



Living (well) with cancer in the precision era

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ABSTRACT

Surviving cancer in the precision era of targeted drugs and immunotherapies increasingly involves surviving-with malignancy. Against this backdrop of precision, innovation and chronicity, this paper offers a person-centred examination of some of the emerging intersections of chronic living and cancer treatment. Using a temporally extended qualitative methodology drawing on solicited diaries and successive in-depth interviews with people receiving precision cancer therapies, we focus on the often opaque worlds of surviving-with cancer, day-to-day, amidst the evolving scene of therapeutic innovation. Tracing how elements of the catastrophic and the mundane are braided through these everyday experiences, we seek to provide an embodied and temporally extended account of everyday life, beyond the binaries of presence/absence of disease, or of death/cure. In so doing, we consider how the normative expectations of treatment, bodies, care and emotions are being reshaped, elevating the moral work of the precision-cancer intersection.

1. Introduction

To live with cancer is, increasingly, to exist amidst the swiftly moving scene of 'precision' medicine. The genomic turn in cancer treatment, and resulting rise of precision therapeutics, has been one of the resounding successes of the Human Genome Project. In everyday practice, this has catalysed a focus on diagnosis through the identification of cancer biomarkers, and treatment with novel targeted and immune therapies that prevent malignant cell replication at the molecular level (Collins et al., 2017). This represents a therapeutic shift from traditional cytotoxic cancer treatments such as chemotherapy and/or radiation (Broom & Kenny, 2021a; Kenny et al., 2021). Decades in the making, this shift is now rapidly accelerating in terms of the breadth of biomarkers being identified and precision drugs being developed. The rise of precision oncology is in turn producing vastly different survivorship experiences

for people living with different types of cancer and with differential access to novel therapeutics (Drake et al., 2018). The diversification of cancer trajectories due to the genomic turn has inserted even greater prognostic uncertainty into clinical care and everyday experiences as cancer is (often) being reconfigured as an illness experienced over the mid-to long-term. Yet, social science analyses of cancer as an illness experience have thus far not sufficiently examined the emergent dynamics of the precision turn as it is interwoven with ongoing undulations of everyday cancer survivorship (Broom & Kenny, 2021a; Dam et al., 2022).

In this paper, we seek a person-centred examination of some of the emerging intersections of malignant living and precision therapeutics, as evident in people's embodied and everyday experiences of cancer. In particular, we consider: surviving-with; surviving and significance; and survival as *moral work*. In doing so, we recentre an embodied and

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temporally extended account of symptoms and side-effects, rather than a snapshot view of the presence/absence of disease, as crucial to fully comprehending the quickly moving scene of precision. That is, we seek to emphasise the importance of backstage illness experiences alongside more widely acknowledged metrics of tumour size reduction, blood counts and other markers of biophysical progress within oncological practice. Using a temporally extended qualitative methodology drawing on solicited diaries and successive in-depth interviews, we focus on the often hidden – and sometimes seemingly mundane – world of surviving-with cancer, day-to-day, amidst the evolving scene of precision cancer therapeutics.

2. Background

As life with cancer has evolved over the course of the late 20th and now 21st centuries, social scientists have been examining the related social, biophysical and cultural undulations (e.g. Bell, 2010; Chapple et al., 2004; Chapple & Ziebland, 2002; Frank, 2003; Stacey, 1997; cf.; Tempini & Leonelli, 2021; Tritter & Calnan, 2002). A key change, among others, is the burgeoning of chronicity in cancer, and its considerable consequences across the spheres of self/identity, social relations and expertise/institution. Precision oncology has created further (and seismic) shifts over the last few decades (Broom & Kenny, 2021a; Kenny et al., 2021), requiring new ways of thinking within/about cancer. Here we outline some important conceptual ideas which prove instructive for comprehending our participants' experiences, and perhaps, the broader scene of cancer in the precision era.

2.1. *Surviving-with*

The rise of precision therapeutics in cancer, albeit highly uneven and frequently inequitable, has fundamentally changed the landscape of cancer survivorship (Tsimberidou et al., 2020). Probably the most significant change is the length of time some people diagnosed with cancer are now surviving, especially for disease/tumour streams with previously very poor prognoses (e.g. Yang et al., 2020 for a review of precision in non-small cell lung cancer). While such patients may never be 'cured', nor their cancer be fully in remission, novel therapeutics now limit disease progression for those with particular mutations and extend survival periods considerably. In this way, precision therapeutics are inducing *surviving-with* cancer as an increasingly prevalent outcome. As such, the precision turn has begun to reconfigure cancer as something one increasingly often survives *with*, rendering cancer a chronic condition, albeit highly structured by socioeconomic divides (e.g. Morash et al., 2018 on determinants of precision intervention).

From a definitional standpoint, cancer has long been 'chronic' – meaning that it encroaches upon the activities of daily living and/or requires ongoing medical attention for a period of one year or longer (Centers for Disease Control and Prevention (CDC), 2021; Tritter & Calnan, 2002). More recently, though, cancer has been recognised as a disease of great diversity in both its biophysical features and survival outcomes as new therapeutic options have been developed (Mukherjee, 2010). From the 1950s, cytotoxic therapies provided the initial push towards increased survival time and life extension – gains that have accelerated, albeit unevenly across tumour streams, until the present day (DeVita & Chu, 2008). For instance, in Australia during the 1980s overall five-year survival across all cancer types was around 50%. Today, this has improved to over 70% (AIHW, 2021). The rise of precision therapies – enabled by the use of biomarkers and the deployment of targeted and immune therapies – has amplified this trend towards extended survival time following a cancer diagnosis. Yet this survival time is increasingly *surviving-with* disease present in the body, rather than survival due to its successful eradication.

