

The social meanings of choice in living-with advanced breast cancer

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Abstract

Individual choice is valorised as a core social value; yet the necessity and desirability of making choices takes on new significance for people living with incurable cancer who are required to make often difficult decisions about treatment, care and family life, amidst considerable vulnerability and precariousness. There has been comparatively little exploration of how choice is negotiated and made meaningful under the spectre of incurability and a contracted future. In this paper, drawing on multiple qualitative interviews with 38 women with metastatic breast cancer, we explore how they experience and give meaning to choice in relation to their health (and beyond) in their daily lives. Our analysis highlights that while exercising choice was sometimes a concealed or silent pursuit, choice was always a socially negotiated and temporally unfolding process, nested within relational and interpersonal dynamics. Choices were also often constrained, even foreclosed, due to situational and relational dynamics. Yet even in the absence of choice, the idea of choice-as-control was discursively embraced by women. We argue that greater attention is needed to the affective, temporal and economic dimensions of choice, and how treatment decisions are asymmetrically structured when considered within the normative context of cancer.

Key words: Choice; decisions; breast cancer; incurability; qualitative research; relationality

Word count: 8980

Introduction

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2 The notion of choice is a pervasive feature of late-modern living. Popular imaginaries position
3 people as individual, rational actors expected to choose from among a range of possible options
4 in navigating their daily lives in desired directions (Adams, 2003; Clarke et al., 2006; Giddens,
5 1994; Schwartz, 2018). The necessity and desirability of choice takes on new significance for
6 individuals living with advanced cancer, which requires a range of difficult choices to be made
7 – including decisions about treatment and care, work and family life (Fotaki, 2010; 2013). And
8 all amidst new experiences of vulnerability, precariousness and unpredictability brought on by
9 the (progressing) disease (Author, 2019). Yet, the imperative *to choose* is enshrined in
10 healthcare through best-practice models of ‘patient choice’ and ‘shared decision-making’
11 (Charles et al., 1999). Such ideals are embedded in cancer care policies as key mechanisms
12 through which to achieve person-centred care and patient ‘empowerment’. Scholars have
13 critiqued the logic of patient choice for its latent responsabilisation and deflection of liability
14 away from health professionals and health systems onto individual patients, instead (Bell,
15 2016; Lupton, 1997). Nevertheless, it is patients who increasingly experience the necessity to
16 choose and bear the consequences of those choices – good, bad or otherwise (Mol, 2008).
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21 Previous scholarship has pointed out that the ideal of patient choice foregrounds the seemingly
22 autonomous individual and obscures how patients are differently situated such that the capacity
23 to choose is unequally distributed across society (Collyer et al., 2015). Furthermore, in
24 navigating increasingly complex therapeutic landscapes, patients (and health professionals)
25 often confront decisions about their care amidst considerable ambiguity (Llewellyn et al.,
26 2018). The ever-increasing commodification of care within both privatised and state-provided
27 healthcare systems in countries such as the United Kingdom, the United States, and Australia,
28 and growing structural inequalities that inflect healthcare provision, seriously undermine the
29 ideal of unconstrained choice (Collyer and Willis, 2019; Coulter, 2010; Van Natta et al., 2018).
30 Treatment advances have improved clinical outcomes for some advanced cancer patients
31 (namely those with access and/or resources) (Hodi et al., 2010). But for others, expanding
32 therapeutic options and clinical pathways mean new challenges of choice, especially when
33 treatments are self-funded, based on incomplete or inconclusive evidence, and resources are
34 constrained (Say et al., 2006). As such, a multiplicity of choices may call into question the
35 pursuit of (sometimes indefinite) treatment vs attempts to live *well* with cancer in daily life,
36 juggling between the quest for longevity and survival and maintaining quality of life
37 (Baszangar, 2012; Fernandez Lynch et al., 2020). While evidence for different treatment
38 options is often ambiguous, even if it were more definitive, the ‘choice’ to pursue or forgo
39 treatment unavoidably involves a range of affective, cultural and embodied dimensions and
40 can rarely be dictated by ‘rational’ knowledge, alone (Bell, 2016; Coulter, 2010; Petersen et
41 al., 2017; Sinding et al., 2010). Additionally, for those with incurable cancer, available
42 treatment options may be limited, while the future they might ideally choose (e.g., of a cancer-
43 free life) is often inaccessible (Bell and Ristovski-Slijepcevic, 2011).
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50 A significant corpus of sociological and clinical research is devoted to whether choice is
51 important to people, what choices matter to them, and the factors and circumstances that shape
52 the decisions that patients and health professionals make (Coulter, 2010; Fotaki, 2008; 2013;
53 Schwartz, 2018). Mobilised under the rubrics of patient preference, informed choice, or shared
54 decision-making, such work tends to describe the aggregated preferences of patients and the
55 mechanisms of how decisions are made. Yet, there remains limited knowledge about the
56 collective *meanings* of choice in the context of illness, affliction and care. This includes how
57 choices are negotiated over time, under the spectre of incurability, and a contracted future (for
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1 exception see Author, 2017). Such concerns are particularly acute for women with incurable
2 breast cancer. Also known as metastatic or stage IV cancer, women living with this type of
3 breast cancer will typically have lifelong treatment and experience considerable uncertainty
4 about their health and longevity. Though there are numerous therapeutic options, including
5 hormone therapy, targeted therapy, chemotherapy and radiotherapy, these vary depending on
6 the specific cancer sub-type and the extent of its spread. The complexity of the disease and its
7 evolving treatment create unique challenges for women as they navigate choices about
8 treatment and care (see Bell & Ristovski-Slijepcevic, 2011; Author 2016). These include
9 considerations about treatment efficacy, side-effects, and the impact on daily life, which can
10 vary considerably depending on women's age at diagnosis (Rocque et al., 2019). Here, drawing
11 on conceptualisations of empowerment, responsibility, autonomy and relationality, we aim to
12 capture the multiple (and shifting) personal and cultural meanings of choice as articulated by
13 women with incurable breast cancer including how they understand and experience choice in
14 relation to health (and beyond) in their everyday lives.
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17 **Choice and the empowerment/responsibilisation dialectic**

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20 A cultural emphasis on 'agentic' choice by empowered patients has taken on
21 increased prominence over recent years, especially in (economically) wealthy industrialised
22 countries. But its historical origins date back, at least, to the women's health movement of the
23 1970s and 1980s, which sought to reclaim autonomy, knowledge and decisions
24 about women's bodies from the (still male-dominated) medical profession (e.g., Tuana,
25 2006). This movement coincided with the rise in medical consumerism (Reeder, 1972;
26 Timmermans and Oh, 2010) and can be tied to the changing structure of healthcare systems,
27 especially within the United States. The market now features prominently in the delivery of
28 health services across a range of wealthy industrialised contexts, including those with
29 nationalised single-payer healthcare systems (e.g., the NHS) (Collyer and Willis, 2019;
30 Greener, 2009; Olsen, et al. 1976).
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35 At the same time, the proliferation of patient health movements around causes ranging from
36 breast cancer to preterm babies to opposition to vaccines (Epstein, 2008) has also lent a popular
37 base to calls for patient empowerment, helping to install patient choice as a driving imperative
38 within health systems across the United States, United Kingdom, Canada, Australia and
39 elsewhere (Greener, 2009; Author, 2020). Yet scholars (albeit within different empirical areas)
40 have warned of the dark side of 'empowerment' logics, of which notions of choice play a key
41 role. Calls to 'empower' (formerly marginalised) subjects risks imposing the kind
42 of responsabilisation that has been identified and critiqued for its individualising consequences
43 (Beck, 1992; Cruikshank, 1999). In health, the intertwined notions of patient empowerment
44 and choice have been closely linked with self-responsibility: namely, the imperative that
45 patients make the 'right choices' in terms of lifestyle, self-advocacy, and treatment options
46 (Bell, 2016). In response, critiques of conceptualisations of patients as rational consumers in a
47 supposedly free healthcare market have emerged, noting that patients/persons rarely have
48 opportunities to choose 'freely' between treatment options and care providers as they would
49 with some other commodities (Van Natta et al., 2018). Moreover, treatment decisions are
50 inevitably constrained by relational dynamics, considerations of time, and financial resources
51 (Sinding et al. 2010). Like all choices, they are shaped by personal and collective dispositions
52 and structural positions (Bourdieu, 1984; Collyer et al., 2015). Nevertheless, the unconstrained,
53 rational patient deliberating over medically defined risks and outcomes persists within
54 healthcare discourses and models of patient-centred care and shared decision-making (Clark et
55 al., 2004). How choice is conceptualised, mobilised and made meaningful in people's everyday
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1 lives as they attempt to navigate their way through illness, affliction, relationships and care,
2 remains underexplored.

