

Life must go on: Everyday experiences of colorectal cancer treatments in London

María Ignacia Arteaga Pérez

Anthropology Department
University College London

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Declaration

I, María Ignacia Arteaga Pérez, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

This thesis examines the everyday experiences of colorectal cancer treatments in London (UK) through an analysis of the caregiving practices that both structure the treatment pathway and afford research participants the possibility of ‘getting on with life’. Drawing on 17 months of ethnographic fieldwork inside and outside a publicly funded gastro-intestinal cancer clinic, this thesis mobilises the perspectives of patients, caregivers and health professionals to complicate what patient experience consists of. In parallel to national efforts that gather standardised metrics to measure patient experience as something that is the exclusive responsibility of the cancer clinic, this thesis offers a detailed and context-specific analysis of the ways in which 10 cancer patients and their support networks deal with and make sense of the requirements, side effects and consequences of colorectal cancer treatments. The chapters unpack the relentless but fragile everyday work that is done by research participants to continue living, foregrounding the ethical, material and affective dimensions at stake in navigating the interruption that bowel cancer treatments pose to their lives. Developing the concept of caregiving as a world-making project, this thesis unpacks the potential of care practices to create different possibilities of experience by improvising, crafting and staging environments for comfortable living. In contrast to ethnographic work that conceives of caregiving through its ritual dimensions and performative effects, this thesis makes an argument for the usefulness of exploring caregiving as moral projects that are organised by the values that participants seek to realise. As such, caregiving understood as world-making not only offers a challenging perspective about the ways in which we cope and make sense of the suffering, frustration and anxiety of being confronted with death, but it also foregrounds the practices through which cancer patients and their support networks strive to reconfigure bodies, selves and relationships for an ongoing life.

Impact Statement

Studies in Psychosocial Oncology have devoted considerable energy in understanding the subjective experience of undergoing cancer treatments. Using the concept of ‘coping mechanisms’, researchers have explored how people affected by cancer psychologically adjust to new demands imposed by treatments, also adjusting their perception of the self. This vein of research has been essential in starting to understand patient experience and tailoring the support, offered by health services, according to patients’ needs. As this approach gains traction in Health research, the operationalisation of ‘coping’ has placed undue emphasis on the psychological traits of participants. This sometimes mobilises a normative view that distinguishes those who are ‘coping well’ versus those who are not, as if those inner traits could be the main and only variable to explain the productivity of people’s efforts to get on with life. This thesis aims to contribute to this area of research by describing, instead, the myriad practices that they articulate to navigate the requirements, side-effects and consequences of cancer treatments in their everyday lives.

Moving beyond a focus on ‘self-management’ that has been increasingly promoted by health professionals and policy makers, this thesis sheds light on an understanding of caregiving as an essential component of ‘patient experience’ during cancer treatments in London. Examining the subjective experience of patients and their support networks within the cultural phenomenon of cancer biomedicine, I asked: how do people who commit to the biomedical imaginary get embedded in the cancer narrative it offers and make such commitment work over time? How do they balance their ethical values with the economic, epistemological and therapeutic values that are also at stake during treatment? How do they navigate the multiple temporalities of cancer, its treatment, and the everyday impact it generates? How do they make sense of what is happening to them and how do they bring about the imagined possibility of living well with others? Articulating conceptual ideas stemming from Affect Theory, Material Culture and theoretical developments looking at situated values, this thesis illuminates three sorts of discussions of relevance for qualitative health research and anthropology. (1) How can we better understand ‘patient experience’ during cancer treatments? (2) How can a focus on the values that organise

caregiving practices enrich discussions of patient-reported outcomes of treatment and measurements of quality of life? (3) How can a research study that examines caregiving as world-making project shed light on the advantages and challenges of using the ethnographic method in health research?

During the last two years, findings of this thesis have been disseminated at several academic meetings in Anthropology, the Social Sciences and Qualitative Health Research, also leading the organisation of the multidisciplinary workshop ‘Crafting Values in Cancer Care across the UK’ at UCL. These opportunities have enabled fruitful exchanges between clinical practice and anthropology that continue unfolding. Furthermore, some parts of this thesis have been, and other parts will be, submitted for publication in peer reviewed journals and edited volumes.

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Chapter 1

Life must go on: Cancer care as a world-making project

1.1 Getting on with treatment

Britta is a British woman in her early 70s. She was invited to participate in the national bowel cancer screening programme, and underwent several diagnostic tests after the screening outcomes suggested the presence of blood on the stool sample she sent back to the laboratory. Britta was harbouring an asymptomatic form of cancer in her intestines. She did not get upset with the diagnosis; she just thought, ‘ok, I have to get on with this’. With a pragmatic attitude that characterised many of the responses to cancer diagnosis I found among my research participants in the London cancer clinic where I did my fieldwork, Britta accepted the recommendation from the clinical team to undergo bowel surgery and remove the tumour. At the theatre, the surgeon found out that the mass in her caecum had already grown and involved some nodules of the lymphatic system, so the team recommended that she receive 12 cycles of adjuvant chemotherapy, ‘as an insurance, not as a guarantee that the cancer will not come back’, the specialist nurse explained to her. After recovering from surgery at home during the Christmas period, Britta embraced chemotherapy in order to manage the risk of recurrence, and signed the consent form provided by the clinic.

I met her for first time while I was shadowing a consultant medical oncologist in the outpatient weekly clinic that took place every Wednesday. Using a standardised form to measure the impact of chemotherapy on patients’ capabilities to carry out everyday activities, Dr W, the consultant, was making sure she was fit enough to receive the next cycle of chemotherapy. ‘I do not have anything to report, Professor. I am doing well,’ she said. Not satisfied with the answer, Dr W asked a few questions

while he started checking the results from Britta's latest blood test: diarrhoea? vomiting? tingling? Britta answered that she had started feeling a tingling sensation in her fingertips, which was exacerbated by the cold weather. Dr W stopped looking at the screen in front of him and paid attention to Britta again. 'Does the tingling go away?' he asked. 'Yes, it happens some days after chemotherapy but then goes away... The cold weather makes it worse,' she repeated. Because she had already started to feel the tingling sensation, which points to the onset of damage to the peripheral nervous system of the body, the team had to stop one of the drugs she was receiving. *Neuropathy* (which is what the 'tingling' side effect is called) can become a serious consequence of treatment, to the extent that she might have 'not been able to walk, tie her shoe-laces or do her buttons' if its impact would have worsened, Dr W explained. Taken by surprise, Britta asked whether the neuropathy would go away after the 12 cycles she was supposed to receive. The answer was that sometimes it is permanent but there is no way of knowing that in advance. The chemotherapy team keeps an eye on it and stops Oxaliplatin, one of the drugs of the regime, if the sensation gets worse either in intensity or duration. Britta looked distressed, but then looked at me – maybe to remind herself that she was being observed – and smiled at the doctor, saying, 'I will report when that [the worsening] happens'. She received from the consultant the order for the next blood test and the prescription for chemotherapy that she had to hand to the pharmacist seeing her next. Afterwards, a brief research introduction took place. Dr W told Britta: 'She is Maria, and she is doing a study on patient experience of treatment. She will tell you about it outside.'

When I invited Britta to take part in my research in the hospital corridor, Britta was still making sense of the unwanted possibility that chemotherapy may stop before the 12th cycle. Because of the way she put it, I did not understand if the problem was stopping treatment or experiencing permanent neuropathy, or both. Irrespective of this, the uncertainty of the scenario made her feel some degree of anxiety. Still, she accepted my invitation to take part in my research and invited me to accompany her during her next chemotherapy cycle on Monday. She took the consent form and the patient information sheet I gave her so she could read it thoroughly during the week and give it back to me, signed, if she accepted the terms. She asked me to find her on Monday, as it was possible that she could not recognise me. I told her not to worry – my research depended on that. When I met her next Monday, we found out together that her chemotherapy cycle had to be postponed despite her intentions being different. The staff nurse registered with the thermometer that she had a high body temperature. Britta had caught an oral virus that needed to be looked after before giving her any more debilitating treatment. As every cycle of

chemotherapy has a negative impact on the immune system, giving chemotherapy when an infection was going on could potentially threaten her life.

Thanks to Britta, I first learnt that patients feel that they have to ‘get on with treatment’. However, it was also part of the answer that some patients gave me when refusing to participate in the study, as if to say ‘there is nothing to study, you just get on with it’. Moreover, CNS A, one of the cancer nurse specialists of the clinic who kindly supported my research, told me in a scoping conversation before I even applied for ethics clearance: ‘patients just continue with their lives during treatment’. Was it, then, that I had chosen a project that did not have much relevance – that people who are affected by cancer simply navigate the cancer treatment by going about business as usual, with patients and their social worlds remaining intact? While acknowledging that ‘getting on’ is the spirit with which patients embrace treatment, this thesis proves that there is more to it than wilful perseverance. Anti-cancer treatments changed the world for my research participants and, with it, they also changed. Throughout the following chapters, I would like to unpack both the clinical dynamics that structure a nationally standardised clinical pathway – which includes diagnosis, surgery, chemo(radio)therapy and palliative care – when treating colorectal cancer in England, and the myriad practices that 10 patients and their support networks learnt and/or improvised to ‘get on with treatment’. Whereas the clinical treatment has as a goal to stave off a cancer-related death, the practices that my research participants articulate, I argue, not only assist them in reducing the damage that cancer and its treatment inflict on the patient, but they also create a different possibility of experience. Caregiving is hence understood as a world-making project through which self, self-world and self-other relationships are reworked, at least during treatment.

1.2 Navigating treatment

Using a presentist logic that combined immediate resolution and future opacity, most of the cancer patients I met put in the effort to comply with every requirement that the cancer treatment posed; at the same time, they stopped planning anything ahead until treatment finished. The imperative to ‘get on with treatment’ started when they accepted that they would undergo surgery, yet it was made visible to me when my research participants undergoing treatment with curative intent expressed, with special emphasis, their desire to finish all chemotherapy cycles without breaks, as soon as possible. The prospect of delaying chemotherapy meant a prolongation of the suffering already generated by the treatment, even though ‘chemo-breaks’ were always arranged not to compromise their own chemo-battered health. Temporally

and ethically, ‘getting on’ was an idiom used by patients to highlight their readiness to adhere to the requirements of treatment, presenting an image of the compliant patient. It is impossible to disentangle whether I received this image of the ‘good patient’ due to my own position in the field – a research fellow who worked alongside a clinical team (which would make it a socially desirable image portrayed to me as a member of the team) – and/or whether it was the product of a wider expectation that the hospital imprinted on patients. Either way, the image was not only mobilised in the discourse, but also in the ways in which patients like Britta coped with treatment, frequently expressing the centrality of being practical in order to deal with the side effects of cancer.

Studies in Psycho-Oncology have devoted considerable energy in understanding the psychological mechanisms drawn by cancer patients and their caregivers to continue on living despite cancer treatments, adjusting routines and perceptions of the self. This vein of research has been essential to start understanding the subjective experiences of cancer treatments, and tailor support according to patients’ needs (Foster et al., 2015; Foster et al., 2016, Grimmet et al., 2017, Retzer et al., 2018, Walshe et al., 2017). However, the operationalisation of ‘coping’ has tended to place undue emphasis on the psychological traits of participants, which sometimes mobilises a normative view that distinguishes those who are ‘coping well’ versus those who are not, as if those inner traits could be the main explanatory variable to understand the productivity of people’s attempts to get on with life. This approach, if not communicated carefully, may tend to blame the patients who are struggling rather than actually support them, as advice may not consider the everyday realities of people affected by the disease. In this thesis, I aim to contribute to this body of literature from a different angle. I choose to unpick the ways through which my research participants get on with life despite treatment by focusing on practices that are articulated to navigate a changing situation. I draw on anthropological work developed by Henrik Vigh (2010), who conceptualises praxis as an array of embodied efforts mobilised in crises situations through which ordinary people seek not only to survive persistent poverty and conflict, but also to forge a future towards improved life chances. Vigh develops the concept of *social navigation* to account for the practical, affective and temporal dimensions of praxis for his young male collaborators living amid a conflict-ridden context in Guinea-Bissau. Aiming to depart from understandings of youth mobilisation in warfare based on ideological reasons, Vigh explores the voluntary involvement of urban young men in the militia as one of the few opportunities they find to realise an expected and desired form of adulthood (economically self-sufficient, able to sustain a family) in a socio-political context of declining and constricted flow of resources that marginalises them. *Dubriagem* is

the ethnographic term with which his participants understand the embodied way through which they must ‘dodge the pulls and pushes of social forces’ (2010, p.149) in an environment permanently in motion. In the author’s words:

Etymologically the word is related to *brouillard*, fog, and *debrouiller* thus indicates a process of gaining clarity whilst moving in an opaque (social) environment. It is an act of demystification. *Dubriagem* is, in this perspective, both emplotment and actualisation; it is simultaneously an act of analysing possibilities within a social environment, drawing trajectories through it and actualising these in praxis. (Vigh, 2010, p. 150)

Marked by both the attentiveness to stay safe from immediate dangers and the forward movement to plot and actualise imagined futures in a shifting and uncertain context, I find Vigh’s concept of social navigation productive to unpack the ways in which my research participants coped with the effects of anti-cancer treatments in London. In my view, the range of experience that *dubriagem* covers is inspiringly similar to my participants’ idiom of ‘getting on with treatment’. Living amid a different kind of crisis that fogs the vision of future possibilities and impacts their everyday routines, the practical goal for all my research participants receiving treatment with curative intent was to finish the treatment as an end in itself. After the eighth cycle of chemotherapy, I asked Britta how she was coping with the cumulative effects of the drugs she was receiving. Because I wanted to hear more than just her already available answer ‘I just need to get on with this’, I explained to her that ‘I was intrigued to learn about the *specific* ways in which you cope’, to which she replied in a rushed tone, as if thinking this was obvious:

Britta: If my hands are cold, I put them in my pockets until they are warm again; if I am tired, I rest; if I have [a] dry mouth, I drink yoghurt to populate my mouth with the bacteria that I have lost; if I feel a metallic taste and feel like not eating, I focus on getting at least the proteins from eggs.

Britta, as well as all the other patients who participated in my research, got on with treatment in one form or another, for there are as many ways of navigating treatment as there are patients. Perhaps concealing the emotional work that I later found was part and parcel of the treatment, Britta sought to portray an image of the brave patient. ‘I did not mourn over the diagnosis, even though some of my friends got upset when I told them. I just got on with it,’ she stated. She considered herself

lucky because she felt she ‘was doing extremely good’. After talking to other patients, she had the impression that she was coping better and she was grateful for that (if not also proud). We could read Britta’s words as wanting to portray an image of herself that corresponded to the description of the ‘cancer s/hero’ that Stacey (2013) criticises as unrealistic and normative: a strong-minded woman for whom treatment happens swiftly and who is affected by no major side effects and, more importantly, could show that she was embracing treatment while coping relatively better than other patients she met, judging from her physical and mental responses. Yet Britta seemed to give for granted the material resources that she had at her disposal and the fortune of having caught the cancer at a stage of growth that was still amenable for surgery with curative intent.

Treatment was envisioned as just a granular form of interruption for Britta. It was marked by a beginning and an end that she just had to endure momentarily. The truth, however, is that treatment does not always work: Surgeons are not always able to fully resect the tumours. Toxicity builds up and may impair the body, sometimes for long time. Cancer growth might not respond to the drugs and instead keeps growing. Being ‘cured’ and ‘not cured’ are fluid categories, as fluid as cancer trajectories are. Due to the uncertainty about the existence and spread of patho-physiological growth and due to the possible long-term consequences of treatment (among which neuropathy is only one), cancer may well be considered a chronic condition. Thus, any analysis of cancer experience needs to consider the processual and dynamic form in which self and world are co-constituted over time. Enacting ‘motion within motion’ (Vigh, 2009), my research participants developed skills to deal with the side effects and consequences of treatment at the same time that institutional dynamics and the cancer forms present in their bodies kept changing, sometimes beyond their control and awareness.

The potential fragmentation of healing narratives and the inherent opacity of what the future will bring are crucial aspects for understanding anti-cancer treatment as a temporal experience in which meaning-making and world-altering practices occur. Understanding chronicity as the context of cancer treatment enables us to look at the temporal experience of cancer from a different perspective, which may also enable us to conceive of the increasing promise of treatments to sustain lives affected by advanced cancer, as well as other types of experiences in which diseases are treatable but not curable. It is at this point that my conceptual approach departs from Vigh’s understanding of navigation practices in war-torn societies marked by stunted temporalities. It may be possible that the haziness of the cancer experience does not only demand risk reduction mechanisms in order to survive, but also an

opening towards becoming aware of the different possibilities on the horizon that are practically realisable.

Instead of exclusively focusing on treatment with curative intent, exploring treatment efficacy and survival as ‘end outcomes’, this thesis dwells on the day-to-day affective, material and ethical aspects of anti-cancer treatments that may or may not work. Unpacking treatment and its impact in people’s lives *temporally* enables us to understand how desires, practices and environments are articulated by people affected by cancer and are reshaped in relation to immediate outcomes and imagined futures. Rather than depicting my research participants as merely bearing the burden of treatment, I argue that anti-cancer treatments are not only evidence of bodily suffering caused by the voluntary subjection to medical power, but also an experience that motivates the process of ethical formation that has real effects on the self and the world of my interlocutors. Many of my interlocutors in their capacities as patients and caregivers conceived of anticancer treatments as threshold experiences that invited them to consciously decide to carve out fragile environments throughout the treatment period; inhabiting those fragile environments could offer experiences worth living for.

1.3 Suffering for others

Anti-cancer treatments are intimately associated with suffering and endurance – fear of recurrence, pain from surgery and chemical side effects, and the proximity of death. But navigating treatments may also entail creative improvisation and concerted efforts to push forward the limits of bodies, scientific knowledge and kinship relationships. Anti-cancer treatments stand for both, temporal and material ruptures and healing efforts – i.e. the annihilation of malignant tumours with drastic and toxic interventions and the opportunities to craft different possibilities of experience.

I take the idea that cancer is more than just ‘mere suffering’ from Jason Throop’s anthropological exploration of the local understandings of dysphoric experiences in Yap, a Micronesian island in the Pacific Ocean. Throop (2010) is interested in developing a phenomenological understanding of suffering that is culturally patterned, with ‘culture’ offering schemes of perception and intention through which the individual makes sense of the pain caused by strenuous physical effort when working the land of the estate (the *tabinaew*). Throop analyses the physical pain felt mostly by Yapese women as an experience of ethical formation. Virtuous suffering, in this context, is the product of intentionally fashioning somatic modes of physical extenuation into a socially meaningful experience, therefore triggering the acknowledgement by significant others who show sentiments of care and compassion to the sufferer

(Throop, 2008, p. 270). The female sufferer transforms ‘mere suffering’ into virtuous suffering by situating dysphoric experiences in a time frame that stretches beyond the immediacy of the sensation of pain and frames it as service for the community. The female Yapeese, according to the anthropologist, makes sense of her own experience of pain within a broader purpose: the sacrifice that people must make in order to honour their patrilineal ancestors from whom they will inherit the land, therefore securing a future for their own offspring. Such a process informs the transformation of ethical subjectivity. In the author’s words:

[...] by adding a ‘-for’ structure to their suffering, individuals are not only framing their effort and labour as undertaken for the benefit of another. But, are also organizing their subjectivities to align with a temporality that positions them between a past defined in terms of commitment to those ancestors who had previously worked the land, a present which is predicated upon continuing service to and respect for those contemporaries who currently hold title to that land, and a future in which obligations to those of a higher status are to be eventually fulfilled. (Throop, 2008, p. 275)

Transforming ‘mere suffering’ into ‘suffering for’, Throop suggests, assists his female participants to understand themselves as ethical subjects according to culturally sanctioned values. Centrally, such ethically meaningful extenuation of the body would have real effects: women’s efforts are aimed at crystallising in their and their offspring’s entitlement to live and harvest crops in the land that they have intentionally worked for. I find Throop’s anthropological analysis of pain useful to understand the potential of ‘transitivising’ (Throop, 2008, p. 272) dysphoric experiences. My research participants in London, regardless of their gender, also make sense of the suffering triggered by anti-cancer treatments in relation to the values they find worth striving for. In doing so, the experience of treatment sits beyond a passive exercise of extenuation and compliance, and is recast as an experience that connects them to their significant others and the possibilities of life they envision together. While waiting for the pharmacist, Leia (a woman in her late 50s from the Americas) and I were talking about the last Star Wars film that had just come out. I asked her whether that was the last film they would make or whether they will extend the saga. She told me that they will make more, but that it takes a while until they produce them, so she was not sure she could be able to see them all. Thinking that she was hitting the end of treatment and she would be soon in good health, I asked:

– **Ignacia:** Why not?

- **Leia:** Because it takes ages. People should invent those cryopreservation cameras in which they could freeze me and only wake me up when a new Star Wars movie is released. The problem of death is that you miss out on things.
- **Ignacia:** [*A bit shocked by the response*] Yes, but you are not able to feel what you have missed out.
- **Leia:** Yes, but I would like to be present for the things that are enjoyable for me not only Star Wars movies, maybe also meeting a granddaughter.

As a serious fan of the Star Wars movies and an assiduous reader of science fiction literature, her implicit comparison between anti-cancer treatment and cryopreservation cameras to prevent or push forward the implications of death was telling. She wanted to be able to do things she enjoyed, which often referred to the cultivation of relationships. The reasoning behind adhering to treatment was sometimes more explicit for other participants. Ruth, a woman of African background in her 30s (d.2017), embraced treatment ‘because her children need[ed] her’. Simon, a single man also of African background in his late 40s (d.2018), embraced treatment because he still had too much to give to the Catholic church to which he belonged, for the praise of ‘Our Lady’, his most powerful (spiritual) advocate. Elizabeth, a Latin American collaborator in her 50s, told me repeatedly, this time after having gone to an emotionally challenging appointment with the medical oncologist:

Elizabeth: I have told you already that I am not afraid of dying, I have had a good life. The only thing that worries me about dying is that I won’t see my children settling down, being fulfilled. My daughter has already formed her family, but Joseph is still young. [*Elizabeth is crying. Her son Joseph, her sister Rosa and I look at her in silence.*]

People affected by colorectal cancer in London wilfully commit to anti-cancer treatments because of the possibility of being able to continue sharing their lives with the people they love and to work for the causes that passionately enliven them. In doing so, they recast the disruptive experience of treatment, framing it within an intentional and affective pursuit that motivates them to ‘get on with treatment’. Following anthropologist Michael Lambek (2015), this thesis argues that, as clinical evidence organises a treatment pathway, ethical values provide the ‘criteria to act and discern action’ (2015, p.7) in order for patients to embrace it. Real life with (and without) cancer poses compromises. Caregiving practices are therefore shaped and interpreted according to the values that are instantiated in a given situation, which requires people to negotiate their realisation. Thus, in this thesis, caregiving is

approached as organised by my research participants' ethical values as the criteria that inspire practice, offering a way forward to them amid the 'existential excess' that cancer throws at them. Getting on with treatment could be then understood then as a 'guide for living' (2015, p.9) during the time that treatment lasts. Importantly though, those values are not individual, but are constituted as 'culturally meaningful forms' (Munn, 1986, p. 6) that only exist within networks of social relations (Graeber, 2001, p. 9).