Such population level trends in survivorship are accompanied by similarly dramatic changes in the lived experience of affliction, with cancer now often more aptly described as a co-presence (cf. Harrop et al.,

2017), rather than something to be expunged (however desirable that may be). And *surviving-with* cancer, in an ongoing or chronic fashion, as we shall see in our participants' diaries and interviews below, is a different experience to survival characterised as a binary outcome (i.e. in 'cure' or in its absence, death). The rise of *surviving-with* cancer has in turn produced new – or perhaps resisted old – cultural anchors. *Surviving-with* is both ontologically and experientially resistant to erstwhile notions of 'battling against' (disease) or 'fighting for' (life/family) (Clarke & Everest, 2006; Seale, 2001), though it similarly demands forms of perseverance in one's commitment to treatment *in order to live*. *Surviving-with* demands new affective relations and introduces new affective tensions, around dis/comfort with the presence of disease and acceptance, revulsion, or even resignation to cancer's persistence in one's body. *Surviving-with* is temporally protracted, and ontologically liminal, with various relational consequences, for example around the ebbs and flows of collective attention and provision of in/formal care. *Surviving-with* cancer, then, becomes a meaningfully different experience from traditional tropes around cancer survivorship, reconfiguring how it is embodied, discursively represented, and cared for (Olson, 2016).

Living-with cancer in the precision milieu, as articulated in the participant diaries and interviews recounted below, becomes something more-than-mere-survival but also less-than-full-remission or 'cure'. As we shall see, ultimate questions of life and death are displaced by seemingly more mundane issues of symptoms and side effects in the ongoing accomplishment of survival. However, these seemingly mundane concerns belie complex ethical and moral dilemmas around the tolerability of treatment, reasonableness of persistence and acceptable levels of suffering (e.g. 'is this worthwhile?', 'what are the costs?', 'can I withdraw?', 'who gets to decide?', and so on). Upon this evolving terrain of *surviving-with* cancer, ontological assumptions about the nature of disease, treatment and therapeutic possibility shift in light of emerging therapeutic developments, as do the lived experiences of affliction, treatment and day-to-day living.

2.2. *Survival and significance*

As illustrated in much of the classic social science scholarship on chronic illness (e.g. Bury, 1991; Corbin & Strauss, 1985), chronicity requires different/particular forms of affective labour in comparison to the default model of acute or 'life threatening' illness (see also Manderson & Wahlberg, 2020; Manderson & Warren, 2016). Much of this work centres on establishing issues of *credibility* (of symptoms), *validity* (of treatment) and *legitimacy* (of complaints). In the work of Charmaz (1983) and others (e.g. Richardson, 2005; Ware, 1992), a key 'problem' of chronic illness is its discredited or partial status; that is, the difficulty in gaining recognition for its significance. The spectre of malignant disease and the accompanying threat to mortality presented by cancer considerably amplifies this problematic, with chronicity being decentred by the palpable importance of life itself. The rise of precision oncology, then, with its attendant possibility of *non-curative yet non-terminal living* presents an important case for social science consideration drawing across the scholarship of survivorship, cancer experiences, and chronicity (Broom & Kenny, 2021a; Kaiser, 2008; Manderson & Wahlberg, 2020). Chronicity in cancer thus presents a challenge to the concept of survivorship (as surviving *after* cancer), a concept which has already been critiqued for its "individualising moral framework" that obscures the impact of social structures and inequalities, ascribes significance to character (e.g. resilience, virtue), and positions cancer treatment as a 'battle' for longevity at all costs (Broom & Kenny, 2021a; see also Bell, 2010, 2012). In line with our previous critical scholarship on survivorship, this paper seeks to recentre the precision subject and their illness and wellness experiences (good, bad, or otherwise).

In part, the affective dynamics of surviving-with cancer – existing between the poles of death and cure – can be characterised as a clash between the catastrophic and the mundane. The potential finality of malignancy can be seen to overshadow the comparatively small trials and

tribulations of the everyday, yet these everyday challenges remain salient to the prospect of living-on. Veena Das's recent (2021) piece offers a useful way into considering this dynamic of the knowledge (here, of one's potential mortality) and the context within which that knowledge gains meaning (the everyday). Drawing on the philosopher Piergiorgio Donatelli's (2015) discussion of the fragility of the everyday that emerges between the possibilities of destruction and the promise of recovery, Das notes that there can be two possible routes:

The first route is that on which an extraordinary event of traumatic loss functions as both an event and a figure of thought. In contrast with (or parallel to) this view of life as vulnerable to catastrophic events, Donatelli draws attention to the kind of destruction that consists of small, recurring, repetitive crises that define everyday life itself or are grown within the everyday. Rather than taking these two routes as different ways of arriving at the everyday, I propose to look at the everyday and the catastrophic as mutually braided. (Das, 2021, pp.20-21)

Taking Das's consideration of the interwoven nature of the catastrophic and the mundane, here in relation to the mortal threat and daily annoyance of cancer, gives useful purchase on comprehending different scales of significance, particularly as it forces us to pay attention to how the catastrophic event of the dreaded diagnosis interacts with the iterative crisis of perpetual loss in cancer's disruption of everyday living. Positioning the monumental and the mundane as *braided* helps move us beyond the binary of significant/trivial, proposing instead an ongoing process of iterative *becoming* (see Blackman, 2008). Importantly, though, such processes of becoming happen within a context in which accelerating therapeutic innovation and the social norms around illness, affliction and care have meaningful import. As we explore below, both established and emerging moral practices that circulate around cancer powerfully shape the experience of *surviving-with* cancer in the precision era.