3 **Situating choice within care, society and everyday life**

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5 Concurrent to movements towards consumerism in healthcare has been the increasing focus in
6 bioethics' discourse on individual patient choice, shaped by founding principles such as respect
7 for autonomy (Agledahl et al., 2011; Beauchamp and Childress, 2009). However, the focus on
8 autonomous choice have been widely critiqued, as not able to capture the moral facets of
9 making healthcare choices, and the complex realities of people's lives (Callahan, 2003;
10 Drought and Koenig, 2002; Holm, 1995). Feminist philosophers advanced the concept of
11 relational autonomy as an attempt to better account for the situatedness of decision-making and
12 embrace the idea of collective decision-making (e.g., MacDonald, 2007; Mackenzie and
13 Stoljar, 2000; O'Neill, 2002; Oshana, 2016; Shih et al., 2018). These scholars argue that people
14 are always socially embedded in a network of others, and values such as interdependence and
15 care for others play an important role in shaping people's decisions (Held, 1993; 2006).
16 Similarly, Mol (2008) argues that the logic of patient choice can act as an obstacle to the
17 enactment of a logic of care, in which healthcare unfolds in negotiation with the specificities
18 of the person's lived experiences as a central focus. For Mol it is *how* people interact with
19 choice that is of interest, including the normativities, affective connections, inter-relationships,
20 and temporalities that influence how people come to understand and make decisions.
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26 Previous work has also shown how people can 'drift' towards certain decisions, particularly in
27 situations of ambiguity (where there is no obvious or optimal option) because of what is
28 socially valued or expected (Schwarz, 2018). Options for cancer treatment provide a poignant
29 example, where certain courses of action (e.g., treatment options in pursuit of longevity) are
30 **valorised over others** (Charles et al., 1998). Such choices (e.g., to persist, to persevere, to
31 'battle') fulfil relational and gendered roles and align with broader cultural norms within and
32 outside cancer (Sointu, 2006). Collective feelings of optimism and positivity can contribute to
33 normative expectations on patients living with advanced cancer, constraining or silencing
34 options that exist outside of frameworks that emphasis the pursuit of active treatment and
35 survival (Author, 2019; see also Ehrenreich, 2010; Segal, 2012). Patients may choose to endure
36 treatment for others, with active treatment (rather than 'doing nothing') construed as the only
37 course of action (Charles et al., 1998; Steinberg et al., 2015).
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42 Women's experiences of making decisions, especially how it relates to caregiving, and their
43 sense of interpersonal obligation while living with cancer have also been explored. Bell and
44 Ristovski-Slijepcevic (2011) revealed some of the moral dynamics of mothering while living
45 with incurable cancer, arguing that wider expectations related to mothering as altruistic and
46 self-sacrificial placed pressures on women to make decisions that were in the interests of their
47 children and partners, putting the needs of others ahead of their own (Hausegger, 2005). Such
48 accounts also reveal the discordance between patient empowerment tropes within the cancer
49 survivorship and self-help literature (e.g., living with cancer as a time to focus on self-care and
50 reinvention) vis-à-vis the lived realities for women with incurable cancer (Ehrenreich, 2010;
51 Ristovski-Slijepcevic, 2013; **Sinding et al., 2002**; Sontag, 2001; Author, 2016). In the results
52 that follow, we further illustrate some of the *challenges of choice* for women living with
53 incurable breast cancer. We show how, in this context, decision-making proceeds not in an
54 autonomous, individual vacuum, but within the multi-folded contours of the complicated
55 terrains of women's daily lives. In doing so, we highlight the disconnects, dissonances and
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discomforts that emerge between the ideals upheld in cancer survivorship and bioethics discourses and the social and relational realities for women living with incurable cancer.

Methods

Data is drawn from multiple semi-structured interviews with 38 Australian women living with metastatic breast cancer; defined as having spread to another part of the body, such as the liver, brain, bones or lungs. Interviews were conducted as part of a larger research project which explored women's experiences of incurable breast cancer and cancer care, and the experiences of health professionals providing care to this group of women. Ethics approval was granted from a university human research ethics committee.

Purposive sampling and a community recruitment strategy were used to include women with diverse experiences of cancer and cancer care, including those living in metropolitan and regional areas across Australia, those who had been living with metastatic disease for different periods of time, who had experienced different treatment types, and healthcare settings (e.g., public and private, clinic and hospital-based). Within the Australian healthcare system, there is a mix of publicly and privately funded and provided care for cancer patients. Women with metastatic breast cancer can access free or subsidised medical and hospital care and treatment is provided to all citizens via a universal healthcare system, Medicare. Additionally, individuals can choose to access some health services privately, using private health insurance. Recruitment was via flyers, advertisements and presentations to cancer support groups, cancer care and breast cancer organisations and peak bodies, and a cancer wellness centre providing complementary therapies to support people with cancer; direct recruitment via clinicians and community-care workers; and snowball recruitment through women who had already participated. This ensured that a diverse range of women were invited to participate, including women who may not be engaged with care professionals in formal healthcare settings. The recruitment materials were aimed at women who were 18 years or older who had been diagnosed with metastatic breast cancer. Participants who expressed interest in the study were provided with an information sheet and consent form outlining the purpose of the study and what participation involved. They were then contacted via phone to schedule a convenient time for an interview.

In total, 38 women aged 36-74 (mean 57.3, median 57.5) participated in the study. They included women with metastases in the bone (25), lung (15), liver (14) and brain (6). Our sample included participants across a variety of ages, length of time since diagnosis (<1-23 years), and educational attainment. Despite efforts to attract participants from diverse cultural backgrounds, most participants were Australian born and of European descent. Nine participants were receiving disability or other financial assistance and/or living in areas of high social disadvantage. Eighteen women received care in the private health system, 14 women received care in the public health system, and five used a mix of public and private health services. Most were primarily receiving care from their medical oncologist, and some were also using palliative care services. Three participants were not receiving any biomedical treatment at the time of their interview. While most women were engaged with biomedical treatment and care, half were also using some form of complementary medicine or therapy (such as acupuncture, Chinese traditional medicine, naturopathy, medicinal marijuana, or art therapy).

After written informed consent was obtained, an interview was conducted either face-to-face in a location convenient to the participant (e.g., the participant's home) or over the phone (e.g., if a participant lived in a regional area). Where possible, women were interviewed on another

1 two occasions during a 12-month period, to capture the interlinked temporal, affective and
2 relational facets of living with incurable cancer and facilitate rapport building. Four women
3 participated in only one or two interviews, due to ill health. An interview guide was created
4 with input from a metastatic breast cancer consumer, and included questions about women's
5 experiences of cancer, the strategies they used to manage their health, and their familial, social
6 and therapeutic relationships. Interviews were conducted by one author between August 2017
7 and January 2020, were between 30 minutes and two hours duration and were digitally
8 recorded and transcribed in full. Pseudonyms are used to preserve anonymity.
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10 A constructionist approach to thematic analysis (Braun and Clarke, 2006) was used to explore
11 patterns in women's experiences of making decisions, and the meaning they gave to these
12 experiences. First, interview transcripts were read and reread to organise qualitative data into
13 descriptive categories related to 'choice' and 'decision-making' by one author. Data were then
14 examined, and emergent patterns related to women's accounts of their process of making
15 choices, how they constructed choice and the meanings they gave to the choices described.
16 Three authors then examined how experiences and understandings of choice were shaped by
17 values, emotions, illness experiences, and social interactions. Attention was given to how the
18 interviewer participated in the construction of particular narratives within the context of each
19 interview (reflexivity). Themes that were identified in the data were developed and compared
20 across transcripts to identify differences (Green and Thorogood, 2018). After gaining a sense
21 of key themes, we returned to the relevant literature to make sense of emerging findings.
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26 Findings

27 Overview

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31 Participants' accounts revealed how choice was deeply situated within the daily undulations of
32 life both within, but also extending far beyond, the specificities of cancer. Some decisions were
33 framed as personal, even in situations where women described few alternatives or where they
34 felt compelled toward a particular course of action. Other decisions were described as
35 obligations or necessities, tied to accounts of responsibility, duty, self-sufficiency and self-
36 sacrifice. Often the perceived absence of options was related to the particular relational
37 landscape; that is, the situational and relational *foreclosure* of choice, rather than its absence
38 per se. And while making decision was sometimes a concealed or silent pursuit, it was clear
39 that choice was a socially negotiated and temporally unfolding process, nested within relational
40 and interpersonal dynamics.
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44 *'Choice' as relational: The interpersonal dynamics of individuals' choices*

45 Participants' accounts suggested that the process of making decisions and negotiating their own
46 needs and those of their family members and friends was far from straightforward and added
47 to the emotional and practical work of managing cancer. Women frequently framed their
48 decisions as moral, grounded in the best interests of close family and friends. They expressed
49 desire to protect partners, parents and children from avoidable or unnecessary pain and
50 suffering, linking their decisions to their identities as mothers, partners and/or caregivers
51 (Gibson et al., 2012; Bell and Ristovski-Slijepcevic, 2011). Indeed, the privileging of the
52 preferences and needs of others ahead of their own was often articulated by participants as
53 unavoidable. Decisions related to the continuation of active treatment, use of complementary
54 or alternative medicines, and commencement of palliative care were strongly shaped by the
55 wishes or expectations of others, either verbalised or *imagined*. Participants often explained
56 decisions as attempts to minimise the discomfort and distress of family members, even if this
57 increased their own suffering. One scenario in which this dynamic was prominent was in
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1 decisions to continue with sometimes unremitting treatments despite debilitating side-effects
2 or complications. Elma, for example, in her mid-thirties, described “no choice” but to continue
3 with treatment regimens to avoid appearing to “give in”. She was having intravenous
4 chemotherapy after numerous other treatments had been unsuccessful. For many like Elma,
5 decisions needed to be made to demonstrate persistence and willingness to “keep going”:
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7 I don’t know if I would have continued on with treatment if it wasn’t for [my husband] ... I
8 know that if I was to give in and just let chemo stop and just whatever happens with the cancer
9 happens, and however long or short it may take, obviously my mum, my dad, and my sister
10 would be devastated, and [husband’s name]. So that gives me drive to keep going... because
11 chemo is very hard... and it’s never ending. Like, with this chemo it’s pretty much indefinite.
12 I don’t know when there’s an end date, if there is an end date. (Elma, aged 36, Interview 1)
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15 Compliance with treatment regimens and “putting up with” side-effects was often described as
16 a demonstration of strength, courage, determination and optimism, illustrating normative ideals
17 of cancer patienthood (e.g., Author et al., 2019; Steinberg, 2015). Decisions made in the
18 context of end-of-life care, death and dying (e.g., guardianship for children, advance care
19 planning, palliative care) similarly revealed how expectations of women and mothers as
20 selfless and protective played into the lived realities of everyday decision-making (Bell and
21 Ristovski-Slijepcevic, 2011). Living with the knowledge of terminality (and attendant fears
22 and anxieties) often remained unspoken in familial and medical encounters, as illustrated in the
23 accounts of Rebecca and Carol, both in their fifties, despite profoundly shaping how choices
24 were made meaningful in the context of terminality:
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28 See because when you say things like this [about end of life and dying] to people or whatever,
29 or it’s my husband, it’s like, “Oh my god, you’re focusing on death.” “I’m not focusing on
30 death. I’m focusing on having everything in place before then, so I don’t have to worry about
31 it, and you don’t have to worry about it. It doesn’t mean that I’m planning on dying next week.
32 It just means that I’m trying to get things in place.” (Rebecca, aged 51, Interview 1)
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35 Family and friends, it’s difficult... I think [they] would probably say, “Don’t worry about it.
36 You don’t need to do that.” They don’t necessarily want to think about that... I think when
37 you’re going so well, especially our culture tends to put death somewhere else, hide it, don’t
38 discuss it. So, I can’t really discuss that [end of life decisions]. I don’t know that my oncologist
39 is the right person because she’s doing as much as she can with my health... (Carol, aged 57,
40 Interview 2)
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43 For some participants, silences were articulated as emanating from close others, whereas other
44 participants described self-imposing silences, avoiding discussions as attempts to shield family
45 members from upsetting or difficult conversations. The overarching imperative was the
46 maintenance of normalcy for families, inflected by an assumed connection between positivity
47 and recovery. As a result, end-of-life decisions were, for some participants, taboo, to be made
48 privately and alone. And this was not without consequence. The burden and distress of private
49 decisions and the sense of moral obligation this evoked, was evident when some women said
50 they worried about the unforeseen effects of personal decisions, for themselves or their
51 families. These issues tended to be discussed by women in their second and third interviews as
52 is captured in the excerpts from Janet and Kate, both with high-school aged children and who
53 discussed changes in their treatment and cancer progression over the course of their three
54 interviews:
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58 I mean, [putting your family first], that’s the reality. If you do die early, you want to make
59 things as easy as possible for the people who are left behind. [...] this part has been really
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1 difficult for me, that you're being told to prepare for the worst, hope for the best. So, I feel as
2 if I need to prepare to die, like write things down, letters to my kids, and I haven't done that
3 yet. I've done all the will stuff. I just feel as if I'm working so hard just to get my health back
4 [...] As my mobility improves, I think [things will] get better. I mean I've got no plans to go
5 anywhere soon in terms of dying. I'm a very good patient and do what I can. (Janet, aged 61,
6 Interview 3)

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8 I think there's part of me that feels guilty that I'll let my family down if I can't maintain the
9 dosage at the highest level. So, I am hoping that when I have my blood test... that I'll go back
10 on the full dose. (Kate, aged 57, Interview 2)

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12 Janet's quote illustrates the freedom/responsibility tension as well as competing discourses of
13 fighting cancer and prolonging life versus accepting and preparing for death. Like Kate, she
14 wrestled with decisions in the pursuit of her own health, self-care, and wellbeing needs versus
15 her sense of responsibility to family – some of which are irreconcilable. Kate, in recounting a
16 decision imposed on her – to reduce her treatment dose – retained responsibility, revealing her
17 sense of guilt, disappointment and failure. These accounts also point to the temporal dimension
18 of decision-making, including the ongoing, continuous interactional negotiations with family
19 and health professionals amidst changes in treatment and disease progression.

22 23 ***The temporal tussle surrounding decisions of daily (and future) living***

24 Choices about treatment, care, work and family life could not be disentangled from the
25 anticipated or imagined future of living-with advanced cancer (Author, 2017; Llewellyn et al.,
26 2018). Participants discussed the challenges of making decisions about how to live in the now,
27 in relation to the largely unknown, but likely contracted, future. This was particularly evident
28 among young women, women who discussed financial difficulties, and women who had been
29 living with metastatic cancer for longer periods of time. What emerged were frequent
30 considerations (and reconsiderations) of how to spend finite time and financial resources, and
31 the consequences of such decisions (e.g., about participation in paid and unpaid work, care
32 responsibilities, dating, housing and travel for everyday life both now and into the future. Take
33 for example the following excerpt from Lorraine, who had recently stopped working due to ill
34 health:

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36 All those decisions are really hard when you're in this position because you just don't know
37 how long you have. If I knew back when I was 49 I was going to still be here when I was 55, I
38 possibly would have done things differently... the big worry is, now I've retired, have I plunged
39 us into poverty? We could have done so much more had I stayed and worked for another 10
40 years. Have I done the wrong thing? ... There's just all this ongoing financial burden and, again,
41 it's making decisions. If I jump now, am I going to live for another 30 years and be absolutely
42 poverty stricken? I don't know. In the beginning it was, "Your prognosis is bad... Two to five
43 years is usually what you're looking at... there's no choice about it. I don't know. I try to be a
44 pragmatist and just try to think, "I'm here." (Lorraine aged 55, Interview 1)

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46 As Lorraine alludes to, her decisions about continuing work were complicated by ambiguity
47 around prognosis, and the changeable nature of prognosis (see Jain, 2007; Author et al., 2020).
48 Several participants described their initial decisions as made in the context of a (particular)
49 prognosis, and the subsequent social and financial implications of *living beyond prognosis*.
50 Contemplating and foreseeing an imagined future was hindered by the unpredictability of
51 living with an incurable, progressive condition. In practice, the process of deciding how to live
52 in the now, and plan for the future, never unfolded straightforwardly, and was always imbued
53 with emotions. Denise and Amber, both in their early sixties and living with metastatic cancer

1 for ten and four years' respectively, discuss how balancing living in the now with living in the
2 future (for self and others) was continuously being deliberated and negotiated.

3 I've got to be a little careful. I want to do all this stuff, but what happens if I do last several
4 more years and I need care, if I need to be put into a high care facility... that is a bit of a concern.
5 I don't want to leave my husband with nothing. (Denise, aged 63, Interview 1)
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7 You're told that you've got 12 to 18 months to live so you're counting the months thinking,
8 "Oh my god, I may only have nine more months to live" ... But when that time comes and I'm
9 still going, I'm still going through treatment, I'm still here, relief took over... There's always
10 uncertainty in your life. (Amber, aged 62, Interview 1)
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13 Suggestive of the moral responsibility women felt, even in very constrained circumstances or
14 when decisions were imposed on them, participants described their decisions as accompanied
15 by feelings of guilt or anxiety about the possibility of making the 'wrong choice' (Bell, 2016).
16 The negative repercussions of these decisions on themselves and others were described at
17 length (e.g., cancer progression, treatment failure, the hastening of death, increased financial
18 burden on family members, the unaffordability of future treatment or care).
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21 The following excerpts illustrate the inseparability of treatment decisions from relationships,
22 time and money, highlighting the necessity but also the complexity and difficulty of the notion
23 of 'patient choice' as mobilised in any straightforward or linear way (Llewellyn et al., 2018).
24 For instance, Kylie, in her late forties who was actively looking for work and reported financial
25 difficulties, talks about being offered a choice by her oncologist between two treatment options,
26 with a significant difference in cost (one was publicly subsidised, and one was not). The more
27 expensive option was framed as 'better' (reflective of a wider market logic) but was prohibitive
28 due to her limited financial resources. Yet she articulates the failure of the treatment as a
29 personal failing, provoking feelings of guilt and worry that her decision may have shortened
30 her life.
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34 ...my husband said, "No, we'll do it," and I said, "No, we won't," because I'm high-risk. I
35 wouldn't put our family into any – I'm already a financial burden. I'm not going to make it
36 worse. You know what I mean? The hundreds of dollars already spent this year, especially I'm
37 not now working and he's just working part-time, it's a concern nowadays. (Kylie, aged 49,
38 Interview 1)
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41 Making the 'right' choice was just one of many forms of normativity that shaped decisions
42 about how best to *live-with* cancer. Being a good patient, and particularly a good mother, was
43 foregrounded. Tammy, a fifty-year-old with two dependent children living with metastatic
44 cancer for five years, articulates the inseparability of decisions to care of self and their sense
45 of care and responsibility to their children.
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48 When I stopped working it was a very conscious decision. It was because I worked all day
49 every day providing care to others, that I felt I needed to be engaged in self-care at that point.
50 So, things like looking after my diet, looking after exercise, making sure I took up meditation.
51 A friend introduced me to tai chi and so I still practice that every day. I felt like my job then
52 was to be looking after myself, and I still, to some extent, feel that is my main job, to look after
53 myself so I can keep being a good mother to my daughters. (Tammy, aged 50, Interview 1)
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57 Illustrative of the temporal dimensions of choice, decisions about the future could not be
58 disentangled from the multidimensional complexity of participants' daily life. This included
59 the interwoven affective and economic aspects of living-with cancer. Sense of duty, morality,
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1 and time and resource constraints all shaped decision-making, both within the present moment
2 and in the imagined or anticipated future. This involved engaging in an ongoing process of
3 (re)adjustment to the changing demands and expectations of the present and the future; and
4 how resources were mobilised (and rationed) in an attempt to manage uncertainty.

5 *Circumscribed choice/delimited agency*

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8 Despite the relational, temporal and financial dimensions in which decisions were situated, the
9 rhetoric of choice was still highly valued by women. In many instances this was because choice
10 was seen to afford one of very few avenues through which women could assert control or feel
11 empowered in what were otherwise precarious circumstances, even if only at a rhetorical level.
12 Participants talked about the importance (for good patienthood and demonstration of self-
13 responsibility) of being informed about treatment options through conducting careful and
14 judicious research and linked this engagement in decision-making to feeling empowered.
15 Embracing the idea of choice-as-control, often in spite of extremely constrained options,
16 represented, discursively at least, was a way to feel better amid decreasing control over their
17 own body, identity, and life. This is captured by Nancy and Rebecca.

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21 ...with me, my biggest issue was losing control. I didn't have the surgery because it was too
22 late. There was a loss of control there. I wanted one thing and the medical people are telling me
23 another. I think for me to keep control, I had to very much be a part of my treatment decisions.
24 It's all about your head space. You've got to get your head in the right place, and you've got to
25 say, "Okay, I can't do anything about what has happened so far, but I can do something about
26 where I go from here." (Nancy, aged 63, Interview 1)

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29 They don't realise how much it does smash your confidence a bit in that you're relying on these
30 people to keep you alive and you'll hope that they're making all the right decisions for you.
31 I've always been proactive with treatments and that. But now I've got more confident to say
32 more. If I've found something out, researched something, I will take that to my oncologist and
33 say, "Hey, look, what about this?" and she'll say either, "It can't hurt," or, "There's no scientific
34 evidence to say it's going to help, but give it a go if you want. It's not going to harm you. It
35 won't contradict any of the other drugs, so try it and see how you go." I am my own advocate.
36 I have to be, because no one else is advocating for me. (Rebecca, aged 51, Interview 1)

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41 Though many women said they liked actively participating in decision-making, sometimes
42 being presented with options was experienced as stressful or burdensome; especially when the
43 options being presented as a *choice* were prohibitive or had limited evidence base. All women
44 did wish to participate, to varying degrees, in decisions about their treatment, (reflective of
45 more collaborative approaches to choice). Yet a number of women, like Kylie, Danielle and
46 Joyce, talked about the difficulties of trying to judge different treatment options, and the
47 emotional investment this required, instead expressing a desire for their oncologist to guide or
48 make decisions about treatment. Thus, our data also challenges normative assumptions of
49 choice as always desirable to patients (see also Sinding et al., 2010).