In this vein, this thesis shows that 'getting on with treatment' is an idiom that cannot only be understood as stemming from the inherent moralisation of the 'good patient' who agrees with the expectations set by the clinical team. Patient responsibility must be complicated. From the point of view of my participants, committing to anti-cancer treatments stems from the value of 'enjoyable relationality' that they seek to cultivate. In other words, the desire to be there for others and look after them constitutes a kind of ethical value that patients put at the forefront in their discernment and reproduce when consenting to go through treatment considering all the information available to them. However, this does not mean that because they cherish, cultivate and seek to realise values, they are acting in purely rational forms. The relationship between ethical value and action, if anything, is not rational but affective. Affect indeed adds the embodied experience to the act of judgement and discernment, when those practices happen in a more conscious way, as I show in Chapter 6 for the case of the research participants who decided to receive adjuvant chemotherapy. Together with the material and structural components of care, affect also characterises caregiving projects and the worlds of experience they create with frailty and the very possibility of failure and disappointment. Thus, these ethical values that organise caregiving projects are not deterministic but fragile and open to change.

1.4 The ethical argument

'Life must go on' demonstrates that undergoing cancer treatments is not trivial, no matter how much one would like to minimise their impact. In order to keep going on with their lives with and despite treatment, patients and their support networks must navigate an experience that is marked by frustration. Daisy, the wife of Jimmy, a British patient in his 70s, told me that sometimes her husband gets very grumpy, so I asked how she was managing those emotions. The answer: 'With difficulty'. When feeling safe to talk one to one with me in the chemotherapy room, she expanded:

Daisy: It is very difficult, but you just need to get on with this. One day Jimmy was so grumpy when I was driving to come with him to the hospital, that he told me that he wanted the divorce. Jimmy repeated the same thing later during the day when we were sitting in a café that we both really liked. He told me: ‘I don’t want coffee, I want the divorce.’ I felt that he was behaving like a small child having a tantrum!

After 40 plus years together, it was clear to Daisy that Jimmy didn’t want the divorce. The problem was that he felt very ill after chemotherapy and could not manage his own emotions; thus, instead, he pounced on Daisy. From that moment on, early in the treatment, Daisy realised that she could not take her husband’s tantrums very seriously because those were part and parcel of being sick. So, she tried to deal with her husband’s sensitivity by keeping herself busy doing other things, like cleaning up or planning the garden.

As is possible to glean from Daisy’s words and I will show in detail in Chapter 7, committing to the suffering other is an affectively charged experience. This is not only because treatment is harsh on the patient, but also because my research participants aimed to stave off death through it. But when my research participants articulate practices to manage an affective experience in order to keep on with their lives, caregiving is not only affective, but also an ethical practice. Throughout this thesis, I unpack what it means to be affected by cancer from a first person perspective that foregrounds the ethical demands that confronting cancer in the everyday posits to patients and caregivers. Following Mattingly, Dyring, et al. (2018), I consider the experience of cancer and specifically the ethical demand posed by caregiving in terms of an ‘excess’. Excess, in this type of circumstances, is an experience characterised by three features: First, it is just ‘too much’ to be dealt with by the resources at hand, meaning that there is an asymmetry between demand and skill. Second, the situation addresses the person in a specific way as a socially, historically and materially situated relative or patient. Third, as an experience of existential excess, it propels the person to imagine different possibilities for themselves and others (Mattingly, Dyring, et al., 2018, p. 47).

In developing this argument, Mattingly proposes the concept of ‘narrative self’ to understand the experimental and not always coherent way in which Andrena, a Black American mother to a young child with life-limiting brain cancer in the USA, delves into a process of moral re-envisioning at the wake of her daughter Belinda’s cancer diagnosis. After undergoing brain surgery, Belinda had to learn to talk and walk again at her four years of age, and Andrena felt that her closest family was giving up on the child, thinking about her as if there was nothing else to do in order to prevent

her death. In this context, Mattingly introduces the idea of the ‘care for the intimate other’ as a moral project propelled by the existential excess that Andrena faced. As the mother of the child, Andrena did not want to be one more person looking Belinda in the eyes and thinking that she was ‘already gone’ (Mattingly, Dyring, et al., 2018, p. 54), so she embraced therapy in order to create a hopeful scenario, making sure that her daughter could get the best possible care from the physical and speech therapists and enjoy life as a child (not only a patient) for as long as she could. However, the situation also propelled Andrena to re-envision herself in a different way. She befriended a woman who was mothering a girl dying from the same disease, so she could get acquainted with a gloomier situation that was also inevitable for her.

In my own ethnography, I see the resemblance between Mattingly’s argument that caregiving of either oneself or an intimate other generates an ethical demand that addresses the person specifically. Anti-cancer treatments in London also require that my research participants develop skills to meet the demands of cancer, but, more importantly, ask them to experiment with different ways of self-cultivation, such as Daisy’s effort at remaining calm and attentive for the benefit of the patient. Being affected by cancer, as the passivity of the verb signals, is not something my participants chose; instead, it is something that it is thrown at them (patients and informal caregivers alike) in the particular situations they are living. The cancer diagnoses was thrown at Jimmy and his wife Daisy just a few weeks after they had moved houses, in a neighbourhood where they did not know anybody and Daisy was asked not to disclose the information to anybody. For Leia, diagnosis and treatment happened while still looking after two of her three daughters. She worked throughout treatment despite the debilitating side effects that she was suffering because she could not afford not to receive her full salary. Nobody is ever prepared to receive the diagnosis of a life-threatening condition and yet all my research participants embraced treatment within their everyday contexts. This not only means that cancer and caregiving are thrown at you without notice, but it also means that cancer does not happen in isolation. Patients and caregivers then experience a form of existential excess that is situated in their own facticity, which makes the experience of cancer not an exception to the everyday but another component of it that makes it more challenging. In the process, ambivalent emotions have to be managed, appointments have to be attended, bills have to be paid every month, and life futures must be re-imagined.

Moving beyond a focus on ‘self-management’ that has been increasingly promoted by health professionals and policy makers (see Chapter 5 and Chapter 6 for a critical discussion of the uses and limits of the concept in cancer care), this thesis seeks

to shed light on an understanding of caregiving as an essential component of the ‘patient experience’ during cancer treatments in London. I develop the concept of caregiving as a world-making project in which patients, support networks and health professionals engage. Centrally, it argues that caregiving is not necessarily rational (even though vast amounts of information have to be processed); it is underpinned by material, ethical and affective dimensions that change over time.

1.5 Caregiving as world-making projects

I develop the concept of world-making as a heuristic to understand the potential of caregiving practices used by my research participants to keep life going despite treatment. I aim to keep the focus on the pragmatism with which people sought to navigate the cancer treatment, and tease out how and to what an extent practices that were silent and sometimes relentless, create possibilities of experience other than death. As a concept, world-making extends the idea proposed by Ortnner (2005) and Mattingly (2014) that, in order to examine the analytical value of ‘possibility’, we need to tease out the complexity of the subject as a moral agent that is able to shape history (with small h, in ordinary acts) even when that subject is made by History (with capital H). The subject is understood not only as a product of History and its circumstances. Instead, the approach mobilises an understanding of the cultural repertoire in which research participants are embedded not only as a resource to make sense and conform to given organisations of social life, but also as a resource to change these.

Understanding caregiving as a fragile project that seeks to realise ethical values (which produce tension with other values) rather than as a ritual practice where only performative effects are accounted for, I follow David Graeber’s proposition that ‘it is values that bring universes into being’ (2013, pp. 231) in cancer care. In doing so, I also attempt to move away from narrative approaches that exclusively focus on meaning-making as an essential operation to understand cancer experiences in hindsight. Instead, I look to offer a processual and non-deterministic account of the possibilities of experiences that can be articulated in practice. Thus, I use the concept of care as a world-making project to illuminate the myriad practices and affects that my research participants draw upon to minimise toxicity and frustration, repair incontinent bodies, make the relationships they value last, and shape their understandings of themselves when death is imminent. As such, world-making incorporates the challenges and limits that patients and caregivers experiment with at multiple levels throughout the treatment pathway while simultaneously opening

up an analytical space to account for the attempts through which my research participants strive to articulate a life worth living.

In proposing to understand caregiving as a world-making project, I am seeking to illustrate two major points of relevance for an anthropology of cancer. First, that caregiving may be understood as inspired by different kinds of values that animate the articulation of meaningful experiences, rather than as enacted as a ritual process that enacts specific conventions or obligations. Second, that cancer treatments, in their unfolding of timed and sequential clinical interventions, do not only need to be mitigated in their impact on the patient, but also invite people affected to imagine and realise a different possibility of experience. Rather than ‘just getting on’ with treatment, my research participants draw on their already available resources to navigate treatment, shaping their definition of the self and their relationship with the world. And striving to stage or improvise comfortable social environments not only cushions the sick person, but also modifies understandings of the self of those who commit to their care as well. Caregiving can be then analysed as a mode of engagement with cancer through which self and world are phenomenologically co-constituted.

Phenomenological approaches to lifeworlds are not new to anthropology. Using the concept of embodiment, scholars have convincingly shown that there is no world that exists independently of our experience of it (Csordas, 1994, p. 6) (see also Desjarlais and Throop, 2011; McDonald, 2018; Wolputte, 2004). However, in addition to the focus on the lived experience of the situated and embodied self that perceives the world and makes sense of it intentionally and intersubjectively, I would like to offer an account that does not stop in the processes of incorporating what is ‘thrown’ at the subject in its existential immediacy as a being in the world (Heidegger, 1971). Understanding caregiving as world-making makes room for the little spaces for comfort that such a subject may carve out along the way. It foregrounds the plasticity and frailty of body, self and world in cancer care, enabling the incorporation of the idea of possibility to phenomenological approaches concerned with the embodiment of cancer treatments. In doing so, this thesis extends the exploration on the anthropology of becoming that some scholars have recently advanced. Following French philosopher Gilles Deleuze, Biehl and Locke (2017) sought to unpack the notion of becoming as ‘a mode of existence open to improvisation’ despite the ‘constraining effects of social, structural and material forces which are themselves plastic’ (p. 10, Foreword). In this way, world-making shares with the anthropology of becoming a concern about the immanent possibilities for being in the world amid situations that must be endured, in which subject and environment unfold in shifting and contingent ways. Equally, caregiving as world-making seeks to foreground research participants’ experiences

of time and the capacity of what the authors understand as desire, but I examine in terms of ethical values, to try and organise their worlds. Importantly though, a methodological approach to either becoming or world-making, then, requires attentiveness to the unknown in the way we use and write ethnography. Approaching unfinished projects that are frail, where futurity may mean futility, especially in cancer contexts, requires that our mode of doing social science is able to keep the humbleness and tentativeness of our participants' attempts to carve out possible worlds of experience. Here, ethnographic conceptualisations are not set in stone.

1.6 Inspiring works

Important anthropological work on the cultural variability and socio-historical situatedness of experiences of cancer patients and survivors has been published in recent decades (Dein, 2006; Matthews, Burke and Kampriani, 2015; McMullin and Weiner, 2009). Through the analysis of cultural and personal narratives, medical anthropologists have been long interested in unpacking the force with which cultural narratives frame how people affected by cancer *should* make sense of their experiences. These accounts critically reveal the fault lines and modes of violence that promoting those normalising and normative cultural narratives exerts on individual people (Bell, 2012; Bell, 2014, 2017; Bryson and Stacey, 2013; Greco, 2016; Jain, 2013; Stacey, 1997; Steinberg, 2015). Instead of adhering to, or reproducing, explanations, medical anthropology has championed a research approach that foregrounds the voices of people affected by cancer, enquiring into how diverse populations make sense of their cancer experiences while seeking diagnosis, undergoing treatments, and trying to recompose their lives after cancer's aftermath in the context of their everyday lives (Hunt, 1998; Kampriani, 2009; Macdonald, 2013; Mulemi, 2010; Porroche-Escudero, 2014; Lora-Wainwright, 2013; Vindrola Padros, 2011; Wainer, 2013).

In the effort to tease out the practices that co-constitute biomedical approaches to cancer, medical anthropologists have complemented the use of interviews and participant observation outside clinical domains with the possibility of carrying out observation techniques and more regulated participation in clinical domains. Current scholarship on the hospital ethnography of cancer can be characterised as concerning: its situated clinical discourse (DelVecchio Good et al., 1900, 1994; Mattingly et al., 1994); the negotiation of explanatory models that takes place within the doctor-patient relationship (Bell, 2008; Bell, 2009; Fainzang, 2016; Høybye and Tjørnhøj-Thomsen, 2014; Mattingly, 2010); the translation of knowledge practices into therapeutic technologies (Gibbon, 2007; Gibbon, Joseph et al., 2014; Keating and Cambrosio, 2011; Kerr and Cunningham-Burley, 2015); and the impact of the

political economy of health that affords different possibilities of care (Day 2015, 2016; Livingston, 2012; Mulemi, 2010; Sanz, 2017).

Building on this breadth of research, I consider the values that organise my research participants' worlds of experience not only as meanings that are instantiated through practices of care, but also as potentials that could transform the world. In a way, this focus on caregiving as motivated by values has invited me to find a shared theoretical ground beyond the anthropology of cancer but within the discipline of social anthropology that could stand as a fertile terrain – or scaffolding, so to speak – to develop the idea of caregiving as a world-making project. My conceptualisation of caregiving here sits at the border of a strictly phenomenological approach to cancer experiences. For even though phenomenology enables me to understand how intersubjective experiences are constituted within particular cultural contexts, this approach falls short in terms of pulling out the affective, material and ethical complexities of caregiving as experienced by my research participants. I am indebted to three ethnographies that theoretically inspired me to think in these terms, foregrounding the reality effects of interactive and situated practices. I owe to Munn's brilliant ethnography, *The Fame of Gawa*, my understanding of the co-constitution of value and actions (see also Otto and Willerslev, 2013); to Navaro-Yashin's *The Make-Believe Space* my understanding of the affective and material components of caregiving that have the potential to create worlds; and to Mattingly's *Moral Laboratories* my approach to care as moral work that strives for the other's flourishing.

From Munn, an anthropologist who worked in Gawa's Trobriand Island, I take the idea of potency of practices to extend an intersubjective spacetime in immediate experience, a spacetime of self-other relationships formed in and through practices. She analyses the production of symbolic value that economic exchanges of objects create, which was deemed essential for the moral and social order of the Gawan community. In her words: 'Gawangs are concerned with the relative capacity of certain acts or practices to create potentialities for constructing a present that is experienced as pointing forward to later desired acts or material returns' (Munn, 1986, p. 11). Munn argues that value practices constitute the subject as much as their social world; in other words, the extension of spacetime is a process that defines the form in which the world is experienced, which constitutes (or is part of) the actors themselves. The analytical key of the argument here is that the expansion of spacetime is intersubjective – that is, the practices that transform and realise value must be acknowledged as such by the other. Cultural meanings are then implicated in those value practices. However, as much as value is produced by certain culturally meaningful practices, it may also be destroyed. In Munn's ethnography, fame is a

paramount positive value, whereas witchcraft is a negative one, both structuring a moral landscape for the community that assists them in organising their world. Fame expands spacetime. Whereas fame is embodied by the community (and seen through quasi-signs) and gives Gawans the ability to have an immediate experience of heightened control of the world, witchcraft threatens the liveability of the community when reducing equality among members, transcending the equally shared spacetime and provoking jealousy between each other. Thus, negative value has the potential to destroy processes of value creation, which (for Gawans) are processes premised on the equality between parts. As Munn put it: ‘On one hand, the witch is the personification of dominion and radical superordination that negate equalization and balance in intersubjective relations. On the other hand, the witch emerges punitively in contexts where an element of increment or imbalance appears to violate the egalitarian ethos’ (Munn, 1986, p. 233). It is the potential of creating immediate experiences of heightened control that draws me to Munn’s work to understand caregiving as a world-making project. Caregiving, as a set of culturally meaningful practices that are inspired by ethical values, also organises an experience of the world, which not only seeks to stave off death and extend conviviality with the suffering other, but also reshapes human parties involved in dynamics in which cancer cells, affects and materials are difficult to control. However, whereas for Munn values are made commensurable in their impact on spacetime (with fame expanding it and witchcraft reducing it), my ethnographic material indicates that the values acted upon and realised in cancer care require judgement and discernment, as there is no clear delimitation of – for example – therapeutic values. I show in Chapter 6 that, for chemotherapy, the toxicity that creates efficacy and therefore affords survival is at odds with quality of life. Too much of a good thing may end up nullifying the well-being of the person. This is why doses are adjusted and side effects are considered in detail.

Moving from a symbolic analysis of exchange patterns that are organised by moral principles to a spatialised analysis of practices of governmentality, I am indebted to Navaro-Yashin’s understanding of the ‘make-believe’ as a concept that foregrounds the work and materiality of the imagination (2012). Make-believe, for this anthropologist, is a social form that enables her to account for the processes through which the crafting of Northern Cyprus territory historically occurred. As a social space composed in the aftermath of a war that culminated in an unofficial exchange of populations along lines of Turkish and Greek ethnicities, Navaro-Yashin develops the concept of make-believe in order to refer to the labour of imagination and the materiality necessary to constitute the unrecognised state of the Turkish Republic of Northern Cyprus. Such labour, the author argues, entails the constitution

of a space and territory, the modes of governance and administration, and other material practices (Navaro-Yashin, 2012). Analysing both the process of construction of the Republic, and the experience of those who were residing in the territory in the late 90s, the make-believe is understood as a social space marked by a sense of ‘stunted temporality’, of being spatially enclosed (in northern Cyprus) and temporally in a limbo status for an indefinite period of time (until the state is recognised internationally). At the same time, the make-believe state was employed in practice to gloss over the ‘spectral quality’ (p. 13) of the space in which former Greek Cypriots who were residing in the area have an enduring affective ‘phantomic presence’ (p. 14). In other words: current Turk Cypriots residents experience the affective intensities discharged by the remaining fields, homes and belongings that the Greek population left behind due to the war in 1974. Attempting to understand the experience of living in a de facto state, Navaro-Yashin develops a perspective that she calls ‘the affect-subjectivity continuum’ in order to map the entanglement of inner and outer worlds of affect in a ‘spatial cartography’ (p. 24), in which institutional and legal practices and modes of governance are capable of discharging affect beyond human intentions. Like Navaro-Yashin’s argument that affect is not exclusively coming from the interiority of the person – from human subjectivity – but is discharged by the environment (Navaro-Yashin, 2012, p. 21), I see that cancer treatments, and hospitals as well, are experienced as suffused by frustration. This is an affect that not only comes from the existential disappointment that is a mark of the frailty of life and of any caregiving effort, but also from clinical dynamics and physical infrastructures. Like Navaro-Yashin’s description, I see how the hospital discharges a ‘persistent irritable quality’ stemming from environments that harbour ‘phantoms’ in a spectral quality for the people who attend to be treated. However, as I show in Chapter 7, health professionals and research participants I met will consciously negotiate this spectral quality and the frustration that cancer discharges, attuning to each other and staging environments of emotional containment. In more specific terms, I show that, in order to get on with life, support networks apprehend the frustration stemming from anti-cancer treatments as an ethical substance that my research participants worked on in order to prevent its expression and, therefore, avoid further damage to already vulnerable cancer patients.

The third ethnography, and to which this thesis speaks more closely, is *Moral Laboratories*. Here, I will refer to the theoretical ideas that enable me to consider caregiving as an ethical project that opens up temporal instantiations of familial and social transformation. Arguing for a first person ethical approach that fits into the academic development of ordinary ethics (Das, 2007; Lambek, 2010), Mattingly suggests that looking after others involves moral work through which caregivers

consciously deliberate what are the best possible options for patients with chronic conditions in a context of uncertainty. Here, the understanding of possibility is tied to the idea that the world is not a place of already realised ends (Mattingly, 2014, p. 196) but rather an arena in which ethical demands are thrown at the subject, who in turn crafts moral experiments in order to realise a version of the good life. Thus, the potential change that the human subject may make is in the ‘small histories that comprise ordinary life’ (2014, p. 203) (see also Mattingly, Dyring, et al., 2018). Following the Aristotelian idea of human flourishing, Mattingly argues that ethical work sits in the everyday. In her words, ‘cultivating virtue is part of the process of becoming, of unfolding a life in which the future is potential and the present moment contains possibilities, but it is also an end in itself’ (p. 10). Importantly, in a world where many possibilities could be crafted, discernment is situational, considering cultural norms and intersubjective understandings of the scenario. However, she argues, cultural conditions do not only provide resources for normative actuality (reproduction of practices), but also for its transformation or critique (subjunctive potentialities). For Mattingly, the possibilities that caregiving open up for the creation of social worlds are realised through the making of uncertain experiments where tragedy and disappointment work hand in hand with the making of more hopeful scenarios for the ill person to whom one commits. Following a similar line of thinking that also incorporates the cancer patient as a moral agent, and not only the caregiver, in Chapter 8, I unpack some aspects of Ruth’s subjectivity at the end of life. She was a woman from an African background in her late 30s who was the mother of two young children. She created a context where, even if tragedy and disappointment were tremendously real, they did not have the last word.

I take the articulation of ideas stemming from affect theory, material culture and theories on situated values to be the main theoretical contribution of my thesis to the field of medical anthropology in general and to the study of cancer experiences in particular. Through the development of the concept of caregiving as a world-making project, I aim to elucidate the ways in which the temporal unfolding of caregiving practices changes both subjects and the worlds in which they are immersed, shedding light on the frail, malleable and improvisational nature of human efforts to stave off death.

1.7 Institutional and economic context: Cancer care in the UK

Within the NHS, cancer care enjoys a relatively privileged position (Brown et al., 2014). Table 1.1 shows that with expenditure that comprises 5.2% of the annual health budget of the NHS, England spent £5.68 billion on cancer care in 2012–2013. This was just below the 10.31% (£11.28 billion) spent in mental health services and the 6.30% (£6.9 billion) spent in treating problems associated with blood circulation (Jonsson et al., 2017).¹ The NHS spends, on average, £4,192 in cancer care per capita in the UK, a volume that is below the average for countries such as France and Germany, the main points of reference for healthcare policy in the UK (Jonsson et al., 2017). Nevertheless, the NHS is more efficient (providing better value for money) than most of the resourceful healthcare systems (Thorlby and Arora, 2017). Health economists argue that cancer care is expensive because of its high opportunity costs. Drugs are especially pricey, so for every new drug approved, there is a trade-off and health providers must give up treating other conditions if the budget remains constant. Cost-effectiveness is constructed in terms of QALY values – that is, an econometric output that defines the number of ‘quality’ years gained by the medical intervention, adjusting for the current medical condition. The National Institute for Care Excellence (NICE) approves the licensing of drugs whose cost-effectiveness appraisal shows a net ‘health gain’ in terms of years of quality-adjusted life in the population superior to one year, per each £30,000 spent (McCabe et al., 2008; NICE, 2013). Yet, drugs in cancer care tend to lie above that cost-effectiveness threshold and are still approved due to the political commitment to offering cost-free treatment for the disease to eligible British residents (Claxton, 2018, personal communication).