2.3. Morality, estrangement and surviving-with

As we, and other social scientists with an interest in cancer, have frequently noted elsewhere (e.g. Broom & Kenny, 2021a; Chattoo & Ahmad, 2008), *surviving-with* is not only a medical trajectory or illness experience, but also a distinctly moral practice. Often centred on ideas about perseverance and positivity (King, 2006; McCreddie et al., 2010), and even viewed as an illustration of one's moral character (e.g. Broom & Kenny, 2021a), the practice of *surviving-with* takes place against the normative backdrop of the 'good patient' (Steinberg, 2015). As Steinberg describes it: "... the phantasmatic 'good patient' embodies a distinctively neoliberal ethic of care—that is, body-affective imperatives of will, affect, and action—that constitutes cancer as an *imperative field* and in which an *imperative of estrangement* is a core dimension" (2015, p. 118). As she goes on to explain, there is a duplicity to this imperative field in which the cancer subject is called to certain kinds of affect and action, namely self-assertion, repudiation (of loss, grief etc) and distanciation (from the malignancy within one's body) while ignoring the various forms of estrangement that underpin all three. In particular, a) the denial of loss and b) the transference of agency in conforming to the normotic generalisability of treatment (adapted from Bollas's 1987 understanding of 'normotic illness') contribute two elements to this estrangement. But crucially for our argument here, there is a third form of estrangement – from time itself – that features centrally in the precision scene. As Steinberg points out, there exists a type of temporal estrangement "in which one repudiates the *now* in exchange for *later*, exchanges the habitation in one's present life for a phantasmatic futurity ... Indeed, phantasmatic futurity provides the rationale for present brutality" (2015, pp.133-134). In the case of precision therapies, though, this temporal bargain is undermined by the displacement of a disease-free 'later' by the promise, at best, of *surviving-with* cancer, in perpetuity (see also Jain, 2007). The moral work of surviving cancer, then, has been complicated

as precision innovations have extended survival time but without the promise of disease-free futurity.

The moral work of surviving-with cancer, and the particular forms of will, affect, and action that it demands are deeply interwoven with considerations of time – the pursuit of more time, 'spending' it well, 'enjoying' what remains and so on (Kenny et al., 2017). Increased survival time, though, has not been without considerable 'costs', in particular the economic costs of on-going treatment. While the cost of healthcare has always played an important part in the social dynamics of illness and care, precision innovations – and targeted cancer drugs, in particular – have increased the monetary costs of surviving-with cancer quite dramatically over the past decade alone (Tran & Zafar, 2018). Financing survival, whether individually or through government or insurance-based provision, thus occupies a central place in the moral work of surviving-with cancer, which mirrors many of the ideas of value and moral worth that characterise our current epoch. This cultural scene intersects with the allure of precision innovation – promising extraordinary opportunities while incurring extraordinary costs – and has become a dominant force underpinning the moralities of survivorship in the precision age. Once considered as an option, the pursuit of such novel treatments quickly becomes a moral duty – similar to the way in which, as Berlant notes, yielding (in this case to disease) becomes/became the antithesis of the practice of a 'good life' (Berlant, 2011). In a similar vein, Steinberg (2015) argues:

There is, first, an imperative 'will to live'. That is, we are presented with both a presumptive obligation and imperative to 'choose to live' and to be unwilling to compromise that [...]. The willingness to undergo treatment's 'cutting edge' takes on a talismanic power. What it promises to confer is not so much 'freedom from cancer', as it does moral standing [...]. [T]he popular and clinical imperatives of cancer patienthood collide and [...] are suggestive of the underlying social contract of late neoliberalism. [...] In this context, the social contract that offers moral standing as a stand in for, and a talisman of, survival, becomes an inspirational example and a transferable public duty. (pp.129-135)

And there is something else to the precision turn, and the way it inflects cancer survivorship. Its premise of tailoring of therapeutics specifically to the needs and characteristics of particular patients renders people's 'responses' to them very personal, too. The pain and cost of the present, in moral terms, is the practice of participation in innovation, and 'failing' such treatment – one that is in many respects tailor-made to them/their specific cancer – is in many respects worse than 'failing' standard treatment. In sum, the ontology of precision deepens the moralisation of treatment success.

Whilst evolving, the moral work of cancer in the precision era continues to demand particular forms of affect and action (routinely packaged in individualised terms as 'opportunities' to illustrate wilfulness, resilience, strength, tenacity) as part of the social contract of late neoliberalism. But how this is reconciled in the day-to-day lives of people surviving-with cancer in perpetuity remains opaque. Below, participants' diaries and reflections illuminate many of the (often disconnected) elements of the moral work of *surviving-with* cancer, including reflections on gratitude (and access to therapies), perseverance (in tolerating side effects for the sake of another) and luck (in 'discovering' cancer and in simply 'being alive').

3. Methods

3.1. Data collection and sample

The use of diaries as a means of collecting data is an established methodological tool (Elliott, 1997; Jones, 2000; Zimmerman & Wieder, 1977). While researcher journals have long been an accepted source of qualitative data for health research (Jacelon & Imperio, 2005; Jones, 2000), they are rarely used in the social sciences (though see Broom

et al., 2014, 2018, 2015; Broom & Tovey, 2008). The format of a solicited diary encourages the participant to focus on daily activities and upon reflections they value. Although diaries may lack the dialogical complexities and probing allowed in verbal communication, they also allow an examination of seemingly mundane day-to-day thoughts, processes and undulations (Elliott, 1997; Zimmerman & Wieder, 1977). This method has been used in feminist research to access the content of daily life for women and to transcend the *potential* artificiality and power dynamics of face-to-face interviews (see Hampsten, 1989). Despite the textual mode of diary-writing, writing on one's own, in one's own time, facilitates reflection on affective and embodied experiences, as demonstrated in the excerpts presented below. In preparing the diaries for analysis, we were careful to preserve participants' attempts to convey emphasis or emotion (e.g. use of capitals, underlining, punctuation and emojis). A significant benefit of personal diaries is the temporal insight they offer, allowing for flexibility and variation in the narratives presented (Meth, 2003). Incorporating diaries, alone or alongside interviews, thus facilitates better access to participants' temporally extended and (previously) 'absent' reflections (i.e. opportunities to document experiences without the researcher there), thereby improving the panoramic visibility of different dimensions of survivorship. Solicited diaries may also offer empowerment for participants. Indeed, our participants often commented that maintaining the diary was a useful experience, offering pause for reflection and expression of emotions (see also Meth, 2003).

This paper draws on solicited diaries and in-depth interviews, which constituted the patient/community-focused element of a qualitative research program into the contemporary experiences of cancer care and therapeutic innovation in the age of precision medicine (Broom & Kenny, 2021a; Kenny et al., 2021). Data collection took place in 2020 and 2021. Ethics approval was gained through the ethics committee of a large metropolitan hospital on the east coast of Australia. In an earlier phase of our research, we undertook 54 in-depth interviews with people living with cancer with a focus on their social experiences and reflections on receiving targeted and/or immunotherapies during the course of their

treatment. Of those we interviewed, we asked 27 people to complete a hard copy, paper-based diary over a period of one month (30 days), and to participate in a follow-up interview after the completion of the diary. In selecting people to take part in the diary study we aimed to capture some degree of spread according to cancer type, gender and age, although ultimately, we prioritised documenting insights of people currently receiving targeted therapies. Diary-keeping (for research and more broadly) has a cultural history deeply inflected by intersections of gender, class and race, which has methodological implications in terms of who participates in solicited diary studies (Kenten, 2010; Meth, 2003). While many themes explored through the diary questions are continuous with aims of the broader study, this article reports on data exclusively from the solicited diaries, and the interviews with the diarists.

Twenty-one participants completed and returned their diary (19 women; 2 men; aged 35–77 years). Some participants had (so far) received only targeted treatments, while others had also experienced chemotherapy, surgery and/or radiotherapy. Six participants either discontinued the diary, did not send the diary back, or died during the diary phase of the study. Each participant is identified here by participant code, cancer type and age bracket to preserve anonymity. Diaries were returned by mail, de-identified, and transcribed in full, and participants were informed and thanked via phone and email when we received the returned diary. On average, participants wrote 4731 words (ranging up to 16883 words). Fig. 1 shows the diary template and instructions, and Table 1 contains the diary questions which were posed every day over the course of a month.

3.2. Data analysis

The methodology for this project draws on the interpretive traditions within qualitative research. Data analysis was based on four questions adapted from Charmaz's approach to social analysis (1990): What is the basis of a particular experience, action, belief, relationship or structure? What do these assume implicitly or explicitly about particular subjects and relationships? Of what larger process is this action/belief a part?

Fig. 1. Diary template and instructions to participants.

Table 1

Diary questions, each repeated daily.

a. Could you describe how you are doing physically, emotionally and/or spiritually today?
b. Please describe anything of significance that happened today related to your cancer (e.g. medical consultation, self-care activities, discussion with partner/family or friends)
c. Could you write down any thoughts or experiences you've had today regarding your experience of treatment in terms of your day-to-day life? (e.g. costs and benefits, side effects, living with cancer, interactions with media or news, family/friends about treatment)
d. How has your treatment (i.e. chemotherapy/radiation, targeted therapy, and/or immunotherapy) affected your cancer experience and quality of life today? (e.g. quality of life, differences between treatment options, receiving care)
e. Please add any other comments that you may feel are important for us to understand your experience today

What are the implications of such actions/beliefs for particular actors/institutional forms? We approached the analysis of diaries thematically, systematically reading through each diary, writing notes, discussing ideas with colleagues and noting emerging patterns within the data collected. The analysis was driven by Authors AB, KK, LWV and AP who read through the diaries several times to identify key themes, test their validity and develop them further. We each sought to retain the complexity of the respondents' experiences, documenting atypical cases, conflicts, and contradictions within the data. Once emerging themes were established, we searched the diaries for related comments, employing constant comparison to develop or complicate these themes further. We then returned to interview data for comments that could further illuminate the diary themes. The final step involved revisiting the literature and seeking out conceptual tools to make sense of the patterns that had emerged from the data.

4. Results

Across the diaries and interviews, participants who were receiving precision cancer therapies articulated a variety of imperatives of surviving-with cancer – in terms of affective orientation, bodily action and temporal projection. Central here were the profession of good fortune that, despite their cancer diagnosis, they were the lucky recipients of the fruits of the precision turn. Yet the notion of 'success' needed recalibration as cure seemed to recede from the realm of possibility and was replaced by forms of chronicity or *surviving-with* cancer.

4.1. The lucky (chronic) subjects of precision

Most of the diarists enjoyed access to targeted therapies in their specific disease contexts, where even a decade ago, no such options existed. This opportunity elicited strong professions of gratitude and a sense of good fortune, for example, to be living in a time and place in which novel therapeutics are available and to some extent subsidised by the public healthcare system. Several participants had accessed treatments via trials or compassionate provisions by pharmaceutical companies, or were involved in advocacy around wider access to precision therapeutics. Within the "moral cosmology" of cancer, the narrative/normative work of luck is complex (Broom & Kenny, 2021b), perhaps never more so than at the cutting edge of medical innovation, where access to novel treatments is inequitably distributed (e.g. geographically, financially, across cancer types) and the results uncertain.

Beyond hopes of a better prognosis, a common sentiment, as we see below, was of 'luck', of feeling grateful for having the opportunity to receive *anything* other than the traditional triad of chemo/radiation/surgery. However, this gratitude existed in tension with the day-to-day struggles of surviving-with cancer – between the luck of having avoided the catastrophic (mortality) and the small, daily crises involved in managing the 'mundane' (side-effects/symptoms). Such tensions took centre stage when everyday challenges escalated to occupy the affective

scene:

Day 1: Today I awoke with a feeling of anxiety ... my mind is doing somersaults ... Targeted therapy has given me so much freedom in that I have to this point only a few side effects that are fairly manageable. Quality of life is excellent. I take four capsules in the morning and four at night with food. Compared to chemo and the side-effects that we are familiar with, I'm so grateful to have the opportunity to use Alectinib ... Without targeted therapy my prognosis would be extremely poor.

Day 2: Overcome by tiredness at about 8pm. Husband helped with dinner – so thankful for our very loving relationship and his understanding – yet I know he is struggling with thoughts of the future. My emotions overwhelm me. I cry – we cry together. ... Taking the treatment is not a problem. [but] side-effects can be worrisome ... a sense of grief or loss of health in other organs ..., however the alternative [death] is worse!!

Day 3: ... appointment with GP. Oncologist only seems to address the cancer. I need to follow up with GP about side-effects.

Day 5: [People think] – "cancer – what else do you expect?!" – "side-effects will come but that's part of it – it'll only be a few years to put up with"! ... but the extra help that I'd expected [for the side-effects] didn't come – wasn't offered – I needed to chase it down.

Day 9: Every day I think "my treatment is so straightforward, it gives me a sense of having a 'chronic illness' rather than a 'terminal illness'". I wish that all cancer patients could have access to such amazing treatment options.

Day 18: Very aware of time moving extremely quickly. I guess it comes with being given a prognosis of around four years although I feel that during this time medical research will have found a better treatment that will cause ALK positive to be regarded as a chronic disease. [Living with lung cancer, female, 50–60]

As touched on above, and in other participant diaries, there was an evolving mix of exuberance and apprehension – often palpable relief of not being subject to cytotoxic therapies, but in turn, a vacuum of comprehension regarding the need for ongoing care and support for (often unknown) ramifications of targeted therapies. Given the enduring spectre of the catastrophic (in the not-so-distant past of cancer diagnosis), concerns about symptoms and side-effects paled in comparative significance. Yet they were not entirely erased by the clinical focus on steady disease progression. As the same participant noted in their initial interview:

I think it's so amazing that I can have this drug and not have to have chemo. Because in days gone by, that would have been the only option. I think it was 2013 possibly that Alectinib was first used. I'm not sure.

[Later, in the same interview]

I guess it doesn't feel quite as exciting as if, "Oh hey, you're in remission, let's forget about the treatment now." It's like, "Righto, this isn't remission, this is just that we're keeping the cancer at bay at the moment. And so when I told my family, everybody was just so excited, but I hated to break the news that it's not really [...] I'd rather be on it than chemo or anything else [...] we all know that this Alectinib is like a magic. They're magic beans. I take four in the morning and four in the evening and I call them my magic beans.

Many of the diarists found themselves caught somewhere between the divergent paths towards either 'cure' or terminality/mortality. While this new zone provides respite from the immediacy of cancer as a catastrophic diagnosis/mortal threat, it cannot completely ameliorate its threat through the safety of complete remission. Instead of being able to 'forget', or progress, there is new labour – to contend with the daily presence of cancer and the new challenges of managing both symptoms and side effects, and cultural expectations that no longer align with the

increasingly chronic experience of cancer.

4.2. Novelty, normalcy and estrangement

The steady rise of long-term subjects of cancer has transposed concerns from the chronic disease context to an oncological context where they have, until now, been largely absent. In many contexts, a return to everyday life *with*-cancer; existing between death and cure as terminally ill but not imminently dying. Diarists often reflected on their struggles around (attempts at) achieving 'normal' in this zone between the previously 'normal' trajectories towards complete remission or proximal terminality. Here, participants experienced the affective disorientation of their attempts to achieve a sense of normalcy amidst novel disease status (e.g. 'keeping it at bay' rather than 'progressing' or 'remission') and the lack of clear anticipated outcome. The biophysical successes of targeted therapies were thus not easily translatable to the social. Survivorship concerns (e.g. costs of ongoing care, incapacity to work, lack of willingness of others to provide longer-term informal care, and so on) often overlaid the sense of therapeutic success, further destabilising participants' attempts to achieve some semblance of normalcy outside of cancer contexts and inserting, instead, an omnipresent sense of *difference*:

Day 1: Try not to think about things too much. Spoke to my oncologist on Monday, the 22/6, regarding pain & was told to wait till I see him on the 3rd of August. Hope I'm not dead by then. Just kidding ... Day-to-day costs of caring for someone with cancer is my biggest worry. Who will care for me when I can't care for myself. This is a daily worry for me as my partner would not be able to. Cancer support groups are my GO TO. Not the medical professionals. They are never available. Day 5: ... I need something to believe in Brought my Daughter a Gift, I worry so much about leaving her behind. She only has me. My Son won't notice I'm gone, well not like my daughter anyway. This makes me SAD. Day 6: ... Interactions with friend: it's different now. Friends try to understand what it's like living with Cancer, but they don't understand it's not their fault ... Catching up with Old Friends was a real treat ... But you are not just one of the girls anymore you're different. How many more birthdays will I have? Will I be able to celebrate with all my friends for much longer? Your friends are a little lost e.g. don't know what to say ... watching what they say ... it is just Different. [Living with neuroendocrine cancer, female, 50–60]

These excerpts, and other diarists' accounts, raise the very real, but often seemingly peripheral concerns of ongoing survival, even in contexts of spectacular gains in disease outcomes. What we see here shares much coherence with the chronicity literature more broadly (e.g. Charmaz, 2020; Monaghan & Gabe, 2019), articulating such issues as spoiled identity, stigma and the sense of affective distance from one's previous lifeworld. The diarists' accounts of everyday interactions with friends and family illustrate the importance of viewing survivorship practices in relational terms. Surviving-with cancer in an ongoing way, achieved through the therapeutic successes of the precision turn, inserts affective distance/difference into many everyday interactions. While disease successes are recognised and embraced, the enduring relations of survivorship are pervasive. And these are not insignificant relations nor disconnected from the broader cultural scene. As Charmaz (2020) notes, drawing on Zola's classic work on the moralities of chronic illness and disability, the cultural conditions of advanced capitalism valorise individual responsibility, self-sufficiency, autonomy and independence. Such principles often clash with challenges of living-with disease – with these challenges expanding and increasing the longer one lives with illness/disability. Existing pervasive cultural values, as fraught as they are, intersect with enduring problems of credibility/validity in chronic illnesses more broadly (see Charmaz, 2020 on neoliberalism and chronicity). 'Success' (e.g. in keeping cancer 'at bay', as described above) comes at a (cultural/affective) price displacing 'normalcy' both

inter-relationally and inter-temporally, as well. Thus, the experience of time, and the place of disease, treatment, and side effects within it, can become estranging from cultural expectations of typical cancer trajectories. But this estrangement is quickly displaced by the gratitude and perseverance that are continuous with earlier tropes:

I guess I'd have to say it [targeted therapy] made the experience of living with cancer harder because of the side effects, and they went on for so long. So, from starting chemo to finishing Herceptin and Perjeta was nearly a year. Well, finishing the symptoms from it would have been more than a year-and-a-half, which is a long time to slow down and lie on the couch. [...] So it certainly made that aspect harder, but I believe it's made my survival chances better, and that's definitely worth it for me. I'm not ready to die. I could've just said, "No, that sounds horrible. I'm not going to do that." I could have said that about any of it. I didn't. [Living with breast cancer, female, 50–60, second interview]

The emerging tension between the enduring conception of cancer in the cultural imaginary and the novel therapeutic regimens was a regular topic of reflection. In particular, how outward appearances of (relative) wellness clashed with the internal lifeworld of living-with disease. The reduction in the 'usual' signifiers of a life with cancer (such as hair loss) disrupted the social reception (and recognition) of illness. This routinely created a dilemma: 'go along with' the impression of 'good' health whilst being (pre)occupied with the spectre of death, or engage with the problematic impressions of others, which were viewed as increasingly out-of-step with the character of living with disease in the precision era (Gold, 1983; Tseëlon, 1992; see also; Goffman, 1978). Instead of inserting an uncomfortable *difference* into interpersonal relations, the lack of traditional signifiers of cancer imposed an overlay of *normalcy* that undermined the expression and experience of surviving-with cancer:

Day 1: Living with cancer is a doubled-edged sword. My targeted treatment means [there are] minimal [visible] side effects, e.g. dry skin, some red rashes on my legs, nail breakage but these are so minimal that many others see me just as physically fit as I was pre-diagnosis. ... I appear to be totally "normal" to those around me. Day 2: ... People see me as so well that my cancer diagnosis does not enter conversation. Still underlying thoughts of my cancer diagnosis "pop-up" in my thoughts, regularly. It just happens – I think it and then the thought goes away ... My targeted therapy treatment "Osimertinib", has minimal to no effect on my quality of life today. That drug is really a "lifesaver" ... I still have thoughts of my future and longevity of life with my lung cancer diagnosis. I know there are other treatments when my targeted drug ceases working – most likely "combo immunotherapies/chemo." ... But realistically, I don't view my cancer as a "chronic disease" as even with new advances in medications, et cetera I have my own thoughts on how long I have to live. This is not imminent in the present future, but it's inevitable to shorten my lifespan. I do have anxious thoughts at times that when the "Osimertinib" stops working ... Day 20: Still thoughts of my cancer diagnosis pop-up My current drug works wonderfully, but I know it will stop working, probably in a few years, and I'll have progression of my lung cancer. Worst of all the nerve pain will come back & I know the powerful medications don't work. [Living with lung cancer, female, 60–70]

In instances like the one articulated by the participant above, the normalcy assumed by others is incongruent with the pervasiveness of thoughts about cancer and its effect on one's future. In addition, there is a precarity imposed by the always-tentative success of targeted therapies, which may, in the future, 'cease working'. These tensions illustrate lags in comprehension and meaning-making in the context of swiftly changing therapeutics, symptoms, and side-effects, variously disrupting participants' sense of normalcy/difference.

4.3. 'Boring' symptoms and other unimportant things

The diarists, at times, reflected on the performative character of their writings for our study, including, what they expected us as researchers to 'want' them to record. This dynamic both limited what might have been recorded, but also, somewhat paradoxically, provided us insight into what was being experienced behind the scenes. We were also able to probe these dynamics within the subsequent follow-up interviews. In particular, participants reflected on dilemmas of *significance*, which were pervasive within this study, and the centrality of disease-status therein. In line with [Charmaz's \(1983\)](#) articulation of the loss of 'mundane' capacities and questioning of the value of care and the significance of suffering, diary participants similarly experienced tensions between the seemingly small or boring problems (e.g. side effects) and their broader, more significant meanings (e.g. 'gloom and pessimism', below). 'Boring' symptoms articulate how the catastrophic (cancer, a life threatened) and the mundane (everyday suffering and capacities for enacting *and* feeling normality) are mutually braided. Within this, dominant tropes of cancer heroics, so valorised and entrenched in the public imaginary, clash with lived experience of surviving-with cancer in an ongoing way. Very often, the story of therapeutic success, and of disease kept in check, was *also* a story of uncertainty about the significance of suffering and doubts about the salience of accounts of chronicity and disability therein:

Day 14: I do not know whether people see it as unfair that I have survived so long with cancer. I do appreciate my longevity but I hope when I do pass away people won't say I fought a battle as I know I have not done anything special. I have just gone along with the treatments offered as each situation has arisen.

Day 15: if/when I don't write about those things - side effects of treatment - it's not because they're not there. They are always there. Sometimes I can't be bothered, sometimes it feels to tedious, sometimes I just don't want to think about it, or bore you with it. But it's always there.

Day 23: Still, it's just a daily thing [ongoing side-effects]. Today it felt more of a battle. My body didn't want to do anything and then I found my motivation draining away. Just fatigue and numb, sensitive feet ... Why am I writing all this? Maybe it accounts for my sudden gloom & pessimism. Maybe I'm frustrated by the lack of info and knowledge about [targeted drug] Perjeta particularly. There's no-one to ask, either. I don't see the oncologist for another 3 months - or anyone medical, really ... [Living with breast cancer, female, 50-60]

The uncertainty around the significance of 'those things - side effects of treatment', yet their pervasiveness in daily life could be an estranging or alienating dynamic, leaving a sense of loneliness (above) or, as one participant reflected on in an interview, being an imposter:

That's this fine line that you live in all the time. It's like you're almost an imposter. I don't know if anybody has said that. But you do feel like a little bit of an imposter and you wonder who is this person that looks back at you. Because there's so many things going on. [Living with lung cancer, female, 30-40, second interview]

In part, this sense of being an imposter originated from the dissonance between experiences of traditional cytotoxic therapies and novel precision therapeutics, with new targeted therapies seen to be much less 'vile' than chemotherapy, for example:

It [targeted therapy] doesn't smash every single thing in your body. After five months of chemotherapy, I felt totally poisoned. Like every part of me ... And about halfway through chemo I was kind of thinking about my body just going, "What parts are left that are part of me?" And there was a bit, but about two months later I was going, "What part of my body has not been affected by chemo?" ... Every other single part of everything about me had been smashed. Whereas this [therapy], yes, it upsets my fingernails, it upsets my skin, and it upset my eyelashes still for quite a while, but they

seem to be growing back now. But, realistically, this is nowhere near that vile. [Living with breast cancer, female, 50-60, first interview]

This comparative evaluation of the degree and significance of suffering could create considerable tensions within individual participants' reflections, as illustrated by the following diarist who reflected on the palpable importance of loss of everyday life, and the interwoven emotions of gratitude, frustration and sadness:

Day 3: ... Difficult undoing a button, holding egg, dropped knife in cutlery drawer. These things make me disheartened. Can make me have a sad day, weighing deeply on me ... Can't eat onions, cauliflower, corn, peas, deep fried food, oil, cream, full cream milk ... peanut butter.

Day 6: All this effort for 80-90% benefit but you only remember the negative; not being able to do normal life.

Day 10: I am SUPER GRATEFUL I am alive. When you first hear cancer diagnosis, you think you are taking your next and last breath in the doctors room. But MAN! ... yeah those 'highlights' [side effects] were not in the brochure. BUT BUT I am here for my son



Day 21: Soul destroying when treatment impacts everyday things

Day 26: Just over it. Wish I could step away for 24 hours ... NO THINKING OF MY SON FACING THE FUTURE WITHOUT ME Targeted therapy - side effects - treatment - decreases problems but still exists. DEPRESSING - you try and try but still unsuccessful. [Living with lung cancer, female, 40-50]

Despite the considerable uncertainty about the significance of side effects, and the resulting estrangement in participants' experiences and narrations of surviving-with cancer, the imperative to persist and preserve - so familiar from traditional cancer tropes - remained nonetheless:

And if I don't take this medication twice a day forever, it will come back, and there's no two ways about it. So, I know that and I just go, "Well, suck it up." [Living with lung cancer, female, 50-60, second interview]

While the new terrain of precision therapies has introduced a wide range of novel subjects, and relational and temporal dynamics, these do not exist as completely separate from traditional configurations of cancer in the cultural imaginary. Rather, these new tensions exist alongside enduring cultural imperatives that continue to determine what is, ultimately, most important: survival at any cost.

5. Discussion

The cause for celebration of disease reduction or remission seems obvious in the current scene of cancer. And in fact, critique in such contexts is almost taboo. Gratitude and serendipity are pervasive in the narrative construction of disease and illness, and such is the normative space within which living-with emerges. But there is a facile character to such narratives, one that is usefully unravelled by individual accounts of living-with cancer in the precision era, as illustrated within the diaries and the interviews. Such perspectives give pause to recentre the subject (suffering/choice), attend to the relational (caring/care), and consider the temporal disorder of the present in *being* perpetually in treatment. That is, to see life in this context as a tussle between tolerability, loss and luck at being intrepid subjects of the precision epoch. A careful balance between luck and loss, life and death - a balance which often tips over time - with the un/even progression of loss of past identities and capacities yet suspension from immediate mortality in living-with cancer across time.

Backstage, the 'boring' life of the mundane coexists with the constant assessment of the *value of survival*, the *ethics of refusal*, and the *excitement of opportunity*. Suffering takes centre stage framed, often, against the horrors of traditional cancer therapies, which thereby entices a sense of luck and inspires fortitude. But in turn, the precision arc toward tailoring

and personalising deepens the moralities of *investment in the therapeutic present*. Steinberg (2015) offers a useful intervention in this scene, focused on the imperative of future possibility, versus the ‘now’:

Imperative estrangement in the wake of cancer also disallows consideration of the quality of now. There is no place in this imaginary, for example, for the choice of a treatment-free now which will be short – as distinct from a treatment-bound now which may be unbearable, done for the sake of more time, and which may be (and in some cases will almost certainly be) short anyway. There is no room for the acknowledgement that life in prognosis is also a form of now. (p.134)

Following Steinberg, there is value in asking such critical questions, in the precision context in particular, and examining how the answers wax and wane over time and context. In particular, what is allowed and disallowed, whether subtle or explicit. And, what is valued, and how this makes easy/difficult certain choices or positions, in the steady march of living-with. A consistent response, and perhaps the most vital lesson from this work, was the importance of taking seriously the transformation of the ‘social contract’ of cancer in the context of precision therapies. With a sense of illness subjectivities as evolving, including a new choreography of the therapeutic relationship, new forms of *significance* circulate (innovation potential, future breakthroughs, current struggles, mundane side-effects) and thus new moral, ethical and interpersonal tussles emerge.

As we see in many other spheres of disease, ‘unfit’ patients emerge, new practices of ‘waiting’ (however futile) develop, and moral exchanges evolve and inflect affliction and care. Moreover, because precision and targeted treatments convey to participants that they were tailored specifically to them, and not to an anonymous standard patient (Tutton, 2016), ‘failing’ treatment was also more personal. Precision therapies – at least where they are available and accessible – demand new forms of composure and ask for different types of *work* for its subjects. To work *hard* against forms of embodied unravelling, despite the (sometimes) impossibility of such demands. This everyday life in the precision epoch deserves attention, in terms of its normative bases and the new forms of suffering induced between the tragedy of lost certainty and the immense possibilities for life and longevity.

What is evident in this work is that the stretching of material/bio-physical life is subsumed (or, indeed, occupied by) a set of tensions around value, dependencies, and autonomy. A life with cancer, at least for those who narrate it here, is situated within new spaces of remission, speculative futures/innovation, and ideas about intrepidity. It is, no longer – even if this has indeed been in slow decline for decades – infused with the heroics of life or death. Or simply beating or overcoming disease. Rather, it is centred on being with.

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