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53 Well, the doctor says, "It's this one or this one," ...You do have a choice, but I don't know what
54 to make. I do rely on her. If she goes, "Try this," you've got to rely on her expertise. I don't
55 know where else I would go. I don't know anything, so I hope she has the knowledge to do
56 things. (Kylie, aged 49, Interview 1)

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59 You're kind of just thrown into this whole new world and you don't know what you don't
60 know... I don't know if I'm living in denial or ignorant bliss. But I suppose I'm trusting... I

1 think I do need to be a bit more pro-active to learn what's out there. But it's exhausting. You
2 go in circles. (Danielle, aged 49, Interview 1)

3 I didn't need to be making lots of decisions at that stage. I just needed to know what she [my
4 oncologist] thought. Because I trust her and her judgement I just wanted her to give her
5 recommendations about what she thought I needed and that's all I expected from her. I didn't
6 expect her to give me a big pile of decisions to make. You can be a little bit shell-shocked when
7 you get a secondary diagnosis. You think, "What can I do?" You want to know what you can
8 do... It's nice to make an informed decision, but sometimes it's nice to have a bit of guidance
9 from a professional who actually knows more about it than you. (Joyce, aged 61, Interview 1)

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12 As the above excerpts illustrate, for participants, especially those with more illness progression
13 or who had progressed through numerous successive lines of treatment, decisions about
14 treatment and care were made more complex because of increasing side-effects, symptoms,
15 and emotional health difficulties. Accounts suggested an increasing dependency for care on
16 clinicians, as they discussed their trust in oncologists to make decisions. This highlights the
17 limits of consumerist approaches to healthcare (particularly in relation to cancer care), which
18 positions patients as 'conscious choosers' over treatment decisions, given the inherent
19 uncertainties and unpredictabilities of metastatic disease, and asymmetries in power and
20 knowledge between professionals and patients (Sinding et al., 2010; Titmuss, 2004).

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Illness progression was inversely related to treatment options, creating a landscape where choices were progressively ambiguous or obscure (Llewellyn et al., 2018). That is, there was no clear or optimal choice to be made between options in terms of their likely effectiveness. Such circumstances necessitated new ways of thinking about illness and disease progression vis-à-vis medication. Daisy, a single mother with one son, described making decisions based on newness of the treatment (where newer drugs were seen as better). Her excerpt also appears to show how shared feelings of hope (of patients, health professionals, caregivers) imbuing therapeutic options, particularly at later stages of illness may work to constrain choice by silently closing off alternatives (e.g., the option to forgoe treatment) (Author, 2019).

Initially with the metastatic, there's no choice... She [my oncologist] just said, "Right, this is what we think you need." Further down the track, I guess she sort of said, "You could do this or this or this." ... she gave me three possible treatment options I said, "Well, which one has the best prognosis or best outcomes?" and she said, "You really can't tell. Each one works differently for everyone else and all you can do is try it. But if one doesn't work, we've always got other options up our sleeves and what have you." One of the options was a trial... It was also a targeted therapy. So, I guess, that made me really hopeful that it was a targeted therapy and therefore it was possibly one of the newer things that would work really well. I was on it for eight weeks and I felt great. I didn't really have side-effects and after the eight week scan they said it was working... Then I went back eight weeks later, and they said, "No, it's not working anymore." So that was just, again, you're feeling good and then you just go, "Great. I've just been run over by another truck and we're back at square one." (Daisy, aged 52, Interview 1)

Women's accounts appeared to show shifting or deflection of responsibility for decisions about treatment from clinicians and healthcare systems onto individual patients – especially at later stages of illness or when there was a limited evidence-base for treatment – reflecting broader issues of responsabilisation in medicine: Women exhibited a strong sense of self-responsibility over their treatment decisions, assuming the blame for risks associated with these decisions: "Even if they recommend it, it's still my decision to take it. So I've taken the risk." (Rita, aged

52, Interview 1). This highlights the potential unintended consequences of encouraging patient choice, when the evidence base used to judge the risks and benefits of options is ambiguous, but also how the structuring of the cancer therapeutic landscape to advantage some and disadvantage others, may be concealed.

Discussion

Choice has become a central and seemingly immutable cultural logic within the context of (Western) advanced modernity and accompanying social milieu of individualisation (Schwartz, 2018). As reflected in the broader scholarship, the various manifestations of the cultural logic of choice across contexts as diverse as consumer goods, education, healthcare, political representation and reproductive rights, amplify the centrality of choice within the cultural imaginary and imbue it with meaning in our everyday practice. As such, the social valorisation of choice is not merely neutral – it is also political and materialises a range of consequences (Bell, 2016). Related to Berlant’s (2011) work on cruel optimism, the neoliberal/late modern sensibility of a productive citizenry comprised of agentic individuals often obscures its normative and even ‘cruel’ underpinnings. That is, how the idea of choice is alluring while often also simultaneously undermining. Choice-making, decision-taking, and empowerment thus become narrative forms which themselves manifest important consequences in lived experiences as well as for the structure of healthcare systems. And this, as we show, ripples across forms of health and care, and even terminal illness, imposing various forms of normativity with which people living with life-limiting illness must contend.

Of course, the imperative to choose is not the only form of normativity that circulates around disease. Instead, it is layered, in particular, with gendered moralities and ethics of care (and obligation). Choice, in the context of these women with cancer, is situated within gendered dynamics of care for both the self and others. While cancer survivorship and self-help discourse emphasise the importance of self-care, reinvention, and patient empowerment, women’s narratives illustrate how decisions to care for the self, and to care for others, are neither straightforward nor separate from one another (Bell and Ristovski-Slijepcevic, 2011; Author et al., 2019; Gibson et al., 2018). Our findings show the complex *caring work* women must engage with in their lives (and deaths), attempting to simultaneously align familial roles and responsibilities, broader normative discourses of good cancer patienthood (e.g., of informed and collaborative decision-making) and their own needs and wishes. This resonates with Cheryl Mattingly’s (2014; 2013) ethnographic work on moral experimentation, which captures how families engaged in unanticipated moral work as part of caring for their sick children. This work illustrates the challenges experienced by people, as well as the experimentation that they engage in, when making decisions about what is the morally appropriate course of action amidst the multiple (often competing) values and desires of themselves, and of others. She shows how moral work is deeply situated within familial relationships, and dependent on continuously unfolding health and life circumstances. Cultural ideas about caregiving and mothering combined with cultural discomforts and silences about end of life, death and dying, alienate those women living with non-curative cancer, especially younger women with dependent children. Thus, women must incorporate consideration of those who will be ‘left behind’, orchestrating the details of lives beyond the conclusion of their own. In this way we again see the inseparability of ‘choice’ and ‘necessity’ in navigating advanced cancer (see also Bell and Ristovski-Slijepcevic, 2011).

Indeed, the valorisation of choice offered a way for women to discursively reframe necessity or duty as ‘free choice’ (Bell, 2016; Sinding 2010). Arguably, ideals of individualism and self-

1 care, so pervasive in the cancer care literature, may increase suffering if the imposition of
2 distress or guilt tethered to such decision-making is unacknowledged. So too may suffering
3 occur if patients (women) are left to feel like they must grapple with difficult decisions (e.g.,
4 about end of life) alone. Many of the participants in this study expressed a strong desire and
5 responsibility to participate because of what they perceived as a silencing of the experiences
6 of those with metastatic cancer; a likely consequence of what Bell (2014) terms ‘the breast-
7 cancer-ization’ of cancer survivorship research. It is, thus, important to acknowledge that in
8 many ways the participants in this study reflected the demographics of while, middle-class
9 women who have been activated to participate in research meaning that they are unlikely to
10 reflect the experiences of all women with metastatic breast cancer.
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13 The ideals of patient autonomy, person-centredness, and responsabilisation are powerful
14 structuring forces within cancer care, and healthcare more broadly, in terms of the meaning
15 given to particular decisions, and patients’ sense of responsibility over their outcomes (Bell,
16 2016; Sinding et al., 2010). Yet, the *illusion of control* over the unpredictable and
17 uncontrollable that accompanies a choice logic, while experienced by some women as uplifting
18 (at least for a period of time), for many others, ultimately, increased suffering due to a sense of
19 personal failure or disappointment, adding another layer to the emotional and relational work
20 of living with incurable cancer (Mol, 2008; Bandini, 2020). Taken for granted norms around
21 the pursuit of longevity and survival delimit what options are possible (or unspeakable) when
22 living with incurable cancer (Author, 2019; Author, 2017; Bandini, 2020). Opting to pursue or
23 forgo treatment is not symmetrically structured when considered within the normative context
24 of cancer in contemporary societies (Sinding et al., 2010). What is valued culturally in most
25 contemporary Western societies is heavily skewed toward the pursuit of treatment and
26 longevity – sometimes even positioned as a choice between living and dying. This is playing
27 out within a fast-changing, increasingly privatised and complicated therapeutic space, where
28 the costs of novel treatment options are ever growing, but where the benefits and outcomes are
29 often unknown or ambiguous (Say et al., 2006), raising important questions about compassion,
30 justice and equity in contexts of high uncertainty.
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36 **Conclusion**

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38 Our findings advance scholarship on the social meanings ascribed to choice by revealing how
39 various logics (of patient choice and of care), can pull patients in different (often competing)
40 directions, as they grapple with decisions about how to live with, metastatic cancer (Sinding et
41 al., 2002). Our data highlight decisions as ongoing and continuously negotiated social
42 processes, complicated by a range of inter-relational dynamics (see Bell and Ristovski-
43 Slijepcevic, 2011; Steinberg et al., 2015). Findings have policy and practice implications,
44 especially in thinking about what it means to provide person-centred care in contexts of
45 incurability. Patients living with advanced cancer do not only want to be treated as autonomous
46 individuals, but as also always caring and living for and with others, reflective of the
47 importance of an ethic of care logic in practice. This supports the value of focusing policy and
48 research attention to the importance of greater recognition of caring for others in guiding
49 decision-making while living with cancer. But also highlight the importance of future research
50 into how technological innovation in cancer therapy can create both new horizons for patients,
51 but also new ethical and moral responsibilities (Llewellyn et al., 2018), especially given more
52 people are living longer with incurable cancers. Issues such as *living beyond prognosis* (and
53 the social, financial and existential questions this raises), increasing (expensive) therapeutic
54 options for advanced cancer, and eligibility for clinical trials, combined with the emphasis on
55 patient choice and shared decision-making, complicates choice processes for patients, family
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caregivers and professionals in care settings (Bandini 2020; Llewellyn et al., 2018); and perhaps, because of the positive meanings that are attached around agency, freedom, and autonomy, conceals some of the deleterious emotional realities of making decisions in context of life-limiting cancer.

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The social meanings of choice in living-with advanced breast cancer

Abstract

Individual choice is valorised as a core social value; yet the necessity and desirability of making choices takes on new significance for people living with incurable cancer who are required to make often difficult decisions about treatment, care and family life, amidst considerable vulnerability and precariousness. There has been comparatively little exploration of how choice is negotiated and made meaningful under the spectre of incurability and a contracted future. In this paper, drawing on multiple qualitative interviews with 38 women with metastatic breast cancer, we explore how they experience and give meaning to choice in relation to their health (and beyond) in their daily lives. Our analysis highlights that while exercising choice was sometimes a concealed or silent pursuit, choice was always a socially negotiated and temporally unfolding process, nested within relational and interpersonal dynamics. Choices were also often constrained, even foreclosed, due to situational and relational dynamics. Yet even in the absence of choice, the idea of choice-as-control was discursively embraced by women. We argue that greater attention is needed to the affective, temporal and economic dimensions of choice, and how treatment decisions are asymmetrically structured when considered within the normative context of cancer.

Key words: Choice; decisions; breast cancer; incurability; qualitative research; relationality

Word count: 8980

Introduction

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2 The notion of choice is a pervasive feature of late-modern living. Popular imaginaries position
3 people as individual, rational actors expected to choose from among a range of possible options
4 in navigating their daily lives in desired directions (Adams, 2003; Clarke et al., 2006; Giddens,
5 1994; Schwartz, 2018). The necessity and desirability of choice takes on new significance for
6 individuals living with advanced cancer, which requires a range of difficult choices to be made
7 – including decisions about treatment and care, work and family life (Fotaki, 2010; 2013). And
8 all amidst new experiences of vulnerability, precariousness and unpredictability brought on by
9 the (progressing) disease (Author, 2019). Yet, the imperative *to choose* is enshrined in
10 healthcare through best-practice models of ‘patient choice’ and ‘shared decision-making’
11 (Charles et al., 1999). Such ideals are embedded in cancer care policies as key mechanisms
12 through which to achieve person-centred care and patient ‘empowerment’. Scholars have
13 critiqued the logic of patient choice for its latent responsabilisation and deflection of liability
14 away from health professionals and health systems onto individual patients, instead (Bell,
15 2016; Lupton, 1997). Nevertheless, it is patients who increasingly experience the necessity to
16 choose and bear the consequences of those choices – good, bad or otherwise (Mol, 2008).
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21 Previous scholarship has pointed out that the ideal of patient choice foregrounds the seemingly
22 autonomous individual and obscures how patients are differently situated such that the capacity
23 to choose is unequally distributed across society (Collyer et al., 2015). Furthermore, in
24 navigating increasingly complex therapeutic landscapes, patients (and health professionals)
25 often confront decisions about their care amidst considerable ambiguity (Llewellyn et al.,
26 2018). The ever-increasing commodification of care within both privatised and state-provided
27 healthcare systems in countries such as the United Kingdom, the United States, and Australia,
28 and growing structural inequalities that inflect healthcare provision, seriously undermine the
29 ideal of unconstrained choice (Collyer and Willis, 2019; Coulter, 2010; Van Natta et al., 2018).
30 Treatment advances have improved clinical outcomes for some advanced cancer patients
31 (namely those with access and/or resources) (Hodi et al., 2010). But for others, expanding
32 therapeutic options and clinical pathways mean new challenges of choice, especially when
33 treatments are self-funded, based on incomplete or inconclusive evidence, and resources are
34 constrained (Say et al., 2006). As such, a multiplicity of choices may call into question the
35 pursuit of (sometimes indefinite) treatment vs attempts to live *well* with cancer in daily life,
36 juggling between the quest for longevity and survival and maintaining quality of life
37 (Baszangar, 2012; Fernandez Lynch et al., 2020). While evidence for different treatment
38 options is often ambiguous, even if it were more definitive, the ‘choice’ to pursue or forgo
39 treatment unavoidably involves a range of affective, cultural and embodied dimensions and
40 can rarely be dictated by ‘rational’ knowledge, alone (Bell, 2016; Coulter, 2010; Petersen et
41 al., 2017; Sinding et al., 2010). Additionally, for those with incurable cancer, available
42 treatment options may be limited, while the future they might ideally choose (e.g., of a cancer-
43 free life) is often inaccessible (Bell and Ristovski-Slijepcevic, 2011).
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50 A significant corpus of sociological and clinical research is devoted to whether choice is
51 important to people, what choices matter to them, and the factors and circumstances that shape
52 the decisions that patients and health professionals make (Coulter, 2010; Fotaki, 2008; 2013;
53 Schwartz, 2018). Mobilised under the rubrics of patient preference, informed choice, or shared
54 decision-making, such work tends to describe the aggregated preferences of patients and the
55 mechanisms of how decisions are made. Yet, there remains limited knowledge about the
56 collective *meanings* of choice in the context of illness, affliction and care. This includes how
57 choices are negotiated over time, under the spectre of incurability, and a contracted future (for
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1 exception see Author, 2017). Such concerns are particularly acute for women with incurable
2 breast cancer. Also known as metastatic or stage IV cancer, women living with this type of
3 breast cancer will typically have lifelong treatment and experience considerable uncertainty
4 about their health and longevity. Though there are numerous therapeutic options, including
5 hormone therapy, targeted therapy, chemotherapy and radiotherapy, these vary depending on
6 the specific cancer sub-type and the extent of its spread. The complexity of the disease and its
7 evolving treatment create unique challenges for women as they navigate choices about
8 treatment and care (see Bell & Ristovski-Slijepcevic, 2011; Author 2016). These include
9 considerations about treatment efficacy, side-effects, and the impact on daily life, which can
10 vary considerably depending on women's age at diagnosis (Rocque et al., 2019). Here, drawing
11 on conceptualisations of empowerment, responsibility, autonomy and relationality, we aim to
12 capture the multiple (and shifting) personal and cultural meanings of choice as articulated by
13 women with incurable breast cancer including how they understand and experience choice in
14 relation to health (and beyond) in their everyday lives.
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17 **Choice and the empowerment/responsibilisation dialectic**

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20 A cultural emphasis on 'agentic' choice by empowered patients has taken on
21 increased prominence over recent years, especially in (economically) wealthy industrialised
22 countries. But its historical origins date back, at least, to the women's health movement of the
23 1970s and 1980s, which sought to reclaim autonomy, knowledge and decisions
24 about women's bodies from the (still male-dominated) medical profession (e.g., Tuana,
25 2006). This movement coincided with the rise in medical consumerism (Reeder, 1972;
26 Timmermans and Oh, 2010) and can be tied to the changing structure of healthcare systems,
27 especially within the United States. The market now features prominently in the delivery of
28 health services across a range of wealthy industrialised contexts, including those with
29 nationalised single-payer healthcare systems (e.g., the NHS) (Collyer and Willis, 2019;
30 Greener, 2009; Olsen, et al. 1976).
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35 At the same time, the proliferation of patient health movements around causes ranging from
36 breast cancer to preterm babies to opposition to vaccines (Epstein, 2008) has also lent a popular
37 base to calls for patient empowerment, helping to install patient choice as a driving imperative
38 within health systems across the United States, United Kingdom, Canada, Australia and
39 elsewhere (Greener, 2009; Author, 2020). Yet scholars (albeit within different empirical areas)
40 have warned of the dark side of 'empowerment' logics, of which notions of choice play a key
41 role. Calls to 'empower' (formerly marginalised) subjects risks imposing the kind
42 of responsabilisation that has been identified and critiqued for its individualising consequences
43 (Beck, 1992; Cruikshank, 1999). In health, the intertwined notions of patient empowerment
44 and choice have been closely linked with self-responsibility: namely, the imperative that
45 patients make the 'right choices' in terms of lifestyle, self-advocacy, and treatment options
46 (Bell, 2016). In response, critiques of conceptualisations of patients as rational consumers in a
47 supposedly free healthcare market have emerged, noting that patients/persons rarely have
48 opportunities to choose 'freely' between treatment options and care providers as they would
49 with some other commodities (Van Natta et al., 2018). Moreover, treatment decisions are
50 inevitably constrained by relational dynamics, considerations of time, and financial resources
51 (Sinding et al. 2010). Like all choices, they are shaped by personal and collective dispositions
52 and structural positions (Bourdieu, 1984; Collyer et al., 2015). Nevertheless, the unconstrained,
53 rational patient deliberating over medically defined risks and outcomes persists within
54 healthcare discourses and models of patient-centred care and shared decision-making (Clark et
55 al., 2004). How choice is conceptualised, mobilised and made meaningful in people's everyday
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1 lives as they attempt to navigate their way through illness, affliction, relationships and care,
2 remains underexplored.

3 **Situating choice within care, society and everyday life**

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5 Concurrent to movements towards consumerism in healthcare has been the increasing focus in
6 bioethics' discourse on individual patient choice, shaped by founding principles such as respect
7 for autonomy (Agledahl et al., 2011; Beauchamp and Childress, 2009). However, the focus on
8 autonomous choice have been widely critiqued, as not able to capture the moral facets of
9 making healthcare choices, and the complex realities of people's lives (Callahan, 2003;
10 Drought and Koenig, 2002; Holm, 1995). Feminist philosophers advanced the concept of
11 relational autonomy as an attempt to better account for the situatedness of decision-making and
12 embrace the idea of collective decision-making (e.g., MacDonald, 2007; Mackenzie and
13 Stoljar, 2000; O'Neill, 2002; Oshana, 2016; Shih et al., 2018). These scholars argue that people
14 are always socially embedded in a network of others, and values such as interdependence and
15 care for others play an important role in shaping people's decisions (Held, 1993; 2006).
16 Similarly, Mol (2008) argues that the logic of patient choice can act as an obstacle to the
17 enactment of a logic of care, in which healthcare unfolds in negotiation with the specificities
18 of the person's lived experiences as a central focus. For Mol it is *how* people interact with
19 choice that is of interest, including the normativities, affective connections, inter-relationships,
20 and temporalities that influence how people come to understand and make decisions.
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26 Previous work has also shown how people can 'drift' towards certain decisions, particularly in
27 situations of ambiguity (where there is no obvious or optimal option) because of what is
28 socially valued or expected (Schwarz, 2018). Options for cancer treatment provide a poignant
29 example, where certain courses of action (e.g., treatment options in pursuit of longevity) are
30 valorised over others (Charles et al., 1998). Such choices (e.g., to persist, to persevere, to
31 'battle') fulfil relational and gendered roles and align with broader cultural norms within and
32 outside cancer (Sointu, 2006). Collective feelings of optimism and positivity can contribute to
33 normative expectations on patients living with advanced cancer, constraining or silencing
34 options that exist outside of frameworks that emphasis the pursuit of active treatment and
35 survival (Author, 2019; see also Ehrenreich, 2010; Segal, 2012). Patients may choose to endure
36 treatment for others, with active treatment (rather than 'doing nothing') construed as the only
37 course of action (Charles et al., 1998; Steinberg et al., 2015).
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42 Women's experiences of making decisions, especially how it relates to caregiving, and their
43 sense of interpersonal obligation while living with cancer have also been explored. Bell and
44 Ristovski-Slijepcevic (2011) revealed some of the moral dynamics of mothering while living
45 with incurable cancer, arguing that wider expectations related to mothering as altruistic and
46 self-sacrificial placed pressures on women to make decisions that were in the interests of their
47 children and partners, putting the needs of others ahead of their own (Hausegger, 2005). Such
48 accounts also reveal the discordance between patient empowerment tropes within the cancer
49 survivorship and self-help literature (e.g., living with cancer as a time to focus on self-care and
50 reinvention) vis-à-vis the lived realities for women with incurable cancer (Ehrenreich, 2010;
51 Ristovski-Slijepcevic, 2013; Sinding et al., 2002; Sontag, 2001; Author, 2016). In the results
52 that follow, we further illustrate some of the *challenges of choice* for women living with
53 incurable breast cancer. We show how, in this context, decision-making proceeds not in an
54 autonomous, individual vacuum, but within the multi-folded contours of the complicated
55 terrains of women's daily lives. In doing so, we highlight the disconnects, dissonances and
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discomforts that emerge between the ideals upheld in cancer survivorship and bioethics discourses and the social and relational realities for women living with incurable cancer.

Methods

Data is drawn from multiple semi-structured interviews with 38 Australian women living with metastatic breast cancer; defined as having spread to another part of the body, such as the liver, brain, bones or lungs. Interviews were conducted as part of a larger research project which explored women's experiences of incurable breast cancer and cancer care, and the experiences of health professionals providing care to this group of women. Ethics approval was granted from a university human research ethics committee.

Purposive sampling and a community recruitment strategy were used to include women with diverse experiences of cancer and cancer care, including those living in metropolitan and regional areas across Australia, those who had been living with metastatic disease for different periods of time, who had experienced different treatment types, and healthcare settings (e.g., public and private, clinic and hospital-based). Within the Australian healthcare system, there is a mix of publicly and privately funded and provided care for cancer patients. Women with metastatic breast cancer can access free or subsidised medical and hospital care and treatment is provided to all citizens via a universal healthcare system, Medicare. Additionally, individuals can choose to access some health services privately, using private health insurance. Recruitment was via flyers, advertisements and presentations to cancer support groups, cancer care and breast cancer organisations and peak bodies, and a cancer wellness centre providing complementary therapies to support people with cancer; direct recruitment via clinicians and community-care workers; and snowball recruitment through women who had already participated. This ensured that a diverse range of women were invited to participate, including women who may not be engaged with care professionals in formal healthcare settings. The recruitment materials were aimed at women who were 18 years or older who had been diagnosed with metastatic breast cancer. Participants who expressed interest in the study were provided with an information sheet and consent form outlining the purpose of the study and what participation involved. They were then contacted via phone to schedule a convenient time for an interview.

In total, 38 women aged 36-74 (mean 57.3, median 57.5) participated in the study. They included women with metastases in the bone (25), lung (15), liver (14) and brain (6). Our sample included participants across a variety of ages, length of time since diagnosis (<1-23 years), and educational attainment. Despite efforts to attract participants from diverse cultural backgrounds, most participants were Australian born and of European descent. Nine participants were receiving disability or other financial assistance and/or living in areas of high social disadvantage. Eighteen women received care in the private health system, 14 women received care in the public health system, and five used a mix of public and private health services. Most were primarily receiving care from their medical oncologist, and some were also using palliative care services. Three participants were not receiving any biomedical treatment at the time of their interview. While most women were engaged with biomedical treatment and care, half were also using some form of complementary medicine or therapy (such as acupuncture, Chinese traditional medicine, naturopathy, medicinal marijuana, or art therapy).

After written informed consent was obtained, an interview was conducted either face-to-face in a location convenient to the participant (e.g., the participant's home) or over the phone (e.g., if a participant lived in a regional area). Where possible, women were interviewed on another

1 two occasions during a 12-month period, to capture the interlinked temporal, affective and
2 relational facets of living with incurable cancer and facilitate rapport building. Four women
3 participated in only one or two interviews, due to ill health. An interview guide was created
4 with input from a metastatic breast cancer consumer, and included questions about women's
5 experiences of cancer, the strategies they used to manage their health, and their familial, social
6 and therapeutic relationships. Interviews were conducted by one author between August 2017
7 and January 2020, were between 30 minutes and two hours duration and were digitally
8 recorded and transcribed in full. Pseudonyms are used to preserve anonymity.
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10 A constructionist approach to thematic analysis (Braun and Clarke, 2006) was used to explore
11 patterns in women's experiences of making decisions, and the meaning they gave to these
12 experiences. First, interview transcripts were read and reread to organise qualitative data into
13 descriptive categories related to 'choice' and 'decision-making' by one author. Data were then
14 examined, and emergent patterns related to women's accounts of their process of making
15 choices, how they constructed choice and the meanings they gave to the choices described.
16 Three authors then examined how experiences and understandings of choice were shaped by
17 values, emotions, illness experiences, and social interactions. Attention was given to how the
18 interviewer participated in the construction of particular narratives within the context of each
19 interview (reflexivity). Themes that were identified in the data were developed and compared
20 across transcripts to identify differences (Green and Thorogood, 2018). After gaining a sense
21 of key themes, we returned to the relevant literature to make sense of emerging findings.
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26 Findings

27 Overview

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31 Participants' accounts revealed how choice was deeply situated within the daily undulations of
32 life both within, but also extending far beyond, the specificities of cancer. Some decisions were
33 framed as personal, even in situations where women described few alternatives or where they
34 felt compelled toward a particular course of action. Other decisions were described as
35 obligations or necessities, tied to accounts of responsibility, duty, self-sufficiency and self-
36 sacrifice. Often the perceived absence of options was related to the particular relational
37 landscape; that is, the situational and relational *foreclosure* of choice, rather than its absence
38 per se. And while making decision was sometimes a concealed or silent pursuit, it was clear
39 that choice was a socially negotiated and temporally unfolding process, nested within relational
40 and interpersonal dynamics.
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44 ***'Choice' as relational: The interpersonal dynamics of individuals' choices***

45 Participants' accounts suggested that the process of making decisions and negotiating their own
46 needs and those of their family members and friends was far from straightforward and added
47 to the emotional and practical work of managing cancer. Women frequently framed their
48 decisions as moral, grounded in the best interests of close family and friends. They expressed
49 desire to protect partners, parents and children from avoidable or unnecessary pain and
50 suffering, linking their decisions to their identities as mothers, partners and/or caregivers
51 (Gibson et al., 2012; Bell and Ristovski-Slijepcevic, 2011). Indeed, the privileging of the
52 preferences and needs of others ahead of their own was often articulated by participants as
53 unavoidable. Decisions related to the continuation of active treatment, use of complementary
54 or alternative medicines, and commencement of palliative care were strongly shaped by the
55 wishes or expectations of others, either verbalised or *imagined*. Participants often explained
56 decisions as attempts to minimise the discomfort and distress of family members, even if this
57 increased their own suffering. One scenario in which this dynamic was prominent was in
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1 decisions to continue with sometimes unremitting treatments despite debilitating side-effects
2 or complications. Elma, for example, in her mid-thirties, described “no choice” but to continue
3 with treatment regimens to avoid appearing to “give in”. She was having intravenous
4 chemotherapy after numerous other treatments had been unsuccessful. For many like Elma,
5 decisions needed to be made to demonstrate persistence and willingness to “keep going”:
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7 I don’t know if I would have continued on with treatment if it wasn’t for [my husband] ... I
8 know that if I was to give in and just let chemo stop and just whatever happens with the cancer
9 happens, and however long or short it may take, obviously my mum, my dad, and my sister
10 would be devastated, and [husband’s name]. So that gives me drive to keep going... because
11 chemo is very hard... and it’s never ending. Like, with this chemo it’s pretty much indefinite.
12 I don’t know when there’s an end date, if there is an end date. (Elma, aged 36, Interview 1)
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15 Compliance with treatment regimens and “putting up with” side-effects was often described as
16 a demonstration of strength, courage, determination and optimism, illustrating normative ideals
17 of cancer patienthood (e.g., Author et al., 2019; Steinberg, 2015). Decisions made in the
18 context of end-of-life care, death and dying (e.g., guardianship for children, advance care
19 planning, palliative care) similarly revealed how expectations of women and mothers as
20 selfless and protective played into the lived realities of everyday decision-making (Bell and
21 Ristovski-Slijepcevic, 2011). Living with the knowledge of terminality (and attendant fears
22 and anxieties) often remained unspoken in familial and medical encounters, as illustrated in the
23 accounts of Rebecca and Carol, both in their fifties, despite profoundly shaping how choices
24 were made meaningful in the context of terminality:
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28 See because when you say things like this [about end of life and dying] to people or whatever,
29 or it’s my husband, it’s like, “Oh my god, you’re focusing on death.” “I’m not focusing on
30 death. I’m focusing on having everything in place before then, so I don’t have to worry about
31 it, and you don’t have to worry about it. It doesn’t mean that I’m planning on dying next week.
32 It just means that I’m trying to get things in place.” (Rebecca, aged 51, Interview 1)
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35 Family and friends, it’s difficult... I think [they] would probably say, “Don’t worry about it.
36 You don’t need to do that.” They don’t necessarily want to think about that... I think when
37 you’re going so well, especially our culture tends to put death somewhere else, hide it, don’t
38 discuss it. So, I can’t really discuss that [end of life decisions]. I don’t know that my oncologist
39 is the right person because she’s doing as much as she can with my health... (Carol, aged 57,
40 Interview 2)
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43 For some participants, silences were articulated as emanating from close others, whereas other
44 participants described self-imposing silences, avoiding discussions as attempts to shield family
45 members from upsetting or difficult conversations. The overarching imperative was the
46 maintenance of normalcy for families, inflected by an assumed connection between positivity
47 and recovery. As a result, end-of-life decisions were, for some participants, taboo, to be made
48 privately and alone. And this was not without consequence. The burden and distress of private
49 decisions and the sense of moral obligation this evoked, was evident when some women said
50 they worried about the unforeseen effects of personal decisions, for themselves or their
51 families. These issues tended to be discussed by women in their second and third interviews as
52 is captured in the excerpts from Janet and Kate, both with high-school aged children and who
53 discussed changes in their treatment and cancer progression over the course of their three
54 interviews:
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58 I mean, [putting your family first], that’s the reality. If you do die early, you want to make
59 things as easy as possible for the people who are left behind. [...] this part has been really
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1 difficult for me, that you're being told to prepare for the worst, hope for the best. So, I feel as
2 if I need to prepare to die, like write things down, letters to my kids, and I haven't done that
3 yet. I've done all the will stuff. I just feel as if I'm working so hard just to get my health back
4 [...] As my mobility improves, I think [things will] get better. I mean I've got no plans to go
5 anywhere soon in terms of dying. I'm a very good patient and do what I can. (Janet, aged 61,
6 Interview 3)

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8 I think there's part of me that feels guilty that I'll let my family down if I can't maintain the
9 dosage at the highest level. So, I am hoping that when I have my blood test... that I'll go back
10 on the full dose. (Kate, aged 57, Interview 2)

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12 Janet's quote illustrates the freedom/responsibility tension as well as competing discourses of
13 fighting cancer and prolonging life versus accepting and preparing for death. Like Kate, she
14 wrestled with decisions in the pursuit of her own health, self-care, and wellbeing needs versus
15 her sense of responsibility to family – some of which are irreconcilable. Kate, in recounting a
16 decision imposed on her – to reduce her treatment dose – retained responsibility, revealing her
17 sense of guilt, disappointment and failure. These accounts also point to the temporal dimension
18 of decision-making, including the ongoing, continuous interactional negotiations with family
19 and health professionals amidst changes in treatment and disease progression.
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22 23 ***The temporal tussle surrounding decisions of daily (and future) living***

24 Choices about treatment, care, work and family life could not be disentangled from the
25 anticipated or imagined future of living-with advanced cancer (Author, 2017; Llewellyn et al.,
26 2018). Participants discussed the challenges of making decisions about how to live in the now,
27 in relation to the largely unknown, but likely contracted, future. This was particularly evident
28 among young women, women who discussed financial difficulties, and women who had been
29 living with metastatic cancer for longer periods of time. What emerged were frequent
30 considerations (and reconsiderations) of how to spend finite time and financial resources, and
31 the consequences of such decisions (e.g., about participation in paid and unpaid work, care
32 responsibilities, dating, housing and travel for everyday life both now and into the future. Take
33 for example the following excerpt from Lorraine, who had recently stopped working due to ill
34 health:
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39 All those decisions are really hard when you're in this position because you just don't know
40 how long you have. If I knew back when I was 49 I was going to still be here when I was 55, I
41 possibly would have done things differently... the big worry is, now I've retired, have I plunged
42 us into poverty? We could have done so much more had I stayed and worked for another 10
43 years. Have I done the wrong thing? ... There's just all this ongoing financial burden and, again,
44 it's making decisions. If I jump now, am I going to live for another 30 years and be absolutely
45 poverty stricken? I don't know. In the beginning it was, "Your prognosis is bad... Two to five
46 years is usually what you're looking at... there's no choice about it. I don't know. I try to be a
47 pragmatist and just try to think, "I'm here." (Lorraine aged 55, Interview 1)

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51 As Lorraine alludes to, her decisions about continuing work were complicated by ambiguity
52 around prognosis, and the changeable nature of prognosis (see Jain, 2007; Author et al., 2020).
53 Several participants described their initial decisions as made in the context of a (particular)
54 prognosis, and the subsequent social and financial implications of *living beyond prognosis*.
55 Contemplating and foreseeing an imagined future was hindered by the unpredictability of
56 living with an incurable, progressive condition. In practice, the process of deciding how to live
57 in the now, and plan for the future, never unfolded straightforwardly, and was always imbued
58 with emotions. Denise and Amber, both in their early sixties and living with metastatic cancer
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1 for ten and four years' respectively, discuss how balancing living in the now with living in the
2 future (for self and others) was continuously being deliberated and negotiated.

3 I've got to be a little careful. I want to do all this stuff, but what happens if I do last several
4 more years and I need care, if I need to be put into a high care facility... that is a bit of a concern.
5 I don't want to leave my husband with nothing. (Denise, aged 63, Interview 1)
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7 You're told that you've got 12 to 18 months to live so you're counting the months thinking,
8 "Oh my god, I may only have nine more months to live" ... But when that time comes and I'm
9 still going, I'm still going through treatment, I'm still here, relief took over... There's always
10 uncertainty in your life. (Amber, aged 62, Interview 1)
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13 Suggestive of the moral responsibility women felt, even in very constrained circumstances or
14 when decisions were imposed on them, participants described their decisions as accompanied
15 by feelings of guilt or anxiety about the possibility of making the 'wrong choice' (Bell, 2016).
16 The negative repercussions of these decisions on themselves and others were described at
17 length (e.g., cancer progression, treatment failure, the hastening of death, increased financial
18 burden on family members, the unaffordability of future treatment or care).
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21 The following excerpts illustrate the inseparability of treatment decisions from relationships,
22 time and money, highlighting the necessity but also the complexity and difficulty of the notion
23 of 'patient choice' as mobilised in any straightforward or linear way (Llewellyn et al., 2018).
24 For instance, Kylie, in her late forties who was actively looking for work and reported financial
25 difficulties, talks about being offered a choice by her oncologist between two treatment options,
26 with a significant difference in cost (one was publicly subsidised, and one was not). The more
27 expensive option was framed as 'better' (reflective of a wider market logic) but was prohibitive
28 due to her limited financial resources. Yet she articulates the failure of the treatment as a
29 personal failing, provoking feelings of guilt and worry that her decision may have shortened
30 her life.
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34 ...my husband said, "No, we'll do it," and I said, "No, we won't," because I'm high-risk. I
35 wouldn't put our family into any – I'm already a financial burden. I'm not going to make it
36 worse. You know what I mean? The hundreds of dollars already spent this year, especially I'm
37 not now working and he's just working part-time, it's a concern nowadays. (Kylie, aged 49,
38 Interview 1)
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41 Making the 'right' choice was just one of many forms of normativity that shaped decisions
42 about how best to *live-with* cancer. Being a good patient, and particularly a good mother, was
43 foregrounded. Tammy, a fifty-year-old with two dependent children living with metastatic
44 cancer for five years, articulates the inseparability of decisions to care of self and their sense
45 of care and responsibility to their children.
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48 When I stopped working it was a very conscious decision. It was because I worked all day
49 every day providing care to others, that I felt I needed to be engaged in self-care at that point.
50 So, things like looking after my diet, looking after exercise, making sure I took up meditation.
51 A friend introduced me to tai chi and so I still practice that every day. I felt like my job then
52 was to be looking after myself, and I still, to some extent, feel that is my main job, to look after
53 myself so I can keep being a good mother to my daughters. (Tammy, aged 50, Interview 1)
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57 Illustrative of the temporal dimensions of choice, decisions about the future could not be
58 disentangled from the multidimensional complexity of participants' daily life. This included
59 the interwoven affective and economic aspects of living-with cancer. Sense of duty, morality,
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1 and time and resource constraints all shaped decision-making, both within the present moment
2 and in the imagined or anticipated future. This involved engaging in an ongoing process of
3 (re)adjustment to the changing demands and expectations of the present and the future; and
4 how resources were mobilised (and rationed) in an attempt to manage uncertainty.

5 *Circumscribed choice/delimited agency*

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8 Despite the relational, temporal and financial dimensions in which decisions were situated, the
9 rhetoric of choice was still highly valued by women. In many instances this was because choice
10 was seen to afford one of very few avenues through which women could assert control or feel
11 empowered in what were otherwise precarious circumstances, even if only at a rhetorical level.
12 Participants talked about the importance (for good patienthood and demonstration of self-
13 responsibility) of being informed about treatment options through conducting careful and
14 judicious research and linked this engagement in decision-making to feeling empowered.
15 Embracing the idea of choice-as-control, often in spite of extremely constrained options,
16 represented, discursively at least, was a way to feel better amid decreasing control over their
17 own body, identity, and life. This is captured by Nancy and Rebecca.

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21 ...with me, my biggest issue was losing control. I didn't have the surgery because it was too
22 late. There was a loss of control there. I wanted one thing and the medical people are telling me
23 another. I think for me to keep control, I had to very much be a part of my treatment decisions.
24 It's all about your head space. You've got to get your head in the right place, and you've got to
25 say, "Okay, I can't do anything about what has happened so far, but I can do something about
26 where I go from here." (Nancy, aged 63, Interview 1)

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29 They don't realise how much it does smash your confidence a bit in that you're relying on these
30 people to keep you alive and you'll hope that they're making all the right decisions for you.
31 I've always been proactive with treatments and that. But now I've got more confident to say
32 more. If I've found something out, researched something, I will take that to my oncologist and
33 say, "Hey, look, what about this?" and she'll say either, "It can't hurt," or, "There's no scientific
34 evidence to say it's going to help, but give it a go if you want. It's not going to harm you. It
35 won't contradict any of the other drugs, so try it and see how you go." I am my own advocate.
36 I have to be, because no one else is advocating for me. (Rebecca, aged 51, Interview 1)

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41 Though many women said they liked actively participating in decision-making, sometimes
42 being presented with options was experienced as stressful or burdensome; especially when the
43 options being presented as a *choice* were prohibitive or had limited evidence base. All women
44 did wish to participate, to varying degrees, in decisions about their treatment, (reflective of
45 more collaborative approaches to choice). Yet a number of women, like Kylie, Danielle and
46 Joyce, talked about the difficulties of trying to judge different treatment options, and the
47 emotional investment this required, instead expressing a desire for their oncologist to guide or
48 make decisions about treatment. Thus, our data also challenges normative assumptions of
49 choice as always desirable to patients (see also Sinding et al., 2010).

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53 Well, the doctor says, "It's this one or this one," ...You do have a choice, but I don't know what
54 to make. I do rely on her. If she goes, "Try this," you've got to rely on her expertise. I don't
55 know where else I would go. I don't know anything, so I hope she has the knowledge to do
56 things. (Kylie, aged 49, Interview 1)

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59 You're kind of just thrown into this whole new world and you don't know what you don't
60 know... I don't know if I'm living in denial or ignorant bliss. But I suppose I'm trusting... I

1 think I do need to be a bit more pro-active to learn what's out there. But it's exhausting. You
2 go in circles. (Danielle, aged 49, Interview 1)

3 I didn't need to be making lots of decisions at that stage. I just needed to know what she [my
4 oncologist] thought. Because I trust her and her judgement I just wanted her to give her
5 recommendations about what she thought I needed and that's all I expected from her. I didn't
6 expect her to give me a big pile of decisions to make. You can be a little bit shell-shocked when
7 you get a secondary diagnosis. You think, "What can I do?" You want to know what you can
8 do... It's nice to make an informed decision, but sometimes it's nice to have a bit of guidance
9 from a professional who actually knows more about it than you. (Joyce, aged 61, Interview 1)

12 As the above excerpts illustrate, for participants, especially those with more illness progression
13 or who had progressed through numerous successive lines of treatment, decisions about
14 treatment and care were made more complex because of increasing side-effects, symptoms,
15 and emotional health difficulties. Accounts suggested an increasing dependency for care on
16 clinicians, as they discussed their trust in oncologists to make decisions. This highlights the
17 limits of consumerist approaches to healthcare (particularly in relation to cancer care), which
18 positions patients as 'conscious choosers' over treatment decisions, given the inherent
19 uncertainties and unpredictabilities of metastatic disease, and asymmetries in power and
20 knowledge between professionals and patients (Sinding et al., 2010; Titmuss, 2004).

24 Illness progression was inversely related to treatment options, creating a landscape where
25 choices were progressively ambiguous or obscure (Llewellyn et al., 2018). That is, there was
26 no clear or optimal choice to be made between options in terms of their likely effectiveness.
27 Such circumstances necessitated new ways of thinking about illness and disease progression
28 vis-à-vis medication. Daisy, a single mother with one son, described making decisions based
29 on newness of the treatment (where newer drugs were seen as better). Her excerpt also appears
30 to show how shared feelings of hope (of patients, health professionals, caregivers) imbuing
31 therapeutic options, particularly at later stages of illness may work to constrain choice by
32 silently closing off alternatives (e.g., the option to forgoe treatment) (Author, 2019).

36 Initially with the metastatic, there's no choice... She [my oncologist] just said, "Right, this is
37 what we think you need." Further down the track, I guess she sort of said, "You could do this
38 or this or this." ... she gave me three possible treatment options I said, "Well, which one has
39 the best prognosis or best outcomes?" and she said, "You really can't tell. Each one works
40 differently for everyone else and all you can do is try it. But if one doesn't work, we've always
41 got other options up our sleeves and what have you." One of the options was a trial... It was
42 also a targeted therapy. So, I guess, that made me really hopeful that it was a targeted therapy
43 and therefore it was possibly one of the newer things that would work really well. I was on it
44 for eight weeks and I felt great. I didn't really have side-effects and after the eight week scan
45 they said it was working... Then I went back eight weeks later, and they said, "No, it's not
46 working anymore." So that was just, again, you're feeling good and then you just go, "Great.
47 I've just been run over by another truck and we're back at square one." (Daisy, aged 52,
48 Interview 1)

54 Women's accounts appeared to show shifting or deflection of responsibility for decisions about
55 treatment from clinicians and healthcare systems onto individual patients – especially at later
56 stages of illness or when there was a limited evidence-base for treatment – reflecting broader
57 issues of responsabilisation in medicine: Women exhibited a strong sense of self-responsibility
58 over their treatment decisions, assuming the blame for risks associated with these decisions:
59 "Even if they recommend it, it's still my decision to take it. So I've taken the risk." (Rita, aged
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52, Interview 1). This highlights the potential unintended consequences of encouraging patient choice, when the evidence base used to judge the risks and benefits of options is ambiguous, but also how the structuring of the cancer therapeutic landscape to advantage some and disadvantage others, may be concealed.

Discussion

Choice has become a central and seemingly immutable cultural logic within the context of (Western) advanced modernity and accompanying social milieu of individualisation (Schwartz, 2018). As reflected in the broader scholarship, the various manifestations of the cultural logic of choice across contexts as diverse as consumer goods, education, healthcare, political representation and reproductive rights, amplify the centrality of choice within the cultural imaginary and imbue it with meaning in our everyday practice. As such, the social valorisation of choice is not merely neutral – it is also political and materialises a range of consequences (Bell, 2016). Related to Berlant’s (2011) work on cruel optimism, the neoliberal/late modern sensibility of a productive citizenry comprised of agentic individuals often obscures its normative and even ‘cruel’ underpinnings. That is, how the idea of choice is alluring while often also simultaneously undermining. Choice-making, decision-taking, and empowerment thus become narrative forms which themselves manifest important consequences in lived experiences as well as for the structure of healthcare systems. And this, as we show, ripples across forms of health and care, and even terminal illness, imposing various forms of normativity with which people living with life-limiting illness must contend.

Of course, the imperative to choose is not the only form of normativity that circulates around disease. Instead, it is layered, in particular, with gendered moralities and ethics of care (and obligation). Choice, in the context of these women with cancer, is situated within gendered dynamics of care for both the self and others. While cancer survivorship and self-help discourse emphasise the importance of self-care, reinvention, and patient empowerment, women’s narratives illustrate how decisions to care for the self, and to care for others, are neither straightforward nor separate from one another (Bell and Ristovski-Slijepcevic, 2011; Author et al., 2019; Gibson et al., 2018). Our findings show the complex *caring work* women must engage with in their lives (and deaths), attempting to simultaneously align familial roles and responsibilities, broader normative discourses of good cancer patienthood (e.g., of informed and collaborative decision-making) and their own needs and wishes. This resonates with Cheryl Mattingly’s (2014; 2013) ethnographic work on moral experimentation, which captures how families engaged in unanticipated moral work as part of caring for their sick children. This work illustrates the challenges experienced by people, as well as the experimentation that they engage in, when making decisions about what is the morally appropriate course of action amidst the multiple (often competing) values and desires of themselves, and of others. She shows how moral work is deeply situated within familial relationships, and dependent on continuously unfolding health and life circumstances. Cultural ideas about caregiving and mothering combined with cultural discomforts and silences about end of life, death and dying, alienate those women living with non-curative cancer, especially younger women with dependent children. Thus, women must incorporate consideration of those who will be ‘left behind’, orchestrating the details of lives beyond the conclusion of their own. In this way we again see the inseparability of ‘choice’ and ‘necessity’ in navigating advanced cancer (see also Bell and Ristovski-Slijepcevic, 2011).

Indeed, the valorisation of choice offered a way for women to discursively reframe necessity or duty as ‘free choice’ (Bell, 2016; Sinding 2010). Arguably, ideals of individualism and self-

1 care, so pervasive in the cancer care literature, may increase suffering if the imposition of
2 distress or guilt tethered to such decision-making is unacknowledged. So too may suffering
3 occur if patients (women) are left to feel like they must grapple with difficult decisions (e.g.,
4 about end of life) alone. Many of the participants in this study expressed a strong desire and
5 responsibility to participate because of what they perceived as a silencing of the experiences
6 of those with metastatic cancer; a likely consequence of what Bell (2014) terms ‘the breast-
7 cancer-ization’ of cancer survivorship research. It is, thus, important to acknowledge that in
8 many ways the participants in this study reflected the demographics of white, middle-class
9 women who have been activated to participate in research meaning that they are unlikely to
10 reflect the experiences of all women with metastatic breast cancer.
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13 The ideals of patient autonomy, person-centredness, and responsabilisation are powerful
14 structuring forces within cancer care, and healthcare more broadly, in terms of the meaning
15 given to particular decisions, and patients’ sense of responsibility over their outcomes (Bell,
16 2016; Sinding et al., 2010). Yet, the *illusion of control* over the unpredictable and
17 uncontrollable that accompanies a choice logic, while experienced by some women as uplifting
18 (at least for a period of time), for many others, ultimately, increased suffering due to a sense of
19 personal failure or disappointment, adding another layer to the emotional and relational work
20 of living with incurable cancer (Mol, 2008; Bandini, 2020). Taken for granted norms around
21 the pursuit of longevity and survival delimit what options are possible (or unspeakable) when
22 living with incurable cancer (Author, 2019; Author, 2017; Bandini, 2020). Opting to pursue or
23 forgo treatment is not symmetrically structured when considered within the normative context
24 of cancer in contemporary societies (Sinding et al., 2010). What is valued culturally in most
25 contemporary Western societies is heavily skewed toward the pursuit of treatment and
26 longevity – sometimes even positioned as a choice between living and dying. This is playing
27 out within a fast-changing, increasingly privatised and complicated therapeutic space, where
28 the costs of novel treatment options are ever growing, but where the benefits and outcomes are
29 often unknown or ambiguous (Say et al., 2006), raising important questions about compassion,
30 justice and equity in contexts of high uncertainty.
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36 **Conclusion**

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38 Our findings advance scholarship on the social meanings ascribed to choice by revealing how
39 various logics (of patient choice and of care), can pull patients in different (often competing)
40 directions, as they grapple with decisions about how to live with, metastatic cancer (Sinding et
41 al., 2002). Our data highlight decisions as ongoing and continuously negotiated social
42 processes, complicated by a range of inter-relational dynamics (see Bell and Ristovski-
43 Slijepcevic, 2011; Steinberg et al., 2015). Findings have policy and practice implications,
44 especially in thinking about what it means to provide person-centred care in contexts of
45 incurability. Patients living with advanced cancer do not only want to be treated as autonomous
46 individuals, but as also always caring and living for and with others, reflective of the
47 importance of an ethic of care logic in practice. This supports the value of focusing policy and
48 research attention to the importance of greater recognition of caring for others in guiding
49 decision-making while living with cancer. But also highlight the importance of future research
50 into how technological innovation in cancer therapy can create both new horizons for patients,
51 but also new ethical and moral responsibilities (Llewellyn et al., 2018), especially given more
52 people are living longer with incurable cancers. Issues such as *living beyond prognosis* (and
53 the social, financial and existential questions this raises), increasing (expensive) therapeutic
54 options for advanced cancer, and eligibility for clinical trials, combined with the emphasis on
55 patient choice and shared decision-making, complicates choice processes for patients, family
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caregivers and professionals in care settings (Bandini 2020; Llewellyn et al., 2018); and perhaps, because of the positive meanings that are attached around agency, freedom, and autonomy, conceals some of the deleterious emotional realities of making decisions in context of life-limiting cancer.

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Credit author statement

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