Moreover, in 2011, the British government authorised the creation of a ring-fenced bursary: the Cancer Drug Fund (CDF). Initially investing £200 million to give patients access to cancer drugs with potential benefit but that still required more evidence to become fully marketed, it was overspent in 2013. So between 2014 and 2016, the NHS invested £340 million more, enabling hundreds of patients with advanced cancer to receive life-prolonging systemic treatments. In the cancer clinic, the team frequently applied to obtain drugs under specific conditions of drug resistance because the patient’s cancer had progressed on all available standard lines of treatment. For those cases, the always-ready-to-work specialist registrar applied to obtain a more expensive drug for the benefit of the patient, within a set of pre-defined

¹Programme budgeting provides a framework for estimating NHS expenditure across healthcare conditions, also known as ‘programmes categories’, across the whole care pathway. Data for the years 2012–2013 is available at: <https://www.networks.nhs.uk/nhs-networks/health-investment-network/news/2012-13-programme-budgeting-data-is-now-available>

Table 1.1 Programme Budgeting spend all healthcare conditions in England Financial year 2012/13

Category code	Programme category	Expenditure (£bn)	Spend per head (£)	Proportion budgeting	Proportion of expenditure NHS
1	Infectious Diseases	1.55	29.16	1.60%	1.41%
2	Cancers & Tumours	5.68	107.21	6.00%	5.19%
3	Disorders of Blood	1.15	21.72	1.20%	1.05%
4	Endocrine, Nutritional and Metabolic Problems	3.06	57.76	3.20%	2.80%
5	Mental Health Disorders	11.28	212.89	11.90%	10.31%
6	Problems of Learning Disability	1.58	29.80	1.70%	1.44%
7	Neurological	4.44	83.81	4.70%	4.06%
8	Problems of Vision	2.30	43.46	2.40%	2.10%
9	Problems of Hearing	0.46	8.59	0.50%	0.42%
10	Problems of Circulation	6.90	130.16	7.30%	6.30%
11	Problems of the Respiratory System	4.69	88.58	5.00%	4.29%
12	Dental Problems	3.58	67.64	3.80%	3.28%
13	Problems of the Gastro-Intestinal System	4.76	89.91	5.00%	4.35%
14	Problems of the Skin	2.10	39.62	2.20%	1.92%
15	Problems of the Musculoskeletal System	5.34	100.86	5.60%	4.88%
16	Problems due to Trauma and Injuries	3.72	70.19	3.90%	3.40%
17	Problems of the Genito-Urinary System	4.78	90.13	5.00%	4.36%
18	Maternity and Reproductive Health	3.50	66.03	3.70%	3.20%
19	Conditions of Neonates	0.99	18.61	1.00%	0.90%
20	Adverse Effects and Poisoning	0.98	18.52	1.00%	0.90%
21	Healthy Individuals	1.82	34.34	1.90%	1.66%
22	Social Care Needs	3.34	63.10	3.50%	3.06%
23	Other Areas of Spend/Conditions	16.77	316.56	17.70%	15.28%
Total		94.78		100%	

Note: Total NHS expenditure in England is estimated at £bn 109.41 for financial year 2012/2013 (real terms).
Sources: Programme budgeting from NHS networks. Available at: <https://www.networks.nhs.uk/nhs-networks/health-investment-network/news/2012-13-programme-budgeting-data-is-now-available> Health Foundation (2015)

Current NHS spending in England. p.5. Available at:

https://health.org.uk/sites/health/files/FundingOverview_CurrentNHSSpendingInEngland.pdf

drugs that, although had proven efficacy in randomised controlled trials, were not so competitive in relation to the cost/benefit ratio as to make them available for all. The registrar had to argue why standard options are not beneficial for the patient any more, obtaining either a rejection or an approval from the Fund's committee. Fortunately, patients undergoing treatment with curative intent will unlikely need to go through several lines of treatment, as the whole ambition is that after surgery and chemoprevention, the oncological condition would be eradicated.

Within the cancer care ecology, independent organisations also play a vital role in raising awareness, providing healthcare services and supporting people affected by cancer. I focus on prominent charities working with all types of cancer that my research participants were involved in. Among them, Cancer Research UK (CR-UK) stands out as the main independent platform to coordinate translational studies and provide accessible information to the public. Meanwhile, Macmillan Cancer Support stands out as the charity with the most coverage in cancer services, providing: healthcare in partnership with specific hospital trusts; financial, emotional and practical support for people affected by cancer; and opportunities of learning and development information for professionals working in cancer services. Whereas CR-UK disclosed an expenditure of £666 million in research in 2016², Macmillan raised £245 million in 2016 to cover its activities throughout the UK³.

Thus, cancer services are comparatively better funded than health services supporting other conditions, but cancer patients go down a long path to obtaining access to these specialist and resourceful centres. While the NHS remains generally underfunded (Charlesworth and Johnson, 2018), cancer patients are not necessarily better off. In spite of the high volume of taxpayer funds that are allocated for cancer care and the partnerships that the NHS has established with other health services independent organisations, current levels of general funding are not able to cover increasing demand for services in real terms. This fact works against the very mandate to reduce unwarranted health variation across the country, and the socio-economic stratification that such health inequality affects everybody. As sociologist Katherine Smith and colleagues argue:

The prevailing financial and policy environments are hardly favourable, with local government (and particularly authorities in the most deprived areas) being especially hard-hit when it comes to public spending cuts

²This number does not include a higher volume of funding for primary and translational research in oncology that universities and other research centres attract from (inter)national funding bodies and that CR-UK coordinates. Source: <http://www.cancerresearchuk.org/how-we-spend-your-money>.

³This number does not include all the value that hundreds of Macmillan volunteers give when raising awareness of cancer, supporting patients' needs or fundraising for the charity. Source: <https://www.macmillan.org.uk/about-us/what-we-do/our-annual-report-and-accounts/how-we-raise-and-spend-our-money.html>.

[...] It reduces the capacity of the NHS and local authorities to focus on anything other than immediate demands and statutory responsibilities. (Smith, Bamba, et al., 2015, p. 142)

Disparity in healthcare has been complicated by the deep re-organisation initiated in 2012 with the approval of the Health and Social Care Act. The implementation of the bill proved to be the biggest institutional redesign of the NHS in 63 years. It created NHS England and, within it, destroyed bodies such as primary care trusts. The latter were replaced with 'clinical commissioning groups' (CCGs) at the local level (Health and Social Care Act, 2012). With an ideally better grasp of the budget to be decided according to local needs, CCGs were mandated to work in coordination with 'mental health community services', local boroughs and local public health bodies such as the 'Health and well-being boards'. The idea was to create 'integrated care models', which nevertheless have been so far experienced in fragmentation (Ham, 2018). Moreover, private and independent providers were introduced at the primary and secondary levels, allowing them to hold contracts and supply healthcare and social care services at a standard national tariff. With ever so many actors involved, the bill galvanised competition among healthcare providers, ensuring higher and transparent accountability of healthcare performance outcomes. More information would then enable patients to make informed choices (Ham et al., 2015), providing incentives to every service to strive for excellence. In order to enable patients to be informed consumers, NHS Digital was created to curate multiple types of metrics and digital systems. The rationale was that competition would create efficiency and improve quality of care, so new regulation bodies were created to oversee the process. NHS Improvement was established to monitor and inspect public and private secondary trusts, whereas the Care Quality Commission was established to monitor and inspect all social care and healthcare services at every level. In actuality, the restructuring of the system not only created fault lines and fragmentation in the care that patients started to receive (Brown et al., 2014; Cole et al., 2016), but also coordination between actors grew increasingly difficult within a system that promoted competition rather than collaboration (Timmins, 2012). Thus, even though the Care Quality Commission has been a significant independent body that makes healthcare performance auditable, offering results for the public knowledge so they could choose where to be treated, health disparities between trusts and between general practices remain striking.

Deciding to remain available and open to understand the experiences of people affected by colorectal cancer from their own point of view, I spent 18 months (from November 2015 to March 2017) in and out of a cancer clinic that is part of one of

the eight teaching hospitals in London. The hospital belongs to a foundation trust. Receiving public funding, it has the obligation to both treat all eligible patients and adhere to NHS clinical protocols; however, having the status of a foundation, it has some room to decide models of care to better meet the needs of the local community. Moreover, the status of foundation allows it to receive income from private patients and clinical research, re-investing all the profit in improving infrastructure and operations. Within this context, the voices of research participants that the reader will hear in this thesis could be considered fortunate: they had managed to receive treatment in a hospital that was recognised by clinical audits, healthcare professionals, medical students and patients as a service striving for excellence.

During the first three months of fieldwork, while recruitment was taking place, I mapped out the dynamics of the clinic, shadowing six health professionals in their appointments with patients during the outpatient chemotherapy clinic. The team introduced me as ‘Maria, a PhD student’, and patients used to the research dynamics of a teaching hospital in which medical students frequently sit in during appointments, did not seem to mind my silent but all-too-real presence in the room. The team was careful to let me hear, but not see, any clinical examination to respect what for them was the defining boundary between what a medical student and I could do. At the end of those consultations, and when the treating doctor thought it was appropriate (considering their understanding of the patient’s condition and of the inclusion criteria of my research), patients would receive an invitation to participate. Recruitment would happen more or less in the following way, as it happened with Seaus, the first person I recruited, a Western European man in his 60s affected by sigmoid cancer.

- **Dr Z:** Maria here is a PhD student at UCL doing research on patient experience at this clinic. She would like to follow you throughout treatment, so if you are interested, she will invite you to read an information sheet and sign a consent form if you decide to participate.
- **Seaus:** Of course, she can follow me. Why do I need to sign a consent form for that?
- **Dr Z:** Because she will write about you in her thesis, and also because she might ask you questions that we usually don’t ask.

Starting with Seaus, I observed the clinical interactions of a total of 10 research participants who generously let me participate in their treatment experiences and their lives, some of them also giving me access to understand the experiences of the relatives and friends accompanying them. As I show in more detail in Chapter 2, out

of the 10, 30% were born and bred in Great Britain, 50% were women, 50% were 50 years old or younger, and 50% were undergoing treatment with curative intent. After twelve months in the hospital, I invited four of the patients with whom I built the strongest rapport to spend time outside (and inside) the clinic with me for six months. In an effort to make sense of their experiences of cancer in the context of everyday life, I frequently met these four patients and their caregivers in different capacities outside the clinic, going for coffee at their workplaces, shopping with them in their neighbourhoods, organising and praying at church events, and simply talking to them at their homes over a cup of tea. As I got to know them better, my ethnography became richer by drawing on their lives and treatment experiences. To triangulate my own observations with the perspectives of the clinical team, I spent a year observing weekly professional meetings in which the multidisciplinary team discussed approaches to manage patients' medical conditions. At the end of the 12-month stay in the hospital, nine healthcare professionals kindly made time in their busy working agendas to talk with me.

1.8 On clinical interventions and narratives

Anti-cancer treatments are structured in a set of clinical interventions that are used with and without curative intent. *Pathways* are technical guidelines created by the National Institute of Care Excellence (NICE) in consultation with a vast group of professional stakeholders and audited by the Care Quality Commission and the British National Healthcare System (NHS) Monitor bodies. In the NHS, hundreds of complex health conditions have their treatments structured in pathways, which standardise the type, quality and timing of interventions across the country. The aim of their design is threefold: (1) to improve survival and quality of life for the whole population residing in the country; (2) to reduce the geographic variability of such outcomes; and (3) to control the cost-effectiveness of treatments, so that public funds that afford health provisions are sustainable over time. Following the understanding that narratives are not only a way of making sense of abrupt events in one's life, but also a mechanism through which (clinical) experience is created in the interaction between healthcare professionals, patients and caregivers (Mattingly, 1998), in this thesis, I explore the unfolding of a treatment pathway, examining its scope and limits from the point of view of both those who mobilise it in practice and those who embrace it in London. Taking the 'beating cancer' allegory seriously, I seek to skim the hype and bravado out of the question and ask what it takes to commit to the biomedical imaginary. As a concept that I take from DelVecchio Good (2001), an US American anthropologist who explores the affective response of clinical

narratives that invite people to adhere to savage treatments with no proven efficacy, the biomedical imaginary is understood as a discursive construction of resourceful healthcare political economies, fuelled by the hope that biomedicine will bring out ‘many possibilities’ other than death by cancer.

This thesis unpacks a common form of treatment trajectory for both colon and rectal cancers (which may include different interventions) in a way that shows the fluidity of categories in the lived temporality of treatment. By doing that, it includes a description of chemo-radiotherapy even when it is only used when treating patients affected by rectal cancer, and it only foregrounds the description of adjuvant chemotherapy, used with curative intent, but not of chemotherapy for advanced cancers, as the substance of the drug regime is relatively similar (if not in terms of the use of monoclonal antibodies). Combining both treatment trajectories enables me to highlight an essential feature of (colorectal) cancer treatments: that what is curative and what is not for clinical intervention is not fixed, but a consequence that greatly depends on factors beyond the control of health professionals and patients. There is no certainty about the final outcome of cancer treatments; people receiving treatment with curative intent may face long-term consequences that keep affecting their health, or may have a cancer recurrence despite their blind adherence to all therapeutic options. So, just to be clear, this thesis merges two different ‘clinical pathways’ through which the NHS offers treatment to people affected by colorectal cancer, in an effort to understand cancer, its treatments and its effects as a chronic condition for my research participants.

In the study of medical narratives in cancer, much criticism exists about the normative assumption of the ‘hero narrative’ like the one I discussed in relation to Britta’s attitude. I certainly share the concern, for blaming the patient for their ‘lack of success’ is an evaluative rather than a descriptive practice, contrary to the remit that anthropology in general, and this thesis in particular, cares about. Nevertheless, denying the powerful appeal that biomedicine has for the people I met would mean that I have missed an essential part of their treatment experiences. Being deeply aware of the self-selection bias of doing research with people who have already sought and accessed biomedical care in a reputable and resourceful hospital, the patients I met in the clinic felt the appeal of an approach that, following anthropologist Byron Good (1993), is structured in terms of a narrative of progress and rationality. The author suggests that, even though the practice of biomedicine is funded through experimental science that mobilises statistical products, it is animated by a soteriological ethos; that is, the tacit idea that medicine may offer a possibility of salvation from death. Focusing on the subjective experience within the cultural phenomenon of biomedicine, I ask: how do people who commit to the

biomedical imaginary get embedded in the cancer narrative it offers and make such commitment work over time? How do they balance their ethical values with the economic, epistemological and therapeutic values that are also at stake? How do they navigate the multiple temporalities of cancer, its treatment, and the everyday impact it generates? How do they make sense of what is happening to them and how do they bring about the imagined possibility of living well with others?

Starting off with a methodological chapter, I further explain my position within clinical dynamics, issues of access and consent, some of the socio-economic characteristics of my research participants, and my general methodological approach. The ethnographic data of this thesis is presented in six chapters that map out the trajectory of my research participants receiving cancer treatment and the practices through which they navigated this time, seeking to get on with their lives. Situating the colorectal clinical pathway within the NHS, and the NHS within the British welfare state, Chapter 3 offers a quick socio-historical context for both this thesis and the fieldwork that preceded its writing. From the points of view of both the wider system and my interlocutors, the Chapter 4 analyses the structural dynamics that make anti-cancer treatments in the UK stand out as world-making projects. Foregrounding the material, affective and ethical aspects of dealing with cancer treatments, the following four chapters delve into the experiences of bowel surgery (Chapter 5), adjuvant chemotherapy (Chapter 6), emotion work (Chapter 7), and palliative care (Chapter 8) – periods of time in which patients, caregivers and health professionals seek to stave off death and enable cancer patients to continue with their lives. By the end of this thesis, I hope to have provided to the reader valuable material to engage in three sorts of discussions of relevance for qualitative health research and anthropology. (1) How can we better understand ‘patient experience’ during cancer treatments? (2) How can a focus on the values that organise caregiving practices enrich discussions of patient-reported outcomes of treatment? (3) How can a research study that examines caregiving as world-making project shed light on the advantages and challenges of the ethnographic method? I come back to these questions in the concluding chapter (Chapter 9) of this thesis.

Chapter 2

Methodology: Hospital dynamics and careful ethnography

2.1 Multidisciplinary dynamics

The gastro-intestinal (GI) cancer clinical team with whom I carried out this ethnography was composed of three consultants, one specialist registrar, three specialist nurses, and two Macmillan support nurses (one for lower GI cancer patients). They worked in tandem with other professionals of the hospital's cancer division: pharmacists, staff nurses, clinical trial managers, dieticians and, sometimes, medical research fellows. The team ran two different lists in the outpatient chemotherapy clinic on Wednesdays. 'List A' was for new patients and more time was allocated for them, whereas 'List B' was for follow-up patients and it was expected that, unless there was an unforeseen difficulty, appointments would be straightforward. On average, the team provided systemic anti-cancer treatments to 60–70 patients affected by different types of GI cancer every week. I was accepted as a research fellow in this GI cancer clinic, partly because the team thought it would be good to have a '360-degree perspective on how the clinic works', as one of the consultants who I first approached told me. With the advantage of free labour and what was aimed to be 'minimum interference' in clinical dynamics, my project seemed to offer the possibility of obtaining qualitative data that could feed back into their own efforts to improve patient experience in the clinic, even if the findings would not be immediately actionable. This happened within a dual context. On the one hand, the clinic was already embedded in national and local medical professional schemes, enjoying a strong reputation of a team committed to both research and training. On the other hand, cancer clinics throughout England were facing increasing institutional pressure to demonstrate high quality of care in terms of patient outcomes, more efficiency and shorter waiting times as part of a

widening accountability culture. However, if the auditing culture in the UK has turned its gaze towards publicly funded bodies – overlapping with efforts to produce visible outputs through the use of the rhetoric of professional ethical codes of conduct, as Strathern (2003b) argues – then it is almost expected that hospital ethnographers are met by health professionals with scepticism. Marilyn Strathern continues in the afterword of the same volume in *Audit Cultures*:

Audit and ethics are structuring social expectations in such a way as to create new principles of organization [...] Audit/policy/ethics: if this really is a triad of emergent practices, a set of related trajectories, then audit, accountability in a widely acceptable and mobile cultural form, is just one among many changing features of social life. (Strathern, 2003a, pp. 281–282)

In a context where accountability has become a cultural form through which values of integrity and transparency are realised, I ask: How is it possible to determine the work that the clinic does, observing as many dynamics as possible, and not be considered a threat by a clinical team? Clearly, the first step is to build rapport, slowly earning the trust of the interlocutors and making explicit the aims of the research to everybody in the team: a descriptive and non-normative study of patient experiences of bowel cancer treatments that seeks to analyse the potential of caregiving practices to create a possibility of experience other than death. Mechanisms are put in place to gain the trust of others, creating an environment within which the empirical and moral quality of the research can be demonstrated to other stakeholders who value specific types of transparency and research integrity (Strathern, 2003b). The second step is negotiating access that aligns with the parameters and regulations of the institution, which includes translating anthropological research into the language of protocols, hypothesis and recruitment metrics that seem at odds with the ‘improvisational’ nature that has traditionally framed ethnographic research as an open-ended type of enquiry (Cerwonka and Malkki, 2008; Pels, 2003; Sleeboom-Faulkner et al., 2017; Dilger et al. 2015). The third step is occupying a position in the available teaching dynamics to ensure the researcher is welcome. Because the GI oncology clinic was part of a teaching hospital (within the NHS), medical students, post-graduate students and researchers could gain access to carry out non-participant observations of clinical dynamics or longer clinical research studies. At the time I was doing the hospital ethnography, a PhD student in Psychology was also part of the team doing research with us on the cognitive effects of chemotherapy, and a clinical research fellow was running several clinical trials on site. The constant exposure of the clinical team to other researchers meant that health professionals were fairly ‘used to seeing

people coming and going', as one specialist nurse and the trials manager reassured me on two separate occasions, which also made them more open to talking about their work (time being available). More importantly, for this study, it meant that observation in the clinic would not necessarily make professionals uncomfortable, even though a few health professionals preferred to avoid my presence if possible, or declined my invitation for an interview. The team considered the ethnographer and other students as temporary and satellite additions to the team and, unless they had a medical background, the team would make sure that the doctorate did not see the patients' physical examinations. The fourth and last step relates to the political reflexivity of the ethnographer, as I had to make myself cognisant of the power dynamics that structure the field and my own position as researcher within it in order to navigate it (Mills et al., 2003, p. 524; see also Dilger et al., 2015). In hindsight, this aspect was likely to be one of the most formative processes I experienced throughout my fieldwork, for multidisciplinary teams are also structured in hierarchies, with interpersonal frictions being expressed sometimes only through body language that the ethnographer has to learn to decipher. These asymmetries were clearly a product of professionals occupying diverse ranks and being allocated different degrees of responsibility in the clinic. At the same time, they could be made more or less apparent depending on the personalities of the team members. Power and multidisciplinary dynamics informed my interactions during fieldwork in both obvious and subtle ways, affecting the modes of participation I found available in the field. How can I gain access? Where can I sit in team meetings? Where and in front of whom should I speak? How and where can I practically recruit participants? Who can I talk in the clinic with, and about what?

Paradoxically, the hospital's accountability culture is not only a challenge for accessing a regulated field site to carry out health research, but also has implications for the way in which research findings that are sensitive to public scrutiny are produced and circulated. In other words, by doing health research, I am not immune to the institutionally embraced idea of accountability that has slipped into ethics governance in the British healthcare system. As a semi-confessional way to make visible the criteria that defines the practice in the field (Pels, 2003), in this chapter I give an account of the ways in which I navigated a tightly regulated institution and carried out research as a (foreign and female) social science researcher (with a specific personality as well). The dynamic in which the observed is aware of the potential effects of what the observer sees, and vice versa, is one of the many ways in which findings produced from fieldwork become situated.

2.2 Diving into the field

Within a team that was always busy looking after patients, I found camaraderie among medical students and researchers who were also visiting the clinic. A memorable example took place at the beginning of the fieldwork, while I was shadowing Dr Y, one of the senior consultants. Kate, a medical student, arrived in the consultation room. She needed to recruit a patient to follow for some months in terms of clinical appointments, as part of her oncology module within the fourth-year rotation. She had one patient but he stopped replying to her. She thought that this was because he was too unwell. The fourth patient arrived to the room with the expectation of discussing his enrolment in an immunotherapy trial soon to be opened at the clinic. After a moving consultation (which I describe in Chapter 4), the patient and his wife left, and Dr Y offered the medical student the clinical file of the next patient. He recorded the appointment with an audio recording so that the registrar could transcribe it later and send it to the patient and his general practitioner (GP) by post. After that, Dr Y tested Kate's knowledge of microbiology. 'How does chemotherapy intervene in the cells?' the professor asked. Kate grew embarrassed because she did not know the answer. I felt relieved that I was not supposed to know how it worked; I always received explanations that rightly assumed my ignorance on the subject matter. Dr Y explained to me that chemotherapy works by intervening at the cellular level at three different moments: 'replication, transformation and internal structure'. Then he asked me if I had finished the (anthropology) book he recommended I read, and told me to also check out *The Emperor of all Maladies*. He stated that the social history of cancer treatments 'is a must'.

Like most medical students, I wrote most of my field notes in the medical library, just a few steps away from the hospital; I learnt from the doctors and nurses as they did, shadowing consultants in clinics and hospital rounds and attending clinical meetings; I understood the suffering that cancer causes to patients' bodies and minds as they did, by meeting patients face to face and learning from them. However, I was also keenly aware of the irreconcilable gap in expectations that divided us: clearly, they would become medical doctors and I would become an anthropologist. And, because of this, I was also treated differently by the consultants; I was frequently ignored and sometimes avoided – at the end, I was just an observer in their clinical meetings. However, as I showed with Kate's case, I had the benefit of not being entangled in the teaching dynamics that medical students were actually afraid of. I trained myself to understand at least part of the scientific knowledge that medical students need to command to be able to understand how clinical professionals come to see the cancer world and the work that they do. Like medical students, my time

doing research in the hospital changed my character and my understanding of the patient experience of cancer. The clinic was for both them and I a rite of passage; the main difference was how we navigated that process. With a hospital ID always hanging from my clothes that identified me as a researcher, I noticed how medical students and other researchers felt at ease to approach me to talk; how staff and chemotherapy nurses were eager to explain clinical procedures to me; how specialist nurses would welcome me in their consultations or try to answer my questions; how medical oncology trainees (registrars) were friendly and welcoming (but usually too overwhelmingly busy as to engage with me). Wearing the same ID, I also saw how some consultant surgeons censored themselves in front of me or re-explained what they had to say to the patients I was shadowing ‘not to get into trouble’ in case I would write their words down (as a surgeon told me while shadowing Simon, one of my research participants). With a position equivalent to the consultant surgeons, the three regular consultant medical oncologists of the lower GI team that I met may well have been as careful of my presence as the surgeons were. However, I believe that the intense rhythm of the clinic, their interest in supporting empirical research, and the length of my stay in the clinic enabled me to obtain a nuanced understanding of the dynamics taking place inside the hospital. I truly appreciate the openness of the team to my research and I hope to offer valuable material for their own professional reflection.

2.3 Accessing the field

Getting access to carry out hospital ethnography is a time-consuming process, especially in a tightly regulated institution (Van Der Geest and Finkler, 2004). In my case, it required negotiation and the approval of a research protocol by the hospital’s research and development department to obtain sponsorship; it also involved a long process of ethical clearance to obtain institutional access (Dilger et al., 2015; Sleeboom-Faulkner et al., 2017). Several conversations took place with different members of the clinical team before I obtained permission from the Health Research Authority. One experienced clinical nurse specialist, CNS. A, sat with me over coffee and described the types of treatment they carry out as a specialist hospital in cancer care, the outcomes they produce for colorectal cancer patients and the volume of patients they see every year. Dr Z, a young consultant who supported my research, talked to me about the scope of my research, my methodological approach, and the possible areas that may seem problematic to the ethics committee. He told the secretary of the cancer division, who was helping me file the forms to get hospital access, that ‘Maria will touch patients’. I later found out the reason behind that

seemingly odd statement: I had to undergo immunisation. Thus, after having passed the national Disclosure and Barring Service test to make sure I did not hold any criminal record, the occupational health clinic serving NHS workers inoculated me with all the relevant vaccinations I had not had in the past, including several shots for hepatitis B and a shot for tuberculosis.

Another relevant part of conducting research in the clinic was finding a position in, and later understanding, the hospital hierarchy that I described in the initial section of this chapter. I had to work under the supervision of a line manager within the GI cancer clinical team who acted as my fieldwork supervisor and gatekeeper in the clinic. Dr Y, a senior consultant who was a medical oncologist kindly agreed to assume this role. I am thankful that he took on the responsibility and mentored me within the quick-paced dynamics of the clinic, despite the potential inconvenience of having an anthropologist around. He requested approval from the divisional head manager on my behalf, who sent back an email stating that 'he was happy for this research to take place in the GI [cancer] clinic'. Dr Y was also instrumental in helping me obtain a 'research passport' in the hospital (issued by the research and development department), introducing me to other members of the clinical team and the professionals working in chemotherapy, and in helping me devise an answer for the National Research Ethics Service committee when it requested more information before granting me ethical clearance to do research with potentially dying patients.

In July 2015, the NHS ethics committee reviewed my application and I attended a meeting in a city in the north of England. To my surprise, and in contrast to scholars that criticise the bureaucratisation of ethics reviews and the 'out-of-touch' research committee's appraisals to qualitative (and sensitive) research projects (Burgois, 1990; Dilger et al., 2015; Sleeboom-Faulkner et al., 2017), the group of clinical professionals and lay people who read it clearly understood the scope and implications of my research better than I did at that stage. The committee made sure that mechanisms were put in place not only to protect research participants and the clinic, but also to protect me and the work I was about to carry out. By asking me to balance my enthusiasm and curiosity about cancer care, the committee wanted to make sure that: (1) I knew what kind of experiences I was likely to embark on; (2) the terms of the information sheets and consent forms were appropriate for the population I was targeting; (3) I would not waste the time of busy people either working to save lives (team) or getting on with treatment (patients); and (4) I could remain emotionally strong, putting mechanisms in place to shelter myself from possible 'undue' demands that people could make upon my role. The first two issues were tackled through focus groups I carried out with members of two support groups for people affected by cancer in South England (approximately 40 people in total). From these groups,

I not only learnt what it means to be affected by bowel cancer (something I describe in Chapter 5), but they also gave me insight into the concerns that patients have when invited to participate in long-term qualitative research. This opportunity of participant involvement greatly improved the quality of my project design. Some of the issues required that I adjust my methodological approach and consent forms to be signed again by all stakeholders. However, managing to answer how I could avoid bothering busy people was something that spoke to the heart of my research.

The biggest concern of the committee could be phrased in terms of the intrusiveness of research and how I could justify that practice; this was a delicate and genuine challenge. Any kind of long-term ethnographic research may be considered exploitative, especially while working with patients deemed ‘vulnerable’. I had to responsibly own that. So while waiting for several months to obtain all kinds of hospital checks and approvals, I prepared myself to enter the field of cancer. I became a volunteer of an important cancer charity in the UK working with patients, which, even before I started my role as a volunteer, allowed me to learn from its courses in my capacity as a research student working in the field. Together with other volunteers and the staff of cancer clinics in London, I learnt about the risk factors and types of diagnosis from a specialist nurse; about cancer treatments and side effects from another cancer specialist nurse; about the challenges of living in remission and the resources that cancer survivors could access; about palliative care and end of life from a palliative care practitioner; and about how to best have emotion-charged conversations with cancer patients from a professional facilitator. Those four full days of training that took place at different times throughout the first year of fieldwork were later complemented by my assistance to workshops organised by the same charity on prevention of compassion fatigue with a clinical psychologist, and on safeguarding mechanisms to protect people in situations of vulnerability with whom we worked in the charity. Still waiting on ethical clearance that took several months, I spent my time learning from approved online resources created by British cancer charities, with which I prepared myself to understand the basic physiological principles of cancer growth and its terminology, the treatment options for patients affected by bowel cancer, how cancer affects people financially and what resources they can turn to, and how cancer affects relatives. I could not avoid the intrusiveness of my research project, but at least I could be able to be empathetic and make myself useful for the people who decided to participate in it.

2.4 Recruitment and consent

After having cleared the Health Research Authority's access and sponsorship process for this study, I silently sat in different chemotherapy and chemo-radiotherapy clinics as an observer, shadowing different members of the clinical team during the first three months of my project until I had a full sample. Members of the clinical team would ask every patient when entering the room: 'She is Maria, a PhD student, do you mind if she stays?' Sitting in the clinic provided me with an opportunity not only to gain an overview of the diversity of clinical dynamics that structure the treatment pathway for patients, but also, more importantly, to recruit patients. All three medical oncology consultants, one specialist nurse and one research fellow helped me to identify eligible patients in their clinics; some of them, knowing the inclusion and exclusion criteria of my project, they would sometimes brief me quickly about the next patient. If the person was not eligible, I was still allowed to be in the room provided that the patients would not prefer to have me outside. But if s/he was eligible, after the appointment, the staff briefly explained the focus of my research to them with a sentence that went something like what Dr W, another senior consultant, said: 'She is Maria, a PhD student from UCL. She is doing research on patient experience and would like to invite you to participate if you are interested.' Table 2.1 shows the inclusion and exclusion criteria we used to invite patients.

Table 2.1 Inclusion and exclusion criteria

Participant	Inclusion criteria	Exclusion criteria
Patients	<ul style="list-style-type: none"> • 18 years old or older • Undergoing any type of colorectal cancer treatment in hospital • Clinical prognosis over six months 	<ul style="list-style-type: none"> • Clinical prognosis is less than six months at time of recruitment • Under the age of 18 years • Without the mental capacity to consent to participation • Unable to understand spoken or written English and Spanish • Person is not interested
Informal caregivers	<ul style="list-style-type: none"> • 18 years old or older • Shares most of the illness experience of the patients treatment 	<ul style="list-style-type: none"> • Under the age of 18 years • Without mental capacity to consent to participation • Unable to understand spoken or written English and Spanish • Person is not interested
Healthcare professionals	<ul style="list-style-type: none"> • Member of GI cancer clinic at the hospital • Provides direct care to patients going through colorectal cancer treatments 	<ul style="list-style-type: none"> • Professional does not provide direct care to patients in the GI cancer clinic

Table 2.1 makes clear that this study set a minimum clinical prognosis in the inclusion criteria, as people who are closer to dying usually do not receive more treatment in the hospital but are referred to pain management clinics near their homes. There were also implicit criteria when some consultants helped me in identifying patients. A combination between what they found interesting and their perception of how difficult patients were definitely affected their own eagerness when introducing my research. And, in the case of a few patients they knew clearly better than me, they openly recommended that I not approach them, even though they would fit the formal criteria. Was that bias – the unchecked preference for a specific profile of research participant? As long as those cases did not conform to any one specific socio-demographic trait, my impression was that the consultants were protecting patients from the requirements of this project; at the same time, they protected me from a potential participant who would not stay in the research till its end. The fact that I achieved 0% of attrition during the first stage of the research – that is, nobody voluntarily stopped participating before their treatments finished, even when they were reassured they could do it at any time and without repercussions for their medical care – may prove that such strategy was effective.

Whereas the reasons not to participate in the research were straightforward – people were either not interested or they thought that my research posed too big an intrusion in their lives – the reasons to accept to participate were more difficult to understand, especially considering that my role changed during the time they shared their experiences of treatment with me. Nevertheless, it would be possible to say that people accepted: because they openly wanted (to be seen) to give something back to the hospital; because they believed in the project; because they genuinely wanted to help me in my professional training; or because they thought I could act as their watchdog during treatment if required (‘having a second pair of eyes looking at the decisions made in hospital’, as one of the patients would put it). Reasons, of course, could overlap. Five of the people in my patient sample were simultaneously participating in shorter research projects carried out by other staff members of the hospital or general practices to improve cancer services. A few of them were also enrolled as participants of short(er) assignments by medical students from the local university. Hence, in line with the analysis of participation in cancer research carried out by McGrath-Lone et al. (2015), it is possible to say that the patient population I was recruiting and the institutional context of my research facilitated the recruitment of patients. A specialist cancer centre embedded in a teaching hospital in London that looked after bowel cancer patients offered a fertile environment to carry out this and other forms of research with the same participants.

I gave information sheets to invited patients explaining the scope of the study. Written informed consent was obtained after every patient had time to think through the invitation, receive answers to any questions they had about the research, and get back to me by e-mail or phone. Letting the participant approach me if interested to coordinate the first meeting, instead of me chasing them, was the strategy devised to reduce the pressure they may have felt after being invited by their treating doctor. During the first five months of my stay in the clinic, 10 people kindly gave me the opportunity to understand their experience of treatment, at a recruitment rate of approximately 20% (so for every 5 people I would invite, one became a participant). Table 2.2 summarises the socio-demographic characteristics of patients who accepted my invitation to participate. All names are pseudonyms, and identifiable information has been erased to the best of my knowledge to protect the anonymity and confidentiality of participants.

Table 2.2 Socio-demographic distribution of patients

Pseudonym	Gender	Age range	Origin	Work status	Network?
Seaus	Male	60–70 years	West Europe	Self-employed full time	No
Jimmy	Male	70–80 years	Britain	Retired	Yes (2)
Jean	Female	30–40 years	Britain	Student	Yes (2)
Jay	Male	30–40 years	South Asia	Self-employed full time	Yes (2)
Ruth	Female	30–40 years	Sub-Saharan Africa	Employed full time	Yes*
Robert	Male	70–80 years	Britain	Freelance work	Yes*
Britta	Female	70–80 years	West Europe	Volunteer in charity	No
Simon	Male	40–50 years	Sub-Saharan Africa	Fired/volunteer	Yes (2)*
Leia	Female	50–60 years	North America	Employed full time	Yes(1)
Elizabeth	Female	50–60 years	South America	Employed full time	Yes(2)*

As is possible to observe in Table 2.2, the patient sample is balanced in terms of gender, mirroring the distribution of the known prevalence of the disease among the British population. In a sociocultural context in which women still perform most of the everyday caregiving duties, and bearing in mind that qualitative research in cancer care has tended to recruit women (with breast cancer), balancing gender for a cancer type naturally and making the study gender-neutral was important to me. I did not want to preclude the observation of caregiving practices carried out by the people who usually receive them. In terms of the age distribution though, my sample tends to over-represent younger people. Colorectal cancer tends to more proportionally affect people over 60 years old in England, but London hospitals look after a younger population with cancer on average (Saunders et al., 2014). Moreover, my impression was that recruitment was usually easier with younger patients due to the nature of my research and their openness towards my own socio-demographic characteristics. A third important attribute of my sample is the diversity of cultural backgrounds, which partially mirrors the cultural diversity I found in the teaching

hospital (even though I was not able to recruit any of the few patients of East European or Asian backgrounds as they were not interested). Acknowledging this diversity and avoiding the risk of proposing an argument that is either homogeneous or normative has been a central concern in crafting the argument of this thesis.

The first time I met the participants, I would bring two copies of the approved consent form and have the first and only narrative interview. Seeking to understand their cancer story from their own point of view, the initial question with which I started every interview was: *‘Could you tell me the story of your illness up until now? Just begin at the beginning, wherever that might be for you.’* I was interested to know how they made sense of the cancer treatment but, more importantly, I wanted to get to know them as complete persons and that first interview was essential to building a common ground that could be shared and furthered over time while I accompanied them throughout their treatment. Half of the first interviews took place with caregivers also present, as my only concern at that time was that the participant could feel comfortable while talking to me, and meeting the caregivers (if they existed) was in itself an important aspect of my research. In Table 2.2, I show under the category ‘Network?’ that eight of the people who participated in my research as patients enjoyed the social support that relatives and friends could provide. Seaus and Britta were the only two participants who preferred not to refer me to any member of their support network, not necessarily because they were on their own but because they did not feel that anyone else was truly sharing their treatment experience with them. Indeed, when I asked Seaus if I could talk with one of his children (after losing his first wife who took her own life in a moment of profound depression, he married another woman whom he divorced years later), his answer was: ‘Not really, you know how stubborn I am.’ And Britta made clear in one of our conversations during chemotherapy that she did not require support from anybody else. The conversation went like this:

- **Britta:** What sort of questions you want to ask me?
- **Ignacia:** About the support you receive when you need help.
- **Britta:** I am wonderful; I don’t need help.
- **Ignacia:** But let’s say you can’t get up from bed because you are sick, who could help you?
- **Britta:** I am an optimist! I have not thought about that. It won’t happen.
- **Ignacia:** Ok. Let’s say you need money, who could help you?

- **Britta:** [*Laughing*] I don't need money from anybody, I have not thought about that either! [*The nurse approached her to check the pump she would carry home, and Britta tells her that*] She [me] is asking me what would I do if I need money! [*Still laughing. The nurse just looked at me and did not answer*].

Every time I met one of the informal caregivers I was referred to, I explained my research project and asked them if they were willing to participate. Verbal consent was gained from all the caregivers that feature in this thesis, and a subsequent process of consent was carried out with eight of them before interviewing them. Table 2.3 shows the socio-demographic characteristics of the caregivers I interviewed, even though there were at least six other members of patients' support networks with whom I informally spoke several times.

Table 2.3 Socio-demographic distribution of informal caregivers (interviewed)

Pseudonym	Gender	Age range	Origin	Work status	Relationship with patient
Daisy	Female	60–70 years	Britain	Retired	Jimmy's wife
Paul	Male	30–40 years	West Europe	Employed full time	Jean's husband
Amanda	Female	30–40 years	South Asia	Employed full time	Jay's wife
Blessing	Female	20–30 years	Sub-Saharan Africa	Housewife	Ruth's sister in law
Kathy	Female	70–80 years	Britain	Volunteer	Simon's friend
Stephanie	Female	60–70 years	West Europe	Employed full time	Simon's friend
Gregory	Male	50–60 years	Britain	Employed full time	Leia's partner
Sandra	Female	30–40 years	South America	Housewife	Elizabeth's daughter
Joseph	Male	20–30 years	South America	Employed part time	Elizabeth's son

Caregiver interviews were carried out face to face in a place of their choosing, which was never a clinical site. In five of those interviews, the person they were looking after was also present, as those caregivers felt it would have been dishonest to talk with me about their caregiving experience if the cared-for was not there. Relatives felt that however difficult the cancer treatment had been for them, they are not the protagonists of any story. Their self-censorship is in itself one of the normative textures of caregiving in the UK, which I unpack in Chapter 7. Beyond the interviews, I carried out participant observations within the wider support networks of four participants outside the clinic (the ones with asterisks on Table 2.2). Whereas I met Robert's support network only once in his own home, I got to know several of Ruth's, Simon's and Elizabeth's relatives and friends over time in different places: the ward (Ruth), church events and praying groups (Simon), and the chemotherapy clinic and home (Elizabeth).

There was minimal use of the tape recorder in this study. Clinical dynamics were never audiotaped, but quick words were jotted down in between patients or in the waiting room. Even though nine patients signed the consent form accepting that the first interview would be audiotaped, such interviews (and all other conversations)

were not recorded most of the time but written by me as soon as we finished talking. The presence of the recorder was intimidating, and I could observe how patients were spending lots of effort in choosing the right words for their answers. Given that several patients chose to have the interviews in the hospital setting, a context that was already framing their answers, I soon realised that it was likely I would only receive socially desirable answers if I kept recording. What the absence of recording prevented (i.e. having verbatim quotes from patients and caregivers) was a disadvantage clearly offset by the facilitated rapport and therefore openness that the non-recorded conversations made possible. The only exception in the use of the tape recorder was when I conducted semi-structured interviews with 8 members of the clinical team. Interviewees included three consultants (one in medical oncology, one homeopathic physician based in another hospital within the Trust, and one in colorectal surgery), two cancer nurse specialists, a registrar, a staff nurse and a chemotherapy nurse. I approached them individually, explaining the purpose of the interview. The focus was placed on four themes, even though time pressures and interest in research affected how well and deeply I could cover: (1) their exercise of clinical judgement, considering how to draw the line between overwhelming treatments and quality of life, (2) the ways in which their clinical practice was shaped by institutional guidelines and by working in a multidisciplinary team, (3) their challenges while working in cancer care, and (4) their understanding of their professional roles. The audio of those interviews was taped and transcribed verbatim after the interviewees approved of the use of the recorder.

After gaining written consent from patients, I engaged in an ongoing process of verbal consent each time I met participants (patients and their support networks). Every time before a consultation, I asked the patient *'Is it ok if I join you?'* to which most of the participants said yes all the time and even introduced me as their *'shadow'* when meeting health professionals such as surgeons and other nurses I had not met before. Ongoing consent was established to respect the need for privacy of my participants in the hospital at a time that many people find already difficult to endure. Clearly, it was difficult for them to avoid my presence in the clinic or not feel the pressure to meet with me if I was always there and they recognised me as a member of the staff, even if I did not have clinical responsibilities.¹ Still, some of the patients would ask me from time to time not to follow them during some cycles of chemotherapy, either because they would be accompanied by someone else or because they were too tired. While Ruth was on the ward for her last 15 weeks with minimum mobility, ongoing consent to respect privacy was even more relevant, so we

¹No matter how hard I tried to explain my research, few of them would still explain to their friends accompanying them that I was 'a nurse trying to understand their experience of treatment'. Being a female, young, and foreigner member of the hospital staff; it seemed I could tick all the demographic attributes with which they defined a nurse.

decided together that I would text her every time I would come (between one and two times a week, sometimes for five minutes if she was accompanied, and sometimes for over an hour if she was alone and enjoying my company). She knew that it was up to her whether I could meet with her on the ward and for how long that meeting could be. Part of the agreement was that not replying meant that I would not go. Once there, body language played a big role in helping me decide whether I should stay or not.

In Table 2.4, I summarise the cancer type, treatment intention, formation of stoma after surgery, and length of time during which patients participated in this research.

Table 2.4 Type of of treatment

Patient	TNM stage (diagnosis)	Primary (secondary) sites	Treatment intent	Stoma
Seaus	T4N2M0	colon	Curative	No
Jimmy	T3N0Mx	colon	Curative	No
Jean	yT3N2M0	rectum	Curative	Reversed
Jay	yT3N0Mx	rectum (liver, lungs)	Curative	Permanent
Ruth	yT4N2M1	rectum (vagina)	Palliative	Permanent
Robert	T4N2M1	colon (liver, lungs)	Palliative	No
Britta	T3N0Mx	colon	Curative	No
Simon	T3N0M1	colon (liver)	Palliative	Reversed
Leia	T4N1M1	colon (ovary)	Curative	No
Elizabeth	T3N0M1	colon	Curative	Reversed

From Table 2.4, we observe that seven of the participants were treated with curative intent at the time of fieldwork, which mostly meant that their type of cancer was exclusively in the bowel (colon or rectum) or had only spread to a few local nodules of the lymphatic system that were resected by the surgeon. Two of them, Jay and Leia, were undergoing treatment for locally advanced cancer, as it had already spread to other organs such as the liver, uterus and lungs at the time of diagnosis, but were tumours that grew slowly and were still amenable for surgical resection. The prognostic distribution of the group of patients in my sample mirrors the national prevalence of colorectal cancer in the country at the time of the fieldwork, where 60% of the population is expected to live for five years or more.² Thus, there is the 40% who did not enjoy the same prognosis.³ Ruth, Robert and Simon were affected by cancer whose growth was not amenable for surgery, and so chemotherapy and biological therapy were the only treatments they could receive until they proved ineffective – in short, they had what is understood to be refractory metastatic cancer. Their prognosis was then circumscribed to a range between one and five years. As I

²Survival statistics for the year 2015. Available at <https://www.cancerresearchuk.org/about-cancer/bowel-cancer/survival> (accessed on 18th July 2018)

³Survival statistics for the year 2015. Available at <https://www.cancerresearchuk.org/about-cancer/bowel-cancer/survival> (accessed on 18th July 2018)

show in Chapter 8, Ruth's clinical condition quickly worsened after the first cancer recurrence, which eventually killed her in less than a year from that time, while I was still in the field. Simon understood that he had a prognosis of 30 months on average at the time of diagnosis, only if he received chemotherapy, but less than a year otherwise. He adhered to all forms of systemic therapy that the clinical team offered him to de-accelerate the cancer growth, and died early in 2018, while I was still writing this thesis. Robert had defied the statistics and was still alive, although slowly showing signs of physical deterioration, six years after being diagnosed with advanced bowel cancer. He underwent several surgical operations in the hospital not only to resect tumours, but also to palliate the pain. The last time I saw him in the clinic, there was no more treatment available for him, not even clinical trials, so he was encouraged to spare himself the long trip to the clinic from outer London and stay at home, where the local hospice helped him to manage the pain of the cancer that had spread into his bones. Similarly to Ruth's case, who was treated with curative intent until the cancer relapsed, I learnt from a case report recently published by a cancer charity that Jay's clinical condition had worsened and become incurable. Since I was already finishing my thesis, I did not approach him to find out more about his experience.

I recruited most participants while they were undergoing chemotherapy treatment, which is in itself a relevant feature of my fieldwork as it shapes the profile of clinical needs and dynamics I learnt. The exceptions were Jean, who I recruited during the first chemo-radiation treatment before her bowel surgery, and Jay, who had just finished chemotherapy and was on the follow-up protocol when I met him, even though he underwent two small surgeries while I was in the field. Because chemotherapy happened most of the time after surgery and it stood as the last treatment to be received, the average length of participation in this study was six to seven months. This time period comprised all the chemotherapy cycles patients had left to do from the time I met them until the 'end of treatment' meeting that took place a month after chemotherapy was over. Whereas I only followed the process of one bowel surgery with curative intent (Jean), I followed several other patients who were undergoing surgery either to reverse the stoma that had been temporally formed or to resect small tumours in their livers and lungs.

Moreover, as Table 2.5 shows, four patients (Jean, Ruth, Simon and Elizabeth) participated in my research for a longer time period than the rest, becoming my key participants. This is the reason why their voices and experiences appear more frequently and with greater detail in this thesis. While I accompanied all patients receiving chemotherapy to clinics and to receive chemotherapy cycles, some patients, such as Jean and Simon, also invited me to be their shadow in other appointments.

In Table 2.5, I visually describe the types of observation I made with patients inside and outside the clinic. After 12 months in the clinic, I invited five participants with whom I built the strongest rapport to continue participating in the next stage of the fieldwork for six more months. A new process of consent took place, in which I explained the aims of that fieldwork stage and the risk that, as I explained to them at length, ‘by continuing to participate in this research, you could feel that you are not able to move on with your life’. Simon, Elizabeth, Ruth and Jean, the four people who accepted, were reassured that they were able to stop participating at any time or simply stop replying to my text messages. Ruth stopped replying after being sent home to spend the last days of her life, on the fourth month of the follow-up stage.

Table 2.5 Type of observations with patients

	Seaus	Jimmy	Jean	Jay	Ruth	Robert	Britta	Simon	Leia	Elizabeth
Waiting room	X	X	X		X	X	X	X	X	X
Consultation	X	X	X	X	X	X	X	X	X	X
Pharmacist appt			X		X		X	X	X	X
Radiotherapy appt			X							
Chemotherapy cycle	X	X	X		X		X	X	X	X
Pre-surgery appt			X					X		
Ward					X			X		X
Post-surgery appt	X		X	X				X		X
Follow-up appt	X	X	X	X						
Stoma nurse appt								X		
Home			X	X	X	X				X
Off clinic	X	X	X	X				X		X
Participation (months)	5	8	15	8	13	6	6	12	6	11

During six months, I met the four of them on average twice a month, usually outside the hospital. The aim was to understand how they were navigating the experience of cancer treatments in their everyday lives, either in the process of resuming their normal activities once in remission (Jean and Elizabeth) or continuing with life despite treatment for an incurable form of cancer (Simon and Ruth). During that time, my aim was to make myself useful rather than becoming a burden for them. I went to visit Ruth on the ward, bringing whatever she could need from the outside world, offering conversation to ease her boredom, and an eager ear to hear both her complaints and her hopes. I supported the religious projects of Simon, organising events in which we prayed for persecuted Christians around the globe and participating in one pilgrimage and a year of monthly informal prayer groups in London. I offered company to Elizabeth while her children were busy doing other things and she felt stuck at home, not able to work but too sad to be inactive, in pain and alone. We watched television, drank coffee and went window shopping and other errands around her neighbourhood. With Jean, we usually met around the university campus for a coffee or beer, just catching up about our professional and

family lives and the situation of the world around us. At the end of data collection, every patient participating in this research study, the Research and Development office at the hospital, and the Health Research Authority received an ‘End of study notification letter’.

In summary, my methodological approach included 12 months of non-participant observations of ‘naturally’ occurring interactions in the GI cancer clinic, where I first shadowed some of the members of the clinical team and the initial sample of patients, their treatment and follow-up consultations with clinical oncologists, nurses and pharmacists. It also included being present in waiting rooms and for pre-assessments for surgery, post-surgery and chemotherapy cycles. I also joined consultant-led medical rounds on the wards and accompanied some of my participants who were there either recovering from surgery or who were admitted due to medical complications triggered by the fast progression of the cancer. At the same time, I obtained narrative interviews from ten patients and eight of their caregivers, and eight semi-structured interviews from health professionals providing direct care to patients in my sample. After a year in the clinic, I spent six months paying visits to a subsample of participants and their support networks to understand how they carried on with their everyday lives outside (or inside) hospital settings.

My research was more intensive with some people than with others, but it always included as much waiting as the patients had to do in order to receive treatment. The clinic was always busy, so we waited sometimes for hours to see the treating doctor, to receive medical supplies from the pharmacy, to get discharged from the ward, or to start chemotherapy treatment. Within the context of the structural and managerial re-organisation that the NHS was facing in 2013–2014 (and still today), anthropologist Sophie Day writes about the kinds of waiting that take place in cancer care. Drawing upon ethnographic research in a cancer clinic in London, she argues that among the many types of waiting that people affected by cancer do in the clinic, there was not only a felt sense of frustration for the time lost and the indeterminacy of not knowing or failing to understand their clinical scenarios, but there was also a desire: an expectation that ‘someone will take responsibility for your care’ (Day, 2015, p. 170). Waiting, if onerous, brings about other possibilities, such as research.

2.5 Ethnography of care: Value or routine?

This project emphasised the need to look at professional and lay caregiving practices not as routinised or mechanic engagements of ‘bodies speaking to each other’, but as attempts to articulate a different possibility of experience for the people affected by cancer. Such possibilities, I have argued, can be understood as realisations of

values that my research participants embrace, values that act as the compass with which they navigate treatment. In other words, instead of seeing caregiving as a set of routines consisting of ‘habituated physical procedures’ that are delivered due to naturalised obligations, I approach the potential of caregiving as driven by values. This point matters methodologically. People’s disposition to act in certain ways was considered by my research participants as relevant as their behaviour, and this thesis shows the struggle in deciding the most appropriate course of action to reveal the complexity in which deliberation occurs. Subjects are not automatons, but are complex and ambivalent beings (Ortner, 2005). My research participants articulated their decision to embrace cancer treatment as pragmatic, in light of the proximity of death; however, the pragmatism with which they initially told me that they ‘got on with treatment’ was, in reality, easier said than done. As anthropologist Cheryl Mattingly shows for US American families looking after children with life-threatening diseases, sustaining adherence to a time-consuming, toxic and debilitating treatment required juggling priorities, navigating impasses, creating new preferences, and diving into new terrains for which they never felt prepared (Mattingly, 2010). My research participants did not look after themselves or others just because ‘they had to’, but because they deliberately made that their decision.

In saying this, I am consciously departing from the critique that anthropologist Felicity Aulino posed in relation to the presumed sincerity with which Christian-infused caregiving paradigms have been understood in anthropology, paying attention to inner belief and intentions as if whether they correlate to embodied practice of care is more relevant than understanding the effects of those practices. In her words:

In short, the scholarship on care currently misses the possibility that care itself can be separated from particular psychological states and correct intentions, and can in turn be productively understood in terms of practice or, as I argue, as ritual. Conceptualizing care as ritual allows us to get beyond meaning-centred approaches that presume that physical acts and core sincerity are aligned in cases of real care, and to concentrate on what counts most in context. Moreover, it allows us to pay attention to what caregivers do rather than just what they say they do, substantiating moral life as lived. And it brings us closer to the heart of anthropology, where discursive analysis is less important than being there. (Aulino, 2016, p.92)

Thought and deed may not correspond, Aulino argues, which is relevant for understanding a moral experience in her own ethnographic context. For her interlocutors living in rural areas of Thailand and looking after a comatose bed-ridden elderly

woman, outcomes such as cleanliness and lack of bedsores were more important markers of appropriate caregiving (Aulino, 2016, p. 99). Caregiving understood as ritual, the author suggests, disentangles practice from sentiment and gives room to acknowledging that there may be ambivalence in the experience of the caregiver and that, despite this, the person continues providing for others. The emphasis on performance is supported by cosmological formulations of karma and merit stemming from their Buddhist tradition (p. 99). However, disregarding intention and still being an effective caregiver works analytically only until that person leaves the house and disappears from the elderly's social world – an ethnographic detail that Aulino includes in her PhD thesis but erases in her later account (Aulino, 2012). In my research context, burning out or any other social form in which the limits of care arise must be explained rather than black boxed. In contrast to Aulino's ethnography, my research participants engage in reciprocal acts of care, and the professional and lay caregivers whom I met during the fieldwork did care about the intentions of others. The patient's priority was not to assess coherence between belief and action, but to find meaning, a horizon of action, so they could continue navigating treatment, carving out spaces of comfort, and hopefully get on with their lives.

This ethnographic approach is best suited to show a deep engagement with a plurality of voices and positions that reflect the variety of health and illness experiences. Developing an ethical sensibility towards people's values required a reflexive ethnographic exercise in which I constantly tried to achieve a balance between my academic curiosity and the responsibility I had for the consequences of my observations in the field. Moreover, it also implied that I had to be careful about the ways in which I established relationships with participants over time, who, even though they had complex needs and faced difficult situations, allowed me to accompany them throughout treatment. Centrally, boundary making was a continuous exercise, which, even if it sometimes failed, was necessary to define the scope and limits of my role in the field. I will return to reflecting on my ethics of engagement in the conclusion. There, I discuss the cultivation of ethical sensibilities in the field as a key element in understanding the potential of rendering world-making an ethnographic object.

2.6 Writing with care: Creating possibilities in cancer research

Ethnographic research can provide a rich descriptive and contextualised understanding of the experiences of patients, carers and their clinicians when undergoing cancer

treatments, illuminating the practices of care that link to each other in their effort to bring about health and comfort for the ill. For this endeavour, narrative interviews were used, bearing in mind their potential to empower participants to tell a difficult story in their own terms and therefore providing an interpretative safe space in which patients and caregivers could make sense of their own experiences. However, a central point of this research was the felt need of supplementing ‘cancer voices’, a product already widely circulated by cancer charities and mobilised in qualitative research, with a continuous period of observation of clinical and informal interactions of care. Observation techniques afforded me to understand affective and non-verbal issues deeply ingrained in patients’ experiences of treatment. Gestures, which assisted my participants in creating atmospheres of emotional containment or made experiences of great pain visible, are so embedded in everyday interactions that they are difficult to grasp by other means.

In this vein, this thesis draws upon different types of data that emerged from the experience of fieldwork, not as a neutral observer, but as someone who participated in the lives of others, in the spaces that I was allowed to take part. Transcribed interviews and all field notes were coded with NVivo 11, allowing analytical concepts to emerge from the data itself rather than from a previously conceived set of ideas (Corbin and Strauss, 1990). Analysis was a recursive process of ongoing revision. Ethnographic concepts were placed in relation to each other and integrated in categories that seemed significant for my research participants and presented anthropological value (Hastrup, 2004). Ethnographic data was structured across major analytical relationships that shed light on different components of the research question that framed the project. Thematically relevant scientific reports from anthropology and the social sciences, nursing and medicine were then retrieved and iteratively analysed to contextualise the empirical data already gathered and organised. Through the exercise of interpretation and careful comparison between ethnographic data and relevant literature (be that in terms of topic affinity or explicative power), the arguments of this thesis emerged.

Sophie Day (2007), when situating her ethnographic work with sex workers inside and outside a sexual health clinic in London, reflects on the status of evidence that is produced by ethnographic accounts in which data is mediated not only by the participation of the researcher, but also by a dual processes of interpretation carried out first by participants and then by the anthropologist. She writes:

An ethnography of illness is neither about an apparently ‘objective’ disease from the perspective of a clinician, nor the ‘subjective’ experience of suffering produced or ghosted by an anthropologist, but about multiple perspectives and activities in a crisis [] an ethnography attempts to trace

the activities occasioned by illness, the varying perspectives, interventions and participation of different people and their highly contingent interaction. (Day, 2007, p. 31)

Because knowledge is an object that emerges from this dialogical field as circumstantial responses or fluid and even inferential types of evidence, anthropologist Kirsten Hastrup (2004) poses the question of ‘how we may acknowledge the rightness of what cannot be empirical knowledge in conventional positivist terms’ (2004, p. 461). She argues that the mode of generalisation that is possible may not necessarily be horizontal but vertical. This means that the argument of this thesis may not be applicable to every single patient affected by cancer in the UK, so to speak, but it is able to retain core processes through which meanings and practices emerged as significant for the research participants while we were participating in their worlds. In her words:

The connections we make are inferred from our being implicated in them. This, again, locates ‘rightness’ in an epistemological awareness rather than in ontological certainty. It also shifts the objective of generalization from being (primarily) an identification of shared systems of meaning to the processes by which meanings are established, challenged and altered; that is the shift from horizontal to vertical generalization. (Hastrup, 2004, p. 466)

Hence, she argues that the authority of anthropological knowledge rests upon a form of narrative ethics, through which raw data that emerged from a dialogical field – the experience of fieldwork – is selectively and reductively organised. Writing as an exercise of narrative organisation and interpretation includes making careful connections between the experiences of our participants and larger social facts, within a specific frame of enquiry. Reflecting about the process of knowledge production, Maria Puig de la Bellacasa (2012) reflects on the relationship between caring and writing. Following an extensive feminist line of thinking, the author understands the concept of care as ontologically defined by the cultivation of relations that make us interdependent (Haraway, 1988; Laugier, 2015; Tronto, 1993). In her words: ‘Caring and relating thus share conceptual and ontological resonance. In worlds made of heterogeneous interdependent forms and processes of life and matter, to care about something, or for somebody, is inevitably to create relation’ (Puig de la Bellacasa, 2012, p. 198). The author aims to decouple the notion of care from the idea of moral duty, even though she acknowledges that projects of care oblige us to respond for life to be sustained over time (*ibid*). Due to our interdependence as human beings,

the argument states, cultivating relations involves material engagement in labours to sustain interdependent worlds, standing for the flourishing of relations in their diversity in both living and writing. She asks: How does this approach illuminate practices of knowing and thinking? Taking the lead of Donna Haraway's concept of 'situated knowledges' (Haraway, 1988) as an embodied and non-neutral mode of learning that shows the specificity of the practice, Puig de la Bellacasa argues that 'creating knowledge is a relational practice with important consequences in the shaping of possible worlds' (2012, p. 199). World-making here occurs by entering into relation with works from other thinkers, mobilising webs that collaboratively thicken the argument rather than break from what has been shown by others.

I find this point essential in envisioning the scope of a thesis in medical anthropology to inform our understanding of cancer care. Throughout the thesis, I have endeavoured not to create a divide between the realms of meaning and clinical practice (especially in its foundation – particularly considering different modes of evidence) (see Bell, 2017; Mol, 2002), but rather to forge a conversation in which what we gain is complexity in the description of the lived worlds of participants (and not just opponents). This is what the practice of 'thinking with care' means in the context of this thesis. In Haraway's words, it is 're-describing something so that it becomes thicker than it first seems' (Haraway and Goodeve, 2000, p. 108 in Puig de la Bellacasa, 2012). Thus, instead of academic isolation and analytical dis-articulation, the author suggests, we do better by situating our position as knowledge producers within a web of previously articulated ideas that, in one way, sustains our own writing but also reciprocally feeds into the ideas proposed by others. Puig de la Bellacasa argues that, in this vein, writing is not only about representing, but also situating our own ideas between others, creating collectives and populating a world.

Thinking with care is then a way of generating situated knowledge, which primarily depends on the positionality of the observer and the specificity of the context. But care does not necessarily preclude dissent among different perspectives – for standing by the world we are committed to inevitably leads us to refuse some alternatives – and yet, such an endeavour still aims to value the contribution that others have made. In part, this means that we take seriously the way in which others think and we show evidence of that attention, one of the historical tenets of the study of mankind. I believe that Puig de la Bellacasa's argument has political value, especially at the multidisciplinary interface at which cancer care sits. The implications of this proposition, that knowledge is relational, are various. In Chapter 9, I seek to dialogue with a different side of the academic collective, which has committed itself to furthering our understanding of the patient experience and the everyday effects of cancer: the social science studies in oncology. Through this, I establish an informed

conversation about patient-reported outcomes, a qualitative metric widely used to measure the quality of cancer care in the UK, and discuss what an ethnographic account of a modest sample of 10 patients and their caregivers may add.

Chapter 3

Equals, but different – Part 1: The moral economy of health at the time of crisis

3.1 Introduction: A homeless man in the clinic

It was another busy clinic day in the winter of 2016. I was shadowing Dr Z, one of the three regular consultant medical oncologists of the gastro-intestinal (GI) cancer outpatient clinic. Every Wednesday afternoon for a year, I sat in consultation rooms and stayed quiet, observing the stream of patients coming to receive cytotoxic treatments. After what could have been 12 patients in a row, the young consultant was about to give care to a person living on the streets. As with every patient, Dr Z went to the waiting room and called him by his first name, greeted him and the accompanying auxiliary nurse who was pushing the wheelchair in which he was sitting, and slowly walked with them towards the consulting room. I helped keep the room's heavy door open for them to come in and took my place in the corner. This time, the patient was an old man wearing hospital pyjamas, bringing no more belongings than a brown paper bag with a small plastic toy. He had a long and grey beard and a thin body type. It was his first time in the clinic, and he was a bit surprised with the whole situation judging by the way in which he was looking around. The auxiliary nurse who accompanied him did not know about his medical condition, so Dr Z engaged him in a friendly dialogue that went something like this:

- **Dr Z:** Mr. H, do you know why you are here?
- **Mr. H:** [*To the consultant's surprise, Mr. H was lucid and able to respond in perfect English*] I was admitted in A&E after having been bleeding from the

back passage. They [at A&E] told me that it could be cancer and I am now here.

- **Dr Z:** Yes. The bleeding is because you have cancer in your rectum. We can offer you chemotherapy once we sort accommodation for you. Do you have contact with any relative? You might need help during the treatment.
- **Mr. H:** Yes, only a daughter, but she lives in Scotland.
- **Dr Z:** Ok, it would be good if she or someone else could come with you in the next appointment. You are doing well, Mr H, it is nice to meet you.

A routine practice for Dr Z revealed something essential about the British context to me. The encounter was profound, reaffirming the reason that motivated me to do research within the NHS. Mr H was a member of the group whose life expectancy is curtailed at age 47 due to the risks that life on the street poses to those enduring its harsh and isolating conditions (Thomas, 2011). However, in England, Mr H was entitled to receive kind, high-quality and respectful treatment once he became visible to the public hospital as a person affected by cancer. Despite the many challenging experiences and complaints that my research participants voiced about some primary care practitioners neglecting initial cancer symptoms and their everyday struggles post treatment, about the frequent malfunctioning and overcrowding of A&E at the hospital, and about the miserable integration of mental health and oncology throughout the system, in this particular GI cancer clinic, I also witnessed the potential of compassionate and resourceful care that creates the possibility of an experience other than death for everybody. Mr H was the exemplar of clinical and social care working in tandem, in which the healthcare system was attempting to even out those social disadvantages otherwise accumulated in Mr H's life. Centrally, this possibility was only made possible because healthcare was decoupled from people's acquisitive power. There wasn't even a means-test service; in the NHS, only clinical need mattered.

In this and the next chapter, I seek to tease out the socio-material arrangements that make NHS care stand out as one of the bastions of welfare in the UK in an age of increasing austerity. In a country that otherwise distributes social opportunities of fulfilment and survival according to both the income people earn and the place where they live (Marmot et al., 2010; McKenzie, 2015; ONS, 2014; Wilkinson and Pickett, 2010), the fact that NHS cancer treatments are *still* free at the point of care for people who are able to produce appropriate evidence of their eligibility makes the NHS the material engine of care as a world-making project. In the following pages, I contextualise the NHS historically as a fragile but enduring component

of the progressively rationed British welfare state. However, due to the political and economic context in which the NHS was situated at the time of the fieldwork (2015–2017), when the UK referendum to leave the European Union took place, I also look at the emergent idioms of entitlement and deservingness to healthcare and social care. I will argue that such idioms are not only a consequence of the re-structuring of the welfare system in general and the NHS in particular, but they also point to the frailty of the NHS's socio-political foundations as a material equaliser in cancer care. In Chapter 4, I develop the second part of this argument and look at the ways in which my research participants navigated the political economy of health in London, making sense of the treatment they receive in a reputable specialist cancer centre.

3.2 The welfare state: Health and social care via public spending

Constitutionally, the foundation of the NHS has, at its core, the idea that healthcare must be delivered with the same quality standards to all ‘ordinary residents’ (Thorlby and Arora, 2017), irrespective of their background and ability to pay and exclusively based on clinical need (Department of Health and Social Care, 2013). Founded in 1948 after the Second World War, the NHS promised to look after its population ‘from cradle to grave’ as War Coalition Prime Minister Winston Churchill in 1945 put it. Based on the famous report by the economist Sir William Beveridge, chair of an inter-department committee to oversee the coordination of social insurance in the UK, Churchill publicly committed to a gigantic task: the establishment of a welfare system. Such public effort tackled matters of health, education, social services, employment, and housing. In the NHS, health services are paid for through general tax revenue and a minimum of employee contributions, as opposed to insurance premiums. As a monumental public initiative during the time of national reconstruction, the welfare state was progressively established to recuperate the productive and reproductive capacity of the British war-torn but triumphant population, so every British resident could ‘stand on their own two feet’ (Timmins, 2017, ch. 1, para. 15). Moreover, establishing a safety net available to all was a clever initiative for the fiscal sustainability of the project, for the investment in a large, healthy and well-educated workforce could in turn contribute to creating a growing base of taxpayers (Langer and Højlund, 2011). Designed within a liberal context, the NHS and social care as components of the welfare state were thus designed to *enable* British residents to become active – and healthy – members of the political community (rather than creating any sort of paternal dependency). As part of the welfare state, a significant

role was envisioned for the government to direct the organisation, operation and delivery of healthcare. Providing essential material opportunities for all to fare well from birth to death, the state created a robust social contract with the people, reconfiguring relations between the state, the market and the family (Morgen and Maskovsky, 2003).

As Timmins suggests in his socio-historical review of the establishment, controversies and achievements of welfare policies in the UK after the Second World War, welfare has never been a fixed concept in the country. Instead, it could be better understood as a set of ‘services and policies and ideas and taxes, including tax reliefs, *whose boundaries expand and contract over time*’ (Timmins, 2017, Intro, para. 19, my emphasis). Financial and political crises have been a permanent feature of the challenge of promoting people’s well-being via public funds in history. Nevertheless, as Timmins argues in line with several public and independent reports, it is clear that recent austerity measures have hit the NHS and social care the hardest since the inception of the system, making the case for more funding (rather than only increased efficiency savings) for the NHS now a truism (DH, 2000; DH, 2007; DH, 2014; NCSI, 2013; NHSE, 2016).

3.3 Fragile NHS

The British NHS enjoyed great prominence in the media while I was carrying out this fieldwork. First, it was about the negotiations of the junior doctors and the industrial action they took to exert pressure in refuting working arrangements to achieve a ‘Seven days a week NHS’. Two days of total walk out plus several picket lines across the country on five separate days were clear signs of their discontent. Among other things, they voiced their concerns about the governmental imposition of a new contract that – they argued – would jeopardised patient safety. Contemporary to the junior doctors’ struggle, nurses marched in front of Westminster against the cuts on training funding that would force them to pay for their education, even though training included working long shifts in an NHS placement for free. It was clear that the NHS was facing funding pressures, which was in turn feeding a discussion that undermined healthcare professionals’ sense of worth. One of the specialist registrars who worked in the GI cancer clinic explained the issue to me in the following way:

Registrar: In the NHS, there are two issues at the moment: limited funding in an environment in which we need to do more tests, more expensive, to more people; and we want to give more drugs, more expensive, to more people. I don’t know how on earth we will balance that out! The

other issue is the work force morale; we rely heavily on junior doctors. The gap is increasing and it is worrying. Junior doctors are not happy, and they are not able to finish their jobs at 5 pm unless there are more doctors working on it.

The perception that the NHS was under an over-stretched budget was also shared by some of the consultants I interviewed. Dr Z, agreeing with the idea that ‘the situation of junior doctors was a sequelae of NHS underfunding’, remarked:

Dr Z: We don’t spend enough money per GDP as other countries do, so no wonder we are in crisis. Having said that, there are very good things about the NHS. It is a relatively unique institution and, for what it is, it is the best free at the point of care in the world. I agree that it is increasingly difficult for the NHS to continue doing something like what we are doing now, unless we fund it more. But also, not having a free-market healthcare system makes it there are clear areas of inefficiency, of wasted resources. There is no push. I think it is very sad. What we try to do is to offer the best advice based on what we can offer in the NHS and, clearly, some trusts do it in different ways than other trusts do it. Is the NHS failing the patients? I think that what we probably will end up with is that certain specialties will end up being taken out of the NHS.

One of the areas of the NHS that was certainly struggling to keep funding was Complementary and Alternative Medicine (CAM). Since one of my research participants continuously expressed how much CAM was helping them cope with the cancer, my line manager agreed I could try and obtain an interview from the consultant oncologist running the NHS CAM cancer clinic in London. After months of struggling to arrange it, and the generous mediation of Simon (the patient who was looked after by her), I met her on a late Friday afternoon in her consultation. After discussing the benefits of complementary medicine, above all for cancer patients who require better symptom control, I asked Dr V the same question that I posed to other health professionals: is the NHS in crisis? In a friendly but severe tone, Dr V told me that they had always needed to be ‘three steps ahead’. She agreed with Dr Z that it was not only that the system was underfunded (including in her consideration the contractual dispute that junior doctors were facing), but also that there were some efficiency measures that the whole system was being asked to adopt. In her words:

Dr V: Yes. It has never been so difficult. Here in the hospital we are doing well because our books are quite balanced and we have kept the level of care, but we are constantly facing pressures for the infrastructure. We are constantly squeezed. But colleagues are demoralised, junior doctors even more. This efficiency improvements have been difficult. But I always look at the positive side of things. When we needed to give up a big part of the building for the national hospital, I told my colleagues that it was something good because now we would interact more, see each other more often. The managers have learnt to be more efficient in keeping the level of clinical care. There is financial pressure, and not all targets are the best, but some of the restrictions we are facing would help us improve – an expensive complementary drug would stop being funded by the NHS, so we will need to dilute it more, but that is actually good clinically. In general, because so many people want to close the hospital and take this space, we are always three steps ahead.

Dr V had a realistic, but still positive, view on the changes that had been implemented throughout the NHS. Some other consultants were less positive. After 10 months in the field, when one of the weekly multidisciplinary team meetings had finished, a consultant surgeon and I took the same lift to the ground floor. Walking comparatively faster, I went first towards the main door. On the sidewalk, he reached me and asked who I was, as he had seen me in the meeting. After several weeks of planning to ask him for an interview, the serendipity of fieldwork had offered me a chance to talk with him. I introduced myself and my research, and told him:

- **Ignacia:** I have been working with [my line manager] the last 10 months in this hospital, my fieldwork finishes at the end of November. [*With him smiling, I continued*] and actually, I would like to ask you a couple of questions, if possible. I do fieldwork with the oncologists but I would like to know a surgeon's perspective.
- **Dr X:** Of course. It is important. When would you like to have the interview?

Luckily, he was available then, and invited me for coffee and the interview (with my word that it would not take more than 15 minutes). Sitting at a coffee table nearby, I started:

- **Ignacia:** I would like to start with a tricky question: is the NHS in crisis?
- **Dr X:** 150% yes.

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- **Ignacia:** Where do you see the crisis?
 - **Dr X:** In the expansion of the managerial level with the aim of improving the service. The expansion has made it more difficult to deliver clinical outputs.

Dr X's view on the difficult-to-achieve good standard clinical outputs was a common challenge that the whole clinic was facing. In a substantively more detailed way, CNS A explained the challenges of her role:

- **CNS A:** The lack of rooms is one thing, but mainly [it] is the number of patients. I have to see all patients, so I rush between rooms and ask if I need to sort out anything for them. I hate that [Wednesday] clinic. Doctors do not wait for me and patients keep coming. Dr Y and Dr W wait for me in the corridor until I am free, or they take another patient first so when I bring the patient, they are busy. It is just a very bad clinic. If we have 16 patients, I could do it properly, but now we have 65 patients, 5 patients at a time. If the patient needs to talk with me, he knows he has to grab me and ask for more time – I will always make time for them if they are concerned. Yesterday, I was until 11 pm sorting out cases that should had been sorted before. I went for holiday for 3 weeks and got 420 new cases for 'straight to test' (GP's referrals). The new nurse, band 6, you saw her last week, she will start working on 'straight to test'. We made the business case for a band 7 and have been waiting for 2 years. There are no funds. We got the band 6 because we failed in some of the targets.
- **Ignacia:** Which ones?
- **CNS A:** Time target to see patients with suspected cancer referred from GPs. Still, most of the cancer patients come from A&E, and some from other specialty referrals.

On top of the views of health professionals voicing their concern regarding NHS funding in cancer care, the media continued making visible other important issues for the whole system that were affecting patients: the waiting times at several accident and emergency departments when the winter broke; the concentration of speciality centres and maternity wards in fewer hospitals across the country (forcing mothers-to-be to commute longer distances); the privatisation of many primary care services across the country; and the silent struggle of people with mental health conditions who cannot receive treatment because their primary care practices do not offer enough appointments. Those scenes pointed not only to the critical moment that the NHS was facing 70 years after its inception, but they also made evident the

‘postcode lottery’ that British residents had to navigate when seeking treatment, as I will show in the next chapter. Ruth, a patient in her late 30s, told me one day when I visited her in the hospital ward where she was admitted for several weeks:

Ruth: When the Labour party was in power, the birth clinic was better, and the clinical professionals were earning a bit more through bonuses. Now, everything is getting privatised, and you will need to pay a fee if you want to see the doctor sooner. Now, you have to pay 50 pounds to get your medical records to be sent to the work insurance, and 200 pounds a year if you are coming from outside Europe. The inequality is part of this culture, the asymmetry in wages and the concentration of money will never change.

Indeed, the privatisation of healthcare services accelerated its rhythm after the Health and Social Care Act was passed in parliament in 2012. General practices referred some of my informants to private clinics to undergo colonoscopies and other diagnostic tests, which were outsourcing NHS services. Foundation trusts such as the hospital were allowed to make up to 49% of their income from private sources and reinvest the revenues in infrastructure. The hospital had a separate area for private patients who could be seen by the same clinical team, but obtain certain amenities or treatments not covered by the NHS if willing to pay from personal accounts. All the regular consultants of the clinic were part of both public and private oncology centres situated next to each other across the road, provided that they fulfilled the responsibilities of their NHS contracts and acknowledged them before providing professional services outside the institution. This changing environment was critical for the sustainability of a healthcare system starved for funding if it were to continue being organised as originally designed.

3.4 Entitlement to healthcare

Undoubtedly, my fieldwork took place in a heavily loaded political context that informed the rhetoric used by the participants. The NHS featured as a political field in the media and in people’s imaginations in the months leading up to the British Referendum to leave the European Union. Crucially, it was depicted as a fundamental site in which the struggle to sustain the well-being of a multi-national population took place. Many of the patients I met in the hospital considered the NHS to be the bastion of British pride, and saw the healthcare demands of a multi-national population as a threat to its sustainability. How did my interlocutors perceive the

wider political situation of the NHS vis-à-vis their own engagement with it as people receiving publicly funded anti-cancer treatments? In the next sections, I analyse their perceptions in terms of idioms of entitlement and deservingness.

Leia, a woman in her late 50s from North America, experienced recurrent digestive problems; her general practitioner (GP) and the teaching hospital ruled out anaemia, appendicitis and then diverticulitis. Having a family story of colorectal cancer, unsurprisingly for her, the ongoing stomach problems turned out to be symptoms of locally advanced sigmoid cancer. While she waited to obtain the diagnosis, the tumour grew out and reached her ovaries and uterus. While she was receiving the fourth cycle of adjuvant chemotherapy in the cancer centre, she told me her treatment story from the beginning, making sure I could see the gaps she felt in the process not only due to the delayed diagnosis, but also because of the problems in communicating findings at the time of diagnosis, surgery and chemotherapy. I will not replicate the full story here but will mention that it was a nurse from another clinic who told her ‘you probably have cancer, but someone else will come and explain it to you’ while she was wheeled to a different inpatient ward. She had been admitted due to an abscess in her small intestine. She went through two sets of equivalent scans because the consultant did not find the first one, and after the second round, someone called her from the hospital to explain that ‘as your consultant suspected, you have bowel cancer’. No one had told her anything before that communication, until a dedicated specialist registrar at the clinic took the time to read her medical notes and explain what was going on in her body. Despite the many disappointments about the hospital practice that Leia’s story contains, she was grateful for the treatment she was receiving. She explained to me:

Leia: As soon as I was able to walk and eat again after surgery, the pain I endured for eight years disappeared and I was able to drink coffee again. Then I thought, this is a life worth living!

When I enquired on how she felt about receiving treatment in the UK, she lucidly articulated how most of my research participants felt about the healthcare system. She said:

Leia: The NHS is brilliant, because treatments do not depend on who can afford them. We pay it with our taxes, but it is brilliant because the standard of care is not bad, people are just overworked and the system is under-funded. Comparing with [the American country I am from], where the quality of treatment depends on the insurance you have, and you can’t choose the hospital, I strongly support the NHS.

When asking Leia whether the NHS treatment was a privilege for her, she denied it. It was not an unearned advantage because she had been paying taxes for the last 30 years. Therefore, she was *entitled*. This is the idiom of accessing NHS care as a matter of right, something that Jean explained further. Jean is a smart British woman in her late 30s doing academic research but also affected by rectal cancer. It was the last day I would gather data from her experience, after 15 months of her kindly allowing me to accompany her through chemo-radiation, surgery with curative intent, 12 cycles of adjuvant chemotherapy and the colostomy reversal. Achieving ‘clear scans’, she had been ‘on surveillance’ for the last four months and we had been meeting for a chat every fortnight around the city centre while I was following her progress. We were drinking a beer in front of Regent’s canal, enjoying an early spring-like day. Off treatment for the last four months, we talked about off-treatment issues. She told me about her experience in a public school in London, her interest in biology, and her previous incursion in an unfinished degree in genetics that she dropped out from for personal reasons. The beer was going down, and we talked about Brexit in the midst of its media storm after the decision to leave the European Union had been made by the electorate. For her, it was an opportunity for the UK to regain sovereignty and independence from the European Union. We stayed in silence for a minute, watching a dog barking at the ducks on the canal. I broke the silence and asked how she thought her cancer story would have changed if she had more or less money. The conversation that followed was something like this:

- **Jean:** It would have been the same. The only thing I needed [during treatment] was a place to rest.
- **Ignacia:** Yeah, but only because treatment is free at the point of care and all the medical supplies were given by the NHS [to you].
- **Jean:** But everybody receives that!
- **Ignacia:** Everybody who is entitled to receive it because s/he is British. What I am trying to understand is why some of my patients feel so grateful about the NHS. But yeah, I see it is not your case.
- **Jean:** I don’t know. I was raised in a council flat, attended a state school. My family was between working and middle class. But I guess that they were teachers, and they taught me to take the NHS for granted, because we had won that [in the war]. You are right, if I would have been living in the US, things would have been very different paying for treatment and affording stoma supplies.

Jean was raised to feel that she was entitled to receive care by the NHS. Even though she was critical of the working of the system in oncology, primary care and mental health, she thought that healthcare and medical supplies free at the point of care were something she could take for granted. Corresponding to a naturalised conception of the affluence or resourcefulness of the system, Jean was taking for granted not only how the NHS has been historically constituted as part of a wider welfare system that afforded a council flat for her family and public education, but also the fact that she belonged to the political community that made her a natural recipient of such benefits. Everybody receives them, she told me. However, the distinction that draws the line between who is a social citizen and who is not is as historically malleable and unstable as the concept of community itself (Wimmer and Schiller, 2002). The results from the British referendum to leave the European Union were a perfect demonstration of that. In the next section, I show that the change in the definition of the political community entitled to receive care indeed could shape the sustainability of possibility of the NHS as such.

Nevertheless, finding extra sources of money did not seem to appease the uncertainty that several professionals felt about the future of the NHS. The NHS in general, and cancer care in particular, require collaboration with other international sites in the form of the circulation of health professionals,¹ research partnerships and medical technologies for the benefit of British residents. With the general funding environment already threatening the dynamics of care, some of the members of the teaching hospital felt that leaving the European Union was adding insult to injury. Brexit may slow patients' access to novel treatments that could never be marketed in the UK; it may restrict their participation in multi-site pan-European trials funded by transnational collaborations, affecting also the availability to obtain funding for translational research carried out at universities where some consultants worked part-time. Hence, when the Brexit referendum was about to take place in June 2016, the NHS was in a fragile condition, becoming one of the most important political fields of the discussion during the lead up to the election. Conservative politicians argued in the 'leave' campaign that severing ties with the European Union could free millions of pounds that would allow the government to give more funding to healthcare. At the same time, the (misleading) campaign championed that tighter control of immigration borders could spare British nationals from immigrants relying on benefits at the expense of British taxpayers. Many of my research participants

¹As stated in a publication by the King's Fund: 'According to figures from the Health and Social Care Information Centre, 20 per cent of the NHS workforce is non-British as of September 2014. This rises to 30 per cent of doctors, when locums are included. According to figures from NHS Professionals, over and above this non-British staff also account for a significant proportion of agency staff working in the NHS, as approximately 31 per cent of nursing shifts covered by agency staff over the past year were worked by foreign staff on temporary visas' (accessed on 24th May 2018 at <https://www.kingsfund.org.uk/projects/verdict/what-do-we-know-about-impact-immigration-nhs>)

shared the idea that the problem of the NHS, and British social care in general, was due to immigration. While preparing lunch in Elizabeth's home before her stoma reversal, Joseph, her 27-year-old son, came to talk to us in the kitchen. Elizabeth was frying vegetables to mix them with tomato sauce, while I was doing the washing up. Joseph was standing at the corner of the kitchen; he had just come back from giving a college exam. All from Latin America, Elizabeth and I continued our conversation about our experiences as immigrants in the UK, something that happened 15 years ago for her... Until the topic of Brexit came up. Elizabeth stayed silent while Joseph told me:

Joseph: The country has the right to limit the amount of people coming. I know you are student and skilled, but the country can't keep offering benefits to everybody who comes, it is the same that Chile does if a non-Chilean person goes there. I voted leave.

The same concern was voiced by Seaus, a Western European man affected by sigmoid cancer. While receiving chemotherapy given by an attentive and professional Filipino nurse, he told me that 'people are coming to live on benefits' and then reminded me that 'You should not forget we were on an island, so *we* are vulnerable to the rest of the world'. During fieldwork, the Brexit talk was pervasive: in a creative writing workshop organised by a charity to distract cancer patients from their worries, some participants voiced their concern about the British vulnerability to undocumented migrants who will no longer be prevented from coming to the UK once they are at the French border in Calais. Jean, in a more polite fashion, told me that 'now the UK would have the opportunity to decide its own immigration rules, instead of following mandates by the European Union'. After hearing these comments, I realised that some of the people I had met in the clinic were actually showing their dissatisfaction with the multinational mix of people with whom they interacted every day; immigration was not always welcome. However, on the other side of the political debate, the major concern for many of the participants was the public discontent in a multicultural city like London, the hate that some people felt and the insults that were voiced. Daisy remarked:

Daisy: Our daughter-in-law is a bit affected, as she is from Norway. She works at a school and suddenly started to receive some nasty comments. We voted to stay but we don't know what will happen. We don't understand the racism; people should be treated as you want to be treated.

Similar to Daisy's opinion, Britta also did not know what would happen after Brexit but she thought that 'people were finally showing their true colours. Beyond the political crisis itself, I dislike the hate that people show on the streets'. Thus, the Brexit campaign and further negotiations created a wider divide in the circles of people I navigated; immigrants were used as scapegoats² while the NHS functioned as a political battlefield. Even though the idea of developing an explanation for the Brexit vote is obviously far beyond the scope of this thesis, I would just like to suggest that, in contrast to the argument advanced by anthropologist Gillian Evans (2017) about the indigenisation of British politics in the last 10 years, which created an ethnic white working class that became impoverished and disillusioned with the Left and thus turned to the extreme Right party, my research participants who were blaming others 'who were sitting on benefits' were not even born and bred in Britain. They were (nationalised) migrants themselves. Therefore, it seems that, in this case, the argument is not about identity politics but, following anthropologist Insa Koch (2017), may correspond better to the current failure of the state to live up to the expectations of its citizens, as she observed among the multi-national members of an estate in South England. To be sure, migrants are not the only or the major source of increased demand for welfare (including healthcare), it is an ageing population who naturally present more co-morbidities and complex needs (Charlesworth and Johnson, 2018). The figure of the migrant is a scapegoat because healthcare and social care underfunding have been congenital features of the system (Timmins, 2017) and Brexit worked as shorthand to collect and mobilise different types of frustrations with the state. More importantly for this thesis, Brexit and the wider social care and healthcare crises shaped the idioms of deservingness in the moral economy of care while I was in the field. I would like to turn to that now.

3.5 Who deserves social and health care?

Cancer treatments have a huge economic impact on people's lives, even when treatment is paid by taxpayers, making patients vulnerable to falling prey to poverty. But if one is already struggling economically before diagnosis, is one's life worth cancer treatments? Who is worthy to receive social care without blame? In contrast to Jean's idea of 'taking the NHS for granted' and as a matter of right, I turn to Simon's cancer narrative, a man in his early 50s who arrived in London with his family from a Sub-Saharan African country when he was 13 never to go back. By analysing his and other informants' experiences of dealing with social care, I would

²There is evidence to demonstrate that health tourism by inbound patients seeking treatment in the UK has produced a positive net benefit (see Hanefeld et al., 2013).

like to contribute to an increasing literature on the relationship between the poor and the state in the UK, and the moral economies that austerity measures in public spending create for people who are on benefits (Edwards et al., 2012; Garthwaite, 2016; Koch, 2015; McKenzie, 2015).

Simon was diagnosed in 2015 with advanced sigmoid cancer and liver metastasis, so he was receiving life-prolonging chemotherapy (rather than adjuvant chemotherapy given with curative intent). Facing an extremely difficult scenario of economic precariousness and family neglect, his situation got worse while I was shadowing him. His precariousness became an object of the safeguarding team's attention in the surgery ward. He was recovering from a procedure to surgically reverse the colostomy formation. While eating some bread and cheese we had bought from the nearby supermarket to have in the hospital canteen as dinner, he shared with me the anxiety that doctors would stop giving him treatment, frequently asking me who was making the decisions to give patients chemotherapy in the hospital. In his words:

- **Simon:** I just think that at some point the doctors will think that my quality of life is too crap as to keep spending money on me.
- **Ignacia:** No. One of the joys of the NHS is that it does not look at your pocket and does not look at your face before offering you treatment, by law.
- **Simon:** But they take into consideration the quality of life. When they told me the chemotherapy options, they told me how much benefit each drug had.
- **Ignacia:** Yes, because they are giving you all the information so you can make a decision, but it is not the other way around. You are entitled to receive treatment and they will give it to you until its efficacy cannot be proved. However, if you raise a problem regarding quality of life, like the one about the stoma, they do take it seriously. They speed up the [surgical] reversal, as it was in your case.

Simon wondered whether he deserved treatment, for he was afraid that his life was not worth the expenditure that the NHS was undertaking for him. He was aware of the opportunity cost of receiving chemotherapy for an incurable type of cancer and of staying on the ward extra nights while the safeguarding team of the hospital liaised with the council to sort out safer accommodation for him. He stayed on the ward for three weeks, until Simon himself convinced the social worker that he could go and stay for few days in a convent where he was a friend of some nuns. He told me:

- **Simon:** I can't stay in that bed. I am taking the bed of someone else.

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- **Ignacia:** Just take it easy. The NHS is fulfilling its duty to care and offer you the protection you need.
 - **Simon:** Yes, I totally support what they are doing, but I don't understand why they cannot deal with this with me as an outpatient, I even volunteered to go to talk with the council. The social worker told me that now they are using clause 5, so the council is liable. He also told me that even if I refuse, because he asked me, he is obliged to do it and would argue lack of capacity.
 - **Ignacia:** What capacity?
 - **Simon:** That because of the surgery I could not reason properly

Simon's belief that he was 'taking the bed of someone else' goes beyond the entitlement to receive care but also, I would suggest, points to the value of care that he was not sure he deserved. Here, deservingness is not necessarily related to a means-test appraisal that would enable the system to ration its services according to demonstrable need (as currently happens in social care). For Simon, the meaning of the concept was related to the relative worth of his life. Living between a rock and a hard place in economic terms, and enduring a social situation marked by family estrangement, he thought that the resources that the NHS was spending in keeping him alive could have been better spent on someone else. In other words, Simon was aware of the opportunity cost that the hospital was assuming for his benefit, and he felt that he had not earned it. It was like a blessing. Simon felt that the hospital was literally embodying the values it publicly professes at the entrance of the clinical site, resembling a place that gave him peace. Like his experience in the Christian church, he felt supported by kind and helpful people. While having chemotherapy a few weeks after the safeguarding episode, a student came to ask him some questions for an assignment he had to do during his medical training. Simon had consented to participate and had invited me to meet him too. He explained to the both of us:

Simon: Am I the only person on Earth that looks forward to chemotherapy? For me, the hospital it is like church, a safe space in which people care for you [...] If God asks me whether I want the cancer or not, knowing that this might not have happened, I would have chosen it anyway. Here I have met new friends, people who care for me.

Simon lived on the generosity of his friends from church, who continuously helped him with food and pocket money to pay transport, but he was reluctant to apply for social benefits. He hoped that his precarious economic situation would be just

temporary. Concurring with the hesitant approach Simon had to the option of receiving benefits even if he could demonstrate his need to the system, sociologist Kayleigh Garthwaite (2016) describes the shame that British residents who are going hungry feel when approaching the food bank. They have been referred by healthcare or social care services that have accredited their need, as the charity did for Simon. Still, the author demonstrates that accessing benefits is not a choice made to spare the effort of ‘earning’ food. Low wage, insecure jobs and, in this case, a cancer diagnosis coupled with lack of family support ensured an ‘ongoing catastrophe’ that was eroding Simon’s life, as it happens to the poor. Accessing benefits is an essential need in order to get by. But because Simon literally ate through his savings in the first few months, he turned to wider networks of reciprocal support to survive.

Simon did not want to rely on taxpayer money. When his economic situation deteriorated even more towards the end of my fieldwork, he made up his mind. Still, there were other barriers. He was not sure that he was indeed entitled to receive anything if his name figured as a co-owner of a house (in which he did not feel safe to live). Moreover, calling Citizens Advice to enquire made his ‘heart fall into pieces every time’. Understandably, he was snowed under by the whole situation and openly depressed. However, I believe that the resistance to receive income support from taxpayers points to a different feeling. He was ashamed. As anthropologists Langer and Højlund explain:

Restricting welfare as concerning only those who are able to demonstrate they are ‘in need’ defines the support from the state in particularistic rather than universal terms, stressing its potential to divide and stigmatise rather than to redistribute and enable [people] (Langer and Højlund, 2011, p. 3).

Rationing social care by expecting residents to demonstrate need is the mechanism that promotes the idiom of deservingness. Demonstration of need creates a source of differentiation in moral terms (Morgen and Maskovsky, 2003) through labelling that creates a categorical divide between strivers versus shirkers; between the hard-working versus the lazy; between the ones that earned the support versus the ones that get spoiled by taking from it. Indeed, most of my participants who were on social care benefits would be quick to reply that they ‘*were not that type of person*’, as Ruth emphatically told me once when she was admitted to the ward, pointing to the idea that she was a striver rather than a shirker. She continued:

Ruth: I think that the responsibility is of the individual. In countries like ours [hers and mine], we don’t have a safety net so we depend on

ourselves. When people get really dependant on benefits, then they complain when there are cuts, because they rely too much on them. They sit on them.

Even though Ruth was receiving housing benefits and tax exemptions and her children were attending state schools, she promoted the idea of the entrepreneurial subject who manages to live without support from social care, probably because she did not think that all those amenities could be considered benefits. Instead, she proclaimed the values of work. Ruth was grateful for the support from her council, but was also invested in presenting an image of herself as self-reliant and productive, following a normative expectation for welfare recipients in England (Evans, 2017).

Whether gratefulness for social care is to be expected or rejected, it had the potential to drastically change patient experiences of treatment. Elizabeth is a case in point. A woman from Latin America, she has endured a life marked by episodes of life-threatening domestic violence by two partners, followed by long periods of economic precariousness as a single mother working 18 hours a day to provide for her children. Only now, in her 50s, she has started to experience some economic stability. With two adult children already working, a council flat in London and an employer who keeps paying her 75% of her salary despite the fact that she is on sick leave from her job in catering, she is grateful to be in the UK. When I asked how she made sense of the welfare and healthcare she was receiving in the UK, she told me:

Elizabeth: I had always been a good person, hard-working and good-hearted, but life has made me face serious problems: first, an abusive relationship with my (British) husband who beat me up for years. I forced him to get the divorce after he also beat my son, Joseph. But I did not have a stable job, so I had to work as a domestic cleaner 18 hours a day, and then doing street maintenance works for four years to be able to raise my children and afford their education. After the divorce, I applied for social housing and, while I was waiting for that, I had to endure the emotional and economic abuse of the person who was hosting me and my children. Besides my work, I had to keep that house running, cooking and cleaning, and she never gave me a penny. Only when I obtained social housing did the situation start to improve. So, after everything I have suffered in life, I deserve to live in the UK and receive the [social care and employer's] benefits I do.

In a way, Elizabeth's explanation of her entitlement to public benefits (including cancer care) resembles the logic of a welfare state. Like the British population who

fought in the wars, her life had also been devastated and required a new start. That was a possibility given by the council that accepted her application for social housing. To be sure, this logic does not follow a legal version of entitlement or a means-test approach to deservingness. For Elizabeth, she deserved to receive benefits because of her understanding of the moral order. In line with Fassin and Rechtman (2009), who examine how the figure of the victim has recently become a moral category that qualifies for public (and not only clinical) acknowledgement and support, Elizabeth mobilised her biographical position of vulnerability to make sense of her worthiness as a recipient of public funds. It was fair to eventually receive support after all that she had suffered as a lone mother of two, facing situations of severe domestic abuse and economic precariousness. And there was no doubt that this support was facilitating her to continue with life despite treatment. She explained to me during one of our follow-up conversations after window shopping a few miles away from her neighbourhood:

Elizabeth: The [cancer] treatment has been very tough, but it would have been even worse if I would have to worry about money. I am very lucky that my company is still giving me a bit more than half of my wage every month, and that I am receiving this supplementary income from the council. Otherwise, life would have been different.

3.6 Discussion

This chapter has analysed some of the structural dynamics that make anti-cancer treatments in the clinic stand out as a world-making project. Unlike most of the countries around the globe, the NHS is part of a wider – albeit stretched – national welfare arrangement, offering a possibility of experience other than indebtedness and death to people affected by cancer. The UK has worked hard during the last 70 years to achieve a world-class healthcare system, providing ‘excellent value for money’ in terms of administrative efficiency and ‘equitable access to healthcare and care process’ (Thorlby and Arora, 2017). In a report comparing resourceful national healthcare systems (including 11 high-income countries: the US, Sweden, Australia, Switzerland, France, Germany, the Netherlands, Canada, Norway, New Zealand and the UK), the British healthcare system is the top performer according to comparative statistical data that measures access, integration, efficiency, equity and outcomes in public healthcare (Schneider et al., 2017). Yet, such resourcefulness of the NHS needs to be examined not only from the point of view of the structural dynamics that make it possible, but also from the point of view of its users. Throughout this chapter,

I have unpacked the relationship that my research participants establish with the British welfare state while receiving cancer treatments. I have gone to some lengths to explain the structural components of the British welfare system that are relevant for the people I met who were affected by cancer: healthcare, housing and social security. Due to the cancer diagnosis, patients require treatment that is fortunately given free at the point of care in the country; however, because absence at work often worsens one's economic position, some patients require the support stemming from public funds. In order to get on with life during and despite cancer treatments, the NHS – together with other welfare bodies – enabled possibilities of experience other than severe indebtedness followed by death. In that vein, the welfare estate (or what remains of it) stood out as the material engine of my research participants' world-making projects. Yet, this engine is under heavy stress. I have argued that the ongoing rationing of the subsidiary state in healthcare and social care matters are worsening patient experiences of treatment, increasing waiting times and sometimes failing to support patients' needs. Some members of the clinical team would also agree that because the NHS crisis, and the managerial pressure over healthcare workers, it has turned difficult to achieve high clinical outcomes. The disjuncture created by the reconfiguration of the healthcare system through the passing of the Health and Social Care Act is reproducing the fault lines of economic deprivation while simultaneously creating new forms of differentiation in the relationship British residents can establish with the state.

Within this context, anthropologist Sophie Day argues that such institutional transformation tends to erase personal accountability for wrongdoings in the breast cancer clinic in London where she did research. Similarly to the complaints I heard from patients such as Leia, Day documents some of the problems affecting the ecology of cancer care in the clinic at the time of writing, just a few months after the NHS underwent a major structural reorganisation that affected patient experience for the worse: 'Difficulties of transport, waiting for indeterminate periods with little sense of what might happen next, failed communication, lost notes, non-existent appointments, unsigned prescriptions, hospital information technologies that were not integrated across sites and more' (Day, 2015, p. 174). For Day's research participants, it was the disembodied faceless bureaucracy that was responsible for all those happenings that were de-personalising care. In contrast, the clinical staff were seen to be as affected by the chaos as patients were, and patients and caregivers praised the 'flesh and blood people' working in the NHS as kind, skilful and professional people who care for patients' individual needs. Day's interlocutors felt grateful for the kindness of the clinical team even if they had to wait long hours to receive treatment. Hence, Day argues that 'waiting, if the manifestation of bureaucratic indifference, also produces

a routine of care that adds responsiveness and common humanity to expert practice and professional conduct’ (Day, 2015, p. 176).

Day’s argument is useful to understand the sorts of ‘informal care embedded in waiting’ (p. 176) as part of the recognisable and praised features of an institution that, although is changing, makes British residents positively connect with the nation and state. They felt they were not only equivalent citizens, but also subjects that are looked after by an institution they felt it was ‘theirs’. In her words:

A politics of care animates social contracts among strangers, and UK residents associate this vitality with ‘their’ NHS specifically, whose values and practices produce the hyphen between nation and state, citizen and subject, equality and equity (Day, 2015, p. 181).

This again echoes the views of patients like Simon, who found in the hospital kind and caring people such as the ones he befriended in his local church, among several others. However, in Day’s argument, cancer patients, caregivers and even health professionals are described as if they were part of a homogeneous collective relating affectively to the state through the NHS. I would like to complement that analysis of the current situation and argue that, in healthcare as it is happening across the country and around the globe (Clarke, 2004; Evans, 2017; Garthwaite, 2016; Morgen and Maskovsky, 2003), austerity measures have tended to reinforce local idioms of entitlement and deservingness that emerge to legitimise the provision, allocation and, I will argue, embodiment of life-saving health treatments in people’s cancer narratives. This in turn complicates the ‘hyphen’ between the nation and the state in terms of legal and social citizenship. Schematically, idioms of entitlement voiced by my research participants enable us to understand who (they think) belongs to the political community that the British state should serve, who is the ‘we’ through which opposition is discursively built. Meanwhile, idioms of deservingness show how my research participants *affectively* make sense of their position in the slot of the social citizen, the individual who has been granted access. Definitions of entitlement and deservingness may not necessarily overlap, especially after legal definitions of who is a British resident have lost currency. I have argued that, during the lead-up to the British referendum to leave the European Union and after the decision was confirmed, those idioms became pervasive among the patients in the clinic. The political context, fuelled by the media, meant that the NHS prominently featured in the debate. After all, it was the bastion of the welfare state and, therefore, it was a reason to be proud and to be defensive. I discussed how the Brexit talk mobilised deep concerns about the fragility of a project based on multi-national conviviality,

which was voiced by both born and bred people in Britain vis-à-vis nationalised migrants.

Idioms of entitlement and deservingness are produced at the meeting point of people's everyday interactions with the state, through their encounters with the NHS and other public services. These idioms are public representations of statehood that reproduce an affectively charged attachment between the political community and a 'state form'. Following anthropologist Begona Aretxaga, it is possible to understand this affective and normative attachment or 'hyphen' (Aretxaga, 2003, p. 393) between nation and state as a performative product of a public discourse that, in reproducing the imagery of provision and efficiency, gives content and character to the state entity. But Aretxaga argues that the nation is not homogeneous and its relation to the state form is ambiguous; the collective relationship to the state as an entity creates a fantasy of unity that conceals inner tensions such as collective and de facto differences in citizenship (p. 396). Such disjuncture is masked with the symbol of the scapegoat, who, following philosopher Rene Girard (1979), is a ritual repository of the jarring violence in the national community (Aretxaga, 2003, p. 397), a vulnerable and arbitrary victim placed at the community's margin (Jun, 2007). Here, I suggest that the figure of the scapegoat is discursively constructed upon the image of non-British residents and especially migrants who come to use the NHS and 'sit on benefits'. I find Aretxaga's theoretical conceptualisation of the state productive to understand the changes that Brexit brings about. If statehood is performed – that is, it is an entity that comes into being in the quotidian interactions between state officials and the residents of the territory – it is possible to understand that the state is 'a screen for a variety of identifications and as a performative mask for a variety of power discourses and practices' (Aretxaga, 2003, p. 395). Thus, logically Brexit is changing the content of the imagery of the state, shaping the national narrative that organises the collective and determines who belong where. Specifically, for the operation of the NHS and social services, Brexit foregrounds the capacity of the welfare state to render bodies legible and therefore eligible for its care (or not);³ the basic sovereign operation that differentiates bare life from legal (and social) citizenship. However, it is not the evil faceless bureaucrat who is exclusively in charge of this biopolitical operation of population management; with the Brexit case, changes brought about by the reconfiguration of the national community are also the responsibility of the people who made it possible for the state to have this current form.

³Patients seeking care in the NHS are currently asked to demonstrate proof of eligibility with two forms of identification. See: <http://www.bbc.co.uk/news/uk-38060432>.

Policy analysis in healthcare (McKenna, 2017; BMA, 2018) and experts in cancer research (Majeed et al., 2016; Selby et al., 2016) have argued that once Britain labels a part of the political community that made the NHS what it was as the new *other*, potentially striking it off from the healthcare and social care working force and possibly severing the financial agreements that made cancer research strive for the benefit of British residents, the world-making potential of the NHS may be jeopardised if corrective actions are not put in place. The wider British population, my research participants, and the cancer patients coming after them need a stronger healthcare system so that social redistribution of benefits and happier temporal horizons keep being possibilities for all. Having described the wider political and historical context in which the NHS was situated at the time of the fieldwork, in the next chapter, I turn to the forms of advantage and disadvantage that shape cancer care in the country and the practices through which my research participants navigated those forms of inequality.

Chapter 4

Equals, but different – Part 2: Living the political economy of health in London

The clinic is a busy place in which well-dressed clinical professionals, routines and technologies of care run rhythmically day in and day out. The cancer centre has been recently opened with funds from the university hospital trust and a major cancer charity in the UK. The building is bright, spacious and welcoming. There is a colourful artwork hanging from the ceiling at the centre of the clinic that can be seen from the ground floor and the consultation rooms on the first floor. On some Wednesdays, young members of a local musical organisation come to play relaxing and beautiful instrumental music in the ground floor, for the sheer pleasure of the people who are waiting for care. All six floors are illuminated by the use of windows in the central part of the roof, which provides a view of the sky and blurs the material limits of the space. On the third and fourth floors, the chemotherapy rooms are furnished with cushioned divans and other amenities in every aisle, inviting patients to feel comfortable. A kind assistant comes morning and afternoon to offer tea, coffee and biscuits to patients receiving chemotherapy and their accompaniers. At midday, she also offers lunch to the patients.

The warmth of the staff and the brightness of the space reminded me of my conversation with Dr X, one of the consultant surgeons of the GI clinic. We were discussing the scope of the local Cancer Network within which the teaching hospital was embedded, an organisational partnership between different hospital trusts in the region created in 2011 to standardise clinical protocols into treatment pathways, increase the bowel cancer screening uptake, integrate cancer data, and deliver the same clinical outcomes across the area for the benefit of patients. He said:

- **Dr X:** The [area] Cancer Network makes sure that patients receive the same quality of care wherever they are.
- **Ignacia:** But if it is the same quality of care, the same standards of care, why does this hospital keep receiving patients who want second opinions?
- **Dr X:** Surgery in [this hospital] is not better than surgery in [a hospital trust in the north of London]. But that hospital has a lot of immigrant people [sic] and the facilities are not that nice and shiny like here [in this hospital]. So people come to [this hospital] because of the hospital experience, not because the surgery here is better. Do you understand? [This hospital's] staff is kind and nice. The facilities are nice and shiny, that is the difference.

Implicitly recognising the existence of the ‘post-code lottery’ in cancer care when explaining the purpose of the cancer network – that is, that there is variation of the distribution of clinical outcomes according to the place of residency – in Dr X’s view, the regional reputation of the hospital (and the GI clinic) was not due to disparities in the quality of care but rather due to the hospitality niceties and the hospital’s infrastructure. Even though many other health professionals with whom I had the opportunity to speak with would agree regarding the high standard of the cancer clinic (as when a female consultant who attended several multidisciplinary team meetings told me ‘location-wise and building-wise, this is the best hospital in London’), praising the infrastructure of the building is only part of the answer. The National Bowel Cancer Audit (2016) shows that the district hospital in which I carried out my research (a foundation trust financed 75.7% by NHS funds in the year 2016–2017)¹ performs between two and three times better than the worst performing trusts in the same local area in London. Measures include colorectal cancer outcomes such as (1) post-surgical mortality at 30 days and 1 year, (2) availability of Cancer Nurse Specialists (CNSs), nominating one to every patient, and (3) rate of stoma reversal procedures to eligible rectal cancer patients (which is considered a measure of clinical priority to improve patients’ quality of life) (Boyle et al., 2017). These are just some examples that illustrate the systematic disadvantage that residents of certain areas must face in terms of diagnostic delays, ill-equipped clinical teams, and quality of care. As a whole, those factors negatively impact upon the distribution of cancer survival rates and quality of life among the population.

Considering the economic context of healthcare in England, in this second contextualising chapter, I trace the lines between general socioeconomic inequalities that

¹The remaining 24.3% of the income was obtained from other operations such as private patients, research, training and education, pharmacy sales and awards and charitable expenditure.

structure the English landscape and patients' outcomes in cancer care. Combining an analysis of structural dynamics in England and particular experiences of people looking for a diagnosis to receive cancer treatment, I look at the different forms of stratification that affect cancer outcomes inside and outside the clinic. In particular, I analyse the structural dynamics that give rise to enduring inequalities in cancer care in terms of the time of diagnosis, quality of treatment and its outcomes. Through a closer examination of the health-seeking practices of two research participants, I foreground the social determinants of health that shaped their lives and fates. Following this, I describe the ways in which my participants made sense of the treatment they were receiving, by looking at three forms of differentiation within the clinic that made some of them feel either lucky or grateful, partly due to excellent care but also because of the ways in which a 'good reputation' was orchestrated within an institutional context of increasing competition between trusts and highly promoted 'patient choice'.

4.1 Systematic disadvantage in cancer care outcomes across the country

Simon and Ruth were diagnosed with cancer in A&E, and both struggled economically. At the time of writing this chapter, both of them have passed away. Simon knew that something was terribly wrong with him. On top of stomach cramps and rectal bleeding, he started losing weight quite abruptly, to the point that his friends from church started asking him why he was so thin. After admission at A&E with acute pain in the liver, he went for scans and blood tests that confirmed his cancer diagnosis. Without visible regret, he explained to me that even knowing that he might have had cancer, he decided to 'hold on and wait a bit'. Financial issues kept Simon from seeking healthcare; he was working as technology support in a charity under a zero-hour contract, so he 'could not give himself the privilege of not working, otherwise I would not have food to eat and a place to live', he explained. His plan was to save money to stay in hospital for one month, and afford something like 'a buffer, a breathing space'. With a dose of black humour, he explained that he 'was in the race of "money against cancer" and cancer won so now I can't turn the clock back'. But his assumption was right, because while staying on the ward, his landlord's son came to collect his pending rent. When Simon started treatment, he was underweight because of the lack of food, and doctors wanted him fitter to cope better with the chemotherapy drugs. A consultant told him to simply eat everything and whatever he could eat to increase his weight. A cancer charity helped doing

some research to find out places in which he could get food for free, so he reluctantly went to food banks. He told me:

Simon: You will think this is silly, but when I come to the hospital and I see the patients and their families going to the café and getting something to eat before or after the appointments... If I could just do it once... Or going to the cinema and just having a moment to relax, or having a nice meal, I just can't do it.

In opposition to Simon's conscious deferral, some of my other participants were instead affected by a delayed diagnosis in which a combination of wrong diagnoses and apathy on the part of healthcare professionals made them feel that the cancer could have been caught earlier. Ruth was a young woman who, like Simon, became one of my closest research participants. She was a mother of two children going to primary school, married to a man from her own African background. She had been living in London for 25 years and had worked professionally as an assistant accountant during the last years. She was subletting a room in a housing estate from a friend of hers. In it, she slept with her husband and two kids; combining her income with the income that her husband received as a bus driver was not enough to rent a full flat for her family and pay all other expenses. However, that was not a real problem at that time. Her work, domestic responsibilities and participation in an evangelical church filled her life. Until she got diagnosed. Recounting the pathway towards the cancer diagnosis while receiving the third cycle of chemotherapy, she explained to me:

Ruth: The GP underestimated my constipation and pain for months. I was getting weaker and weaker. Because of my age [mid 30s at that time], the GP did not think of cancer until I started bleeding from the back passage. After the blood test, I was called to [this hospital] to do a colonoscopy. It took three months to get a proper diagnosis. Until then, I went to A&E several times, but the unbearable pain and cramps were dismissed as constipation, so I did not even receive painkillers. I lost several kilos because I could not eat anything. I had to wait one month between a blood test and colonoscopy, and then another month to start treatment. At least when they told me that it was [locally advanced rectal] cancer, I felt relieved. I knew that I wasn't crazy, and then I was in a hospital able to treat it.

Ruth received chemo-radiation, surgery with curative intent, and then two lines of chemotherapy until each of them stopped working. Ruth's case was the unfortunate

example of delayed diagnosis combined with an aggressive type of rectal cancer. She, Simon, and Robert were the only three research participants I followed that passed away during the time I was doing this research. However, in contrast to Robert's survival of nine years from the time of the first diagnosis, I tend to think that Simon's and Ruth's fates were intimately related to their delayed diagnosis and economic struggle. The unequal distribution of cancer outcomes across the country follows the social gradient of deprivation. In other words, cancer patients' survival and quality of life are outcomes that mirror other forms in which wealth is unevenly distributed, with negative outcomes affecting poorer populations to a proportionately greater degree. Even though mandatory treatment guidelines and quality standards are agreed by the NICE to be adhered to by all healthcare providers, the performance of hospital trusts and general practices (organised into CCGs) is wide ranging. Just before the system re-organisation of the NHS took place in 2013, the King's Fund – a renown health policy think tank – argued in a publication that 'there is persistent variation across primary care trusts in per capita spending on cancer services' with some primary care trusts spending four times more than others (Appleby et al., 2011, p. 13). Realistically, levels of expenditure impact the human and technological capacity of trusts to commission cancer care services, therefore shaping outcomes such as cancer waiting times (to confirm diagnosis and start treatment) and quality of care. Moreover, a national survey measuring patient experience in hospital in-patient wards showed high variation among the performance of different trusts in aspects such as accessibility, waiting times and post-discharge care (Raleigh, 2015). While the first item points to the pressure faced by the whole healthcare system after social care funding has been consistently slashed (Timmins, 2017), follow-up care after surgery is a proxy that points to the variability of access to information about surgical complications post surgery and about the side effects of medications. Lack of appropriate post-surgical care may lead to life-threatening complications and death. Indeed, there is evidence that measures such as the '30-day post-surgery mortality index' are closely co-related with the deprivation gradient. The authors of another report looking specifically at colorectal cancer trends assert that:

A strong relationship between socioeconomic deprivation and postoperative mortality was observed, with those residing in more deprived areas having a significantly greater risk of death within 30 days of surgery than those residing in more affluent areas. This effect remained despite adjustment for stage of disease, comorbidity and urgency of surgical resection. This finding mirrors other studies that have shown socioeconomic gradients in both the long-term and short-term outcomes of

colorectal cancer. In contrast, there is evidence to suggest that this gradient disappears in a randomised trial setting where patients are given equal treatment, although it is possible that this may be partially explained by participants of randomised trials having a better prognosis than those not participating in a randomised trial. Further evidence is therefore required before it is possible to determine whether inequalities in care may account for some of the socioeconomic disparities observed in 30-day postoperative mortality. However, understanding the causes of the gradient and minimising it has the potential to significantly improve outcomes from colorectal cancer (Morris et al., 2011, p. 812).

Despite the possible selection bias that (the authors argue) could explain the lower impact of social deprivation in the overall survival of colorectal cancer patients who are enrolled in a clinical trial, my reading of the quotation depicts a panorama that is coherent with other structural dynamics. First, unequal levels of infrastructure impede local commissioning of diagnostic tests, which in turn shapes the differences in the timing of diagnosis. Second, overstretched healthcare professionals cannot meet the demand, making support for cancer patients beyond treatment a variable luxury. Both factors help us to explain not only why patients from deprived areas are diagnosed at a later stage (thus making survivorship less likely), but also why, if they survive treatment, their quality of life is poorer. This is not only to say that the NHS could do better; comparatively, the average survival rates for colorectal cancer patients in the UK are lower than other resourceful countries with similar cancer incidence and healthcare budgets (Maringe et al., 2013, p. 919). However, these results are not the responsibility of a single institution within the NHS, but of the whole system. In part, it is based on the capacities and decisions made by CCGs that assess the local healthcare needs and contract services from hospitals, charities and private and other healthcare providers to meet them.

With the UK enjoying a robust database of cancer-related statistics and specialised collection mechanisms for measuring cancer care performance through the National Cancer Intelligence Network (NCIN), it is possible to observe that most CCGs are failing cancer targets. The *British Medical Journal* published in 2016 the results of *NHS England's New Clinical Commissioning Group Improvement and Assessment Framework*, describing a staggering difference among CCGs. Most of them do poorly regarding the mandatory two-week target within which patients with a general practitioner (GP) urgent referral must be seen by cancer diagnostic teams. At the same time, the rate of emergency presentations, which is the route to cancer diagnosis more closely correlated with shorter survival time for colorectal cancer,

is still high and wide ranging across the country. Failing the ‘two weeks wait’ and the ‘emergency presentation’ targets is telling. One-year survival after diagnosis is associated with the route through which patients are diagnosed and ‘emergency presentations’ (when cancer is not only symptomatic but life-threatening to the point of requiring admission in A&E) vary widely across the country. In concrete terms, the report measured four aspects of cancer care: (1) early diagnosis (stages I or II are associated with improved survival); (2) 62-day waits for treatment after a referral from a GP (a second national target to speed the beginning of treatment after diagnosis); (3) one-year survival rate; and (4) overall patient experience. Eighty-six per cent of the 209 CCGs in the country were judged to require improvement (Lacobucci, 2016), with 10 percentage points between the best and worst performing CCGs (64% to 74%) in the one-year survival component, and 30 percentage points between the best and worst performing CCGs (67% to 96%) in the patient experience component (Edwards, 2016).

The NCIN graph depicting the survival of patients affected by colorectal cancer in England by route of diagnosis as emergency presentation is striking:

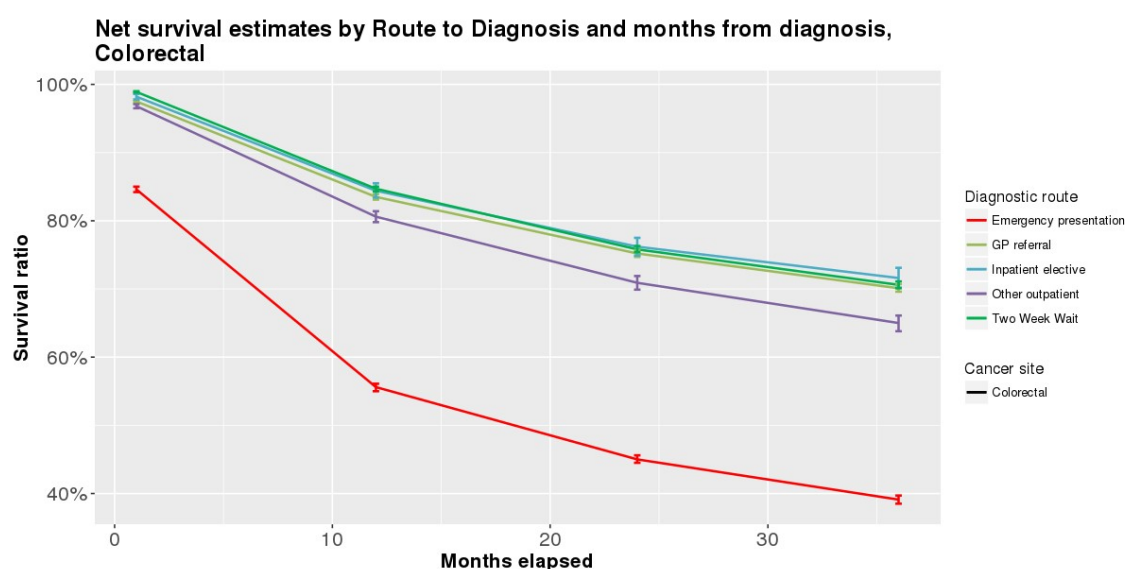


Figure 4.1 Net survival estimates by route of diagnosis

In the graph, the red line shows the ‘loss of net survival’ for people diagnosed with colorectal cancer as emergency presentation. This means that there are lives that could have been saved if diagnosis could have happened earlier. For the patients receiving a diagnosis after an emergency (that pushed them to go to A&E), over the course of two years, the proportion of patients still alive (for the years 2011–2015) is less than 50% of the total; that is, between 20% and 25% lower survival rate than people diagnosed by the GP and offered an urgent diagnostic referral under

the two weeks wait scheme. Importantly, delayed diagnosis intersects with economic status, presenting the same socio-economic gradient described above for the case of patients receiving care in NHS hospital trusts. Cancer Research UK, using data from the National Cancer Registration and Analysis Service (NCRAS) collected in 2014, asserted that:

Late stage at diagnosis of bowel cancer in England is associated with higher deprivation. Among adults aged 15-99 in England, 57% of those in the most deprived areas are diagnosed at stage III or IV, versus 54% of those in the least deprived areas (NCRAS, 2016).

In sum, the higher incidence of patients affected by colorectal cancer diagnosed at a later stage with harsher deprivation scores, combined with the lower rate of survival of those patients diagnosed late, leads to the logical but unfair conclusion that people affected by colorectal cancer who live in more deprived areas tend to face a higher mortality than comparable groups living in better-off neighbourhoods. Hence, put bluntly, a wide variation in performance of the CCGs may explain, in part, why poorer people are dying from colorectal cancer sooner. But mortality is not the only outcome that counts. With almost 60% of the people diagnosed with colorectal cancer living for five years or more, the quality of life of people living in remission must be also included in the picture. Macmillan Cancer Support has shown that holistic needs assessments, one of the four tools designed by the National Cancer Survivorship Initiative in England as part of the ‘recovery package’ to improve cancer survivors’ quality of life, has not been rolled out in all cancer centres, denying available professional support to people who may need it. Moreover, the report shows that, in 2014, 11% of cancer patients in England did not have access to a cancer nurse specialist (CNS) to coordinate their care (NHSE, 2016). As I became aware in my own field site, CNSs were the most knowledgeable people in the clinic regarding the intricacies of patients’ lives and treatments. They sometimes accompanied consultants to the appointments or did the follow-up with a patient who did not present major clinical difficulties. They were available throughout the day, and also remotely, to help patients manage uncomfortable side effects of treatment (including surgery, radiotherapy and chemotherapy). Moreover, CNSs were the staff members in charge of managing patients’ treatment pathways in multidisciplinary meetings, where they advocated for patients’ preference. They were also responsible for the follow-up protocol supporting patients who had finished treatment with curative intent and were ‘on surveillance’. CNSs also did most of the administrative work, booking diagnostic tests and referrals to other clinics and giving detailed but understandable information to patients when they were offered new treatments.

The CNSs I met in the clinic felt genuinely over-stretched by the demands of an ever-growing volume of patients at the clinic, regretting ‘how difficult [it was] to get more patient contact and not just do firefighting’, as a senior cancer nurse specialist, CNS A, put it for me. They were the key workers accompanying patients throughout the treatment pathway, and they made it possible for the team to work as smoothly as possible. Essential for the clinic, CNSs’ relentless care tended to be overshadowed by the roles that were performing the ‘heroic’ part of cancer care in the hospital.

4.2 Orchestrating reputation

Against a backdrop of unequal distribution of delayed diagnosis, quality of treatment, and supported follow-up pathways defining the opportunities of the life and death of people affected by cancer in England, my research participants felt that managing to receive treatment in this GI clinic was reassuring, irrespective of the eventual outcomes. Health professionals were not only kind to them, but they also felt that the physical and human capacity to look after patients was superior. My participants might not necessarily know the statistics I presented above, but some of them have learnt from experience that it was better to trust this hospital than the local ones. This reputation is what drove people to seek treatment and second opinions in that trust. Within a health policy context that promotes competition between healthcare providers, enables patients to choose where to be treated, and mobilises vast amounts of information about providers’ performance to the public for easy comparison, the clinic constructed an image of itself as a gravitational force in the urban ecology of cancer care. One Wednesday, Dr Y, a consultant oncologist said emphatically to another in the pre-clinic meeting: ‘This clinic does not lose patients, it always gains more’, meaning literally that there are more referrals from patients coming to the clinic than from the clinic going somewhere else. Economically accommodated people who got in touch with the consultants in their private clinics were sometimes transferred to the NHS to receive faster treatment by the same consultant. That was Seaus’ case, a Western European businessman in his late 60s who was affected by sigmoid cancer but otherwise healthy. He went to see one of the consultants in his private clinic after a lung infection did not clear up with a course of antibiotics. The private consultant confirmed that he had cancer and suggested he could come to this public hospital, as the wait could be shorter than doing the surgery privately (by surgeons who were working in both the NHS and privately).

The specialisation of knowledge and the trust that the clinical team inspired in patients were other motivating factors in terms of receiving treatment at the hospital. Legally, British residents can choose the specialist hospital in which they would like

to be looked after, and the hospital cannot refuse an urgent cancer referral when it is made appropriately. Against the practical convenience of receiving chemotherapy near home, Jimmy, a British man in his late 70s, decided that he was willing to commute for longer in order to access proven professional expertise. Jimmy was diagnosed with bowel cancer through the bowel screening programme. I met him while he was receiving adjuvant chemotherapy to minimise the chances of cancer recurrence. He explained to me:

Jimmy: After the surgeon doing the colonoscopy had confirmed the diagnosis, I immediately asked him whether he could be in charge of the bowel resection. I was following my gut instinct that told me to trust the surgeon.

Later on, even though he was receiving the standard treatment that he could have accessed closer to home, Jimmy's local surgery told him that they did not know how to dispose of toxic waste, so he should give the pump away to the main hospital. He did not trust the way in which local nurses would handle the PICC line either; 'the stakes are too high to overshadow the risks', Jimmy and his wife Daisy explained to me. The couple preferred to spend four hours on public transport to make sure that he was 'in expert hands'. Eventually, Jimmy and Daisy commuted from Essex by train and tube every week, at least twice, to get blood tests, receive the treatment, disconnect the chemotherapy pump emptied after 48 hours, and flushing and bandaging the PICC line (a central catheter inserted in the arm to receive infusion chemotherapy). The same situation corresponds to Robert, a British patient in his 80s who commuted by train for two hours to receive treatment in this clinic for years. As a long standing patient who was well known in the clinic, Dr Z told me:

Dr Z: Robert did the extra mile. Because his cancer was growing slowly, we were able to do stuff [to resect the tumours in the bowel, the liver and the lungs]. He has lived the double than an average patient [with the same clinical condition]. He is very grateful.

Through the discussion of my participants' challenges to obtain a diagnosis, and the practices through which they sought healthcare in the clinic, I hope to have illustrated the diverse pathways that patients traverse in order to receive high-quality care in the clinic. Yet reputation is a relative value, built in contrast to other experiences. These practices also show some of the ways in which my research participants made sense of the apparent inequality that structures secondary care

in terms of infrastructure and expertise regarding the care of cancer patients. In the next section, I explore how they made sense of receiving publicly funded cancer treatments in the clinic.

4.3 Embodying privilege, a matter of differentiation

By looking at the patients' feelings about receiving cancer treatments in the hospital, in this section, I would like to unpack the gratitude that the people I met in the field expressed for the NHS and the hospital in particular. My aim is to shed light on the ways in which my research participants experienced the (unearned) advantage of receiving gold-standard cancer care for which the majority of them would be otherwise unable to pay (something that may be specific to the socio-demographic characteristics of my research sample). Gratefulness is here shaped by my participants' awareness of different forms of stratification in the clinic. I look at some of my research participants' practices of othering based on comparisons of national healthcare contexts, patients' prognoses and eligibility to receive targeted drugs (from trials and from the CDF) based on the genetic make-up of their tumours as relevant distinctions that assisted them to make sense of their treatment experience.

At first, I became aware of the privilege of being looked after in the NHS through the othering discourse that my foreign research participants used to articulate how they made sense of their own 'fortune'. Comparisons with African, Latin American and North American countries were used by my participants to make sense of their cancer experience. In one of the several visits I made while Ruth was receiving cytotoxic treatments, she told me how lucky she was to be living in the UK and not in her country of origin. She remarked:

Ruth: I have been thinking what to do to pay back. Maybe I could set up a charity so people in my country could receive free colostomy appliances as it happens here. People with stomas really struggle there... I would be dead by now if I would have had the cancer there.

Embedded in the language of reciprocity is Ruth's gratitude, a sentiment which was shared by many other patients. Britta is a Western European lady in her 60s who frequently remarked that 'healthcare professionals are so kind, receiving you always with a smile'. Elizabeth shared Britta's appreciation too. She told me:

Elizabeth: The system here is so ordered that it sends things by post [she receives, from the hospital, sachets of laxatives to prepare her bowel before

surgery, and stoma appliances from her GP]. I am grateful, surprised of how things work here. Doctors and nurses treat you kindly, respectfully, like horizontally. In my country, they don't treat you well even if you pay them for that. I know everybody loves their profession, but the kindness and effort they put *here* [in the UK] when treating you goes beyond that. And you get referrals to the specialists you need, be it the pain consultant, or the liver consultant.

Seaus showed his appreciation for the chemotherapy team just before Christmas by bringing 30 slices of pineapple and cream cake to the staff working in the room. We were sitting together at the chemotherapy suite while he was slowly receiving his 11th out of 12th cycle of FOLFOX, one of the main cytotoxic combination regimes used to treat colorectal cancer. While talking about his business in the cattle industry and his earlier life, he was paying close attention to whispers and full-handed napkins that circulated among nurses. It was his treating professional, Nurse R, who came to say thank you for the gesture. He replied: 'You are welcome. It is December, it is Christmas'. Seaus was the participant of this research who enjoyed the most comfortable economic position, and therefore he was able to express his gratitude with cake and not only words and smiles.

The previous snippets show that England, and more specifically the NHS, stands out in my research participants' cancer narratives as an essential actor of their lived experiences despite their clinical condition. My informants are deeply aware that many areas of both the healthcare system and the cancer pathway could run more swiftly and smoothly. Yet, they consider that the hospital is not only a space populated by kind and trustworthy professionals, but also a safe or life-giving space that differs strikingly from other experiences of healthcare they have undergone. In a similar vein, my participants used to make sense of their 'fortune' by drawing on their vicarious knowledge of other patients in the clinic who were doing worse. Similar to the 'hierarchy of suffering' among breast cancer patients in cancer support groups in Canada that Bell and Ristovski-Slijepcevic (2011) analysed, the curiosity of my research participants to know how other cancer people were doing during treatment struck me. Simon used to compare how his medical condition was deteriorating in contrast to another patient with incurable cancer of a similar background whom we met together in the waiting room of the outpatient clinic. Ruth not only compared what would have happened if she had been living in her home country, but she also made repeated comments about a young family with a toddler where the wife was affected by cancer. I heard her telling her friends in the clinic:

Ruth: As a family, they commute to London every fortnight and pay several thousand [of] pounds for monthly cycles of Avastin [a licensed chemotherapy drug previously included in the CDF to treat colorectal cancer, but discontinued].

Britta and Seaus used to make the point that, at their age, cancer is not such a big deal because the problem is when cancer affects children ‘who are innocent, and have all their life before them’, as Britta told me. That was the reason that motivated Seaus to fundraise money and volunteer to organise a Christmas celebration in the cancer ward at his local children’s hospital.

These sorts of comparisons enabled my participants to feel fortunate and sometimes relieved for their own cancer pathway. As such, comparisons were strategic, done to make themselves feel better; at the same time, they offered a resource to make sense of their future. Whereas for Bell and Ristovski-Slijepcevic, the hierarchy of suffering crystallised the ‘unthinkability of mothering with terminal illness’ (2011, p. 644), eliding other forms of suffering that the group was experiencing, I would like to suggest that for my participants, the hierarchy of suffering enabled them to identify the ambiguity of seeing their own future in the fate of others while offering a possibility of differentiating themselves from these others as relatively ‘more fortunate people’. As such, in comparing themselves to others’ clinical conditions, gratefulness was a sentiment that expressed the apparent relative advantage my research participants were momentarily enjoying, helping them to accept the cancer diagnosis within the mental schema through which they looked at their own lives. The acceptance of the cancer diagnosis and the experience of treatment are therefore situated within a context in which a collective of people who were either facing equivalent situations is acknowledged and a praised healthcare institution is looking after them.

4.3.1 Fitting in the molecular target

The molecuralisation of cancer care is a third source of differentiation between patients, for the ‘trialisation’ of cancer care was an important factor for understanding the reputation of this clinic. The clinic’s consultants were always eager to recruit patients for the trials, some of them being the leads of projects testing different formulas of systemic treatment in the hospital. In meetings, they did not only spend time in making sure they could enrol patients in clinical research projects they found appropriate and for which patients were eligible, but they also showed their enthusiasm when another doctor, or the trials manager, managed to recruit a patient in theirs. Dr Z told me once: ‘We want everybody to be in that trial, it is a very

benign thing.’ In one of the pre-clinic meetings, before all the other professionals had arrived, Dr W was discussing with the trials manager of the clinic how to increase the recruitment for one specific drug trial that was closing soon. The conversation went something like this:

- **Dr W:** It is better to scan the maximum amount of people within the target.
- **Trials manager:** [*Surprised*] How do you expect me to do it?
- **Dr W:** [*Smiling*] I don’t know, but I want you to do it.

Anthropologists have described how the translation of wet-lab findings into trials and treatments has modified the shape and intent of cancer treatments, bringing about a diversity of stratified pathways that follow clinical protocols to address specific biological targets (Day et al., 2017; Keating and Cambrosio, 2011). At the same time, the embrace of clinical trial research as a complement of, or substitute to, treatment has spun a process of increasing aleatory advantage, as enrolment depends on both the genetic make-up of patients’ cancer tumours and patients’ luck in the randomisation process (Jain, 2013). For the purpose of my argument, I consider biological therapies available via the Cancer Drug Fund (CDF) as part of the ecology of precision medicine in colorectal cancer in the UK. Mutations in RAS genes have been the most studied biological markers of colorectal cancer until recently, a finding that has been progressively translated into clinical practice. Two of my participants with incurable bowel cancer received treatments based on monoclonal antibodies as part of their chemotherapy regime through the CDF, provided that they matched the treatment specification: a tumour genetic make-up characterised by ‘RAS wild type’. With lower toxicities, antibodies such as *Cetuximab* enabled people affected by colorectal cancer to prolong their lives. The ‘progression free survival’ of Cetuximab, as an output of randomised clinical trials testing the efficacy of the drug, was defined at 12 months (median) from the moment of randomisation of the patients into treatment and control groups (Ciardiello et al., 2014; Tejpar et al., 2014). In other words, patients enrolled on the trial testing Cetuximab, on average, spent 12 months on the drug before their cancer got worse (it progressed). Those results were welcomed by NICE technology appraisal and served as evidence to incorporate Cetuximab into the CDF. Today, this monoclonal antibody forms part of the cocktail available to clinical teams to be used as the first line of treatment for patients with metastatic colorectal cancer. However, even though Cetuximab is approved by NICE, it is not standard treatment.

The clinic had grown part of its reputation through its interest in participating in research-based treatment protocols. During my time there, I heard a number of

conversations about patients asking consultants to be incorporated into trials. ‘TAS 102’ was a double-blind trial for ‘non-refractory metastatic colorectal cancer patients’ (that is metastatic cancer not responsive to standard treatments) to test the efficacy of a new drug against placebo, in which some patients in the clinic got involved. For patients enrolled in the (double-blind) intervention arm of a trial that incorporated 800 participants, it proved to increase the survival by two months in average (Mayer et al., 2015). As it happened with Cetuximab, these results were quickly considered by NICE for its successful inclusion in the CDF in 2015. Another example from my own research participants is Robert, an English retired goldsmith in his late 70s affected by sigmoid cancer who benefited from a different type of trial. He would commute fortnightly from Essex by train, with the help of a former bouncer from his jewellery shop who befriended him. He had gone through three ‘lines’ of treatment and several surgeries, but the cancer kept slowly ‘progressing’, spreading to his bones and liver. There were no standard treatment options for him any more, so one consultant – after unsuccessfully applying to the CDF for non-standard alternatives with potential benefit – managed to get drugs in tablet form from a clinical trial offering a ‘compassionate scheme’. Thus, even though Robert was not eligible to receive the drug, he still benefited from the pharmacological product for a few months because the company accepted the consultant’s request to access experimental drugs that have not been yet approved by the European and national regulatory bodies. Robert only stayed on the compassionate scheme for a few months. He found it difficult to follow the treatment regime despite the support offered by the specialist nurse, and toxicities were high. He then switched to supportive care delivered by the local hospice. That decision gave him some peace, and spared him from commuting to London so often.

The drug clinical trials that created more expectation in the clinic were the ones testing new systemic treatments for people with advanced cancer, measuring their efficacy against standard treatments. For each of them, the team interpreted the trial’s suitability in relation to the development of the condition, the timing of the recruitment, and the likelihood that the patient would benefit from it. This was particularly relevant for people whose cancer was not responding to one of the four main NHS standard treatments for colorectal cancer that cannot be cured, and many people affected with incurable liver, brain or pancreatic secondary cancer came to be seen by consultants, sometimes from other countries like France or Germany. One Wednesday when I was shadowing one of the senior consultants, Dr Y, a young British man came in with his wife looking for a second opinion. The consultant checked the clinical history of the patient, complained that it was incomplete (coming from another hospital trust) and went to talk to another doctor running a trial to

check the possibility of enrolling this patient. Then Dr Y explained that ‘patients, most of the time, come here to be reassured’. I felt this was not the case; the patient was desperately looking for a way to prolong his life and hence be there for his five-year-old and seven-year-old daughters. He explained his clinical history: with no history of cancer in his family, he was diagnosed six years ago with colorectal cancer. He underwent surgery and chemotherapy, but the cancer recