to the GP’s to be examined for these problems and my request for an urgent referral to a gastro-enterologist was declined.* Polly.

The above accounts are two out of many that tell stories of how it has become increasingly difficult to untangle the therapeutic effects of cancer treatment from its many other effects. In the process of therapy, radiation is doing damage to other parts of the body, yet women describe how their whole bodies are denied. While breaking effects down into specific effects such as bowel and bladder effects can be effective in getting the various issues recognised and support made available, it does not take into account how the different effects and demands of radiotherapy affect the body and cross into people’s lives in multiple and overlapping ways. Effects of treatment are not discreet or isolated phenomena; instead, they are experienced simultaneously. Cancer cells are damaged at the same time as healthy tissue, and while healthy tissue to some extent is able to repair the damage, the immediate effects as well as longer term effects on stem cell replenishment can leave patients with acute and late bowel or bladder effects, amongst others. Effects can linger, come and go, and accumulate over time. Yet, these temporal diverse and overlapping effects are rarely addressed in patient leaflets that typically describe effects in discreet terms, nor in treatment pathways that separate primary treatment from other kinds of care (Ecks, 2021; Pedersen and Obling, 2020). However, when treatment effects are categorised and split in time and space, their complexity and entanglement remain subordinate and deprioritised. The danger with this kind of temporal fragmentation, as DiGiacomo (1989) argued, is not only that ‘patients only catch fragmented reflections of themselves’, but it may also leave little or no choice in how their symptoms are confronted.

### Incomplete Effects

When undergoing treatment, patients will be provided with consent forms that will list expected and common ‘side effects’ of the treatment as well as some information about what those effects may look like. Teresa, for example, was told that her skin would be sore afterwards, while Anna was told the skin would go red like sunburn. Yet, neither experienced the skin effect in this way. Instead, Teresa describes her experience as ‘painful’, ‘sheer horror’ and ‘terrifying’, and Anna describes her sore skin ‘more like a third-degree burn’.

*I was told that my skin would be sore afterwards and that once the treatment ended the effects would continue – but at no point was I prepared for the pain, and sheer horror of what that would look like. Neither did they explain that going to the loo would be so difficult – I remember crying with pain – just didn’t know what to do with myself. My skin was blistered and black and went into large holes – I remember the smell too – it was terrifying.* Teresa.

*I was told the skin will go red like sunburn… As the weeks go on your skin starts to bubble and is more like 3rd degree burns than a little sun burn.* Anna.

Descriptions and explanations of treatment effects are necessarily always incomplete or limited. While patients consent to having had the aims and possible ‘side’ effects of treatment explained to them, it is hard for anyone to fully comprehend what the implications of such effects will be for the individual, both physically, mentally, sexually and socially, and temporally. This makes it ever more urgent that conversations about treatment effects do not start and stop at the consent stage, but as Melissa describes in her narrative below, frequent discussions throughout treatment and after would not only help prepare patients for what may come, but the responsibility of getting the care and support needed would become more distributed.

*Side effects to treatment were mentioned including loss of fertility and menopause, bowel problems, lymphedema but I cannot remember being advised of any other long-term issues. This may have been related to the stress at the time and my fear, but I feel it would have been helpful to have this discussed more frequently throughout treatment so I could have prepared myself more for what was to come*. Melissa.

The narratives tell us that it is impossible to decide beforehand how the effects of radiotherapy treatment will be experienced by the individual. The skin effect, for example, will materialise differently depending on the individual and their response to the radiation. Explanations and discussions of treatment effects are therefore better done without recourse to knowledge of a preferred biomedical outcome, in the case of the skin effect, as sore skin..

## Discussion

The hierarchical taxonomy of effects - integral to the contemporary paradigm and methodology of biomedicine (Etkin 1992; Martin, 2006; Montagne, 1996) and underpinned by ‘prevailing cultural conceptions of therapeutic efficacy’ (Persson, 2004: 55) arguably ignores the seemingly collateral effects of treatment that are negotiated and unfold in the lived experience of disease and treatment. We have seen in the women’s accounts the consequences of such codification and ordering of outcomes, in that women feel obliged to carry on, manage the uncertainty of their effects, accept and normalise their experiences, and endure and bear the pain and discomfort. The hierarchy of effects to some extent works to silence the women’s discomfort, and instead, they are made to feel responsible for the effects of their treatment as they find ways to cope and manage the multiple, overlapping and interrelated effects of treatment in their daily lives.

Carrying on, managing through different means, bearing and enduring the discomfort and pain from treatment are arguably responses shaped by larger social structures that organise cancer treatment experiences. Those include ideas and discourses around survivorship, self-care and individual responsibility (Bell, 2014; Korfage et al, 2006; Pertl et al., 2013; Segal, 2012; Schultze et al., 2019; Sidenius et al., 2019) as well as larger biomedical discourses and forces that structure patients’ bodily experiences (DiGiacomo, 1989; Pedersen and Obling, 2020). The latter includes the introduction of cancer treatment pathways, but which are argued to create an ‘increasingly temporally asymmetrical’ healthcare system, as the use of temporal devices such as calendars, clocks and schedules to structure and standardise treatment and the ways effects are dealt with, exist in tension with patients’ temporal experiences of treatment and effects (Ihlebæk, 2021; Pedersen and Obling, 2020).

The hierarchical and temporal orderings that we have focused on in this paper are not purely about the temporal structuring and organisation of treatment, but as DiGiacomo (1989: 62) argues, such orderings are also ‘rhetorical effort[s] to influence the patient’s experience of illness and the oncologist’s experience of treating the patient’. Ordering effects into primary and secondary effects are discursive efforts that are ‘rooted in a metaphor whose significance is in part temporal: short-term inconvenience for long-term gain’ (DiGiacomo, 1989: 62). The consequence of such temporal fragmentation in clinical discourse, however, is that patients are made to feel that they must bear and endure their discomfort and pain, thus leaving their suffering more or less unspoken and unheard.

Yet, what would happen if the effects of treatment are not dealt with by carrying on, normalising or hoping things will get better? What if we stop presenting effects as ‘side’ effects, and instead start with the notion that radiotherapy treatment is a trajectory of ambivalent, temporally diverse and overlapping effects, some of which are urgent and therapeutic, and some of which the opposite – late, chronic, damaging and life-changing? What if we take seriously radiotherapy treatment as a pharmakon, therapeutic and toxic, *at the same time*? Doing so means destabilising the hierarchy of effects and its discursive temporal ordering to allow radiotherapy treatment to exist as a movement between effects that shift between and criss-cross the therapeutic and the toxic, at different times and duration. It means attending to patient experiences of treatment and effects, without prioritising the therapeutic capacities of treatment over its toxicity on temporal grounds, and without presenting the toxic effects as temporary, whether such effects present themselves early or late.

Life after treatment is increasingly getting attention within cancer care and radiotherapy, albeit slowly. New guidance from the General Medical Council on shared decision-making and consent (GMC, 2020) highlights the importance of considering and understanding patients’ priorities, including ‘the importance a patient might attach to different outcomes’, beyond conventional medicalised measures such as survival. In 2021, the Royal College of Radiologists also launched a suite of national, standardised radiotherapy consent forms, including for gynaecological cancer, that capture late effects, an area that has historically been neglected in favour of acute or early effects in consent discussions (RCR, 2021). The increased use of patient-reported outcome measures (PROMs) is also said to make the case for radiotherapy late effects clinics (Oliver et al., 2022) as the provision of such clinics in the UK remains insufficient (Adams et al, 2014).

Our research adds to such efforts to improve services and experiences for patients, a concern with how treatment effects are categorised, ordered and talked about. When medical treatment models are over-relied on, such as the hierarchical and temporal ordering of effects into primary/therapeutic and secondary/temporary effects, we forget to imagine and act on effects in other, better ways.

## Conclusion

Living with the demands and long-term impacts of cancer treatment is increasingly part of people’s lives. In response, we propose taking the ambivalence of radiotherapy seriously, whereby doing so, we are offered an opportunity to re-negotiate understandings of efficacy, outcome and accountability. Through the lens of the pharmakon, we argue that with ambivalence, it is possible to orient ourselves differently to treatment and its effects, with focus shifting away from a hierarchy of effects, where effects are understood and treated as medical events happening in clock-time, and instead towards an understanding of treatment effects as ‘life effects’ that are temporally diverse and situated in local life stories (Ruckenstein, 2019). Going through treatment and living with its effects is an entanglement of the therapeutic and the toxic, incompleteness and unpredictability, messy temporalities and the undecidable, thus impossible to order and categorise the effects of treatment. Orienting ourselves to ambivalence, however, then becomes productive of reflection and of generating new ways of supporting patients who undergo radiotherapy treatment for cancer. This is a plea to expand our notions of efficacy and outcome, interrogating the efficacy of treatment beyond its clinical outcomes (Webster et al., 2009) in the form of ‘cure’ and survival figures, and to pay attention to how the ambivalent effects that medical interventions inevitably generate are experienced by patients – as well as clinicians (Rosengarten et al., 2004). The question for health care then becomes how best to respond to such ambivalence without denying patients opportunities to speak up and be heard. This arguably involves a redistribution of responsibilities and a reconfiguration of what it means to be accountable to patients and their wellbeing. Elsewhere, we have published a call to action for all, outlining a manifesto for change [Author].

## Competing Interests

Authors declare no competing interests.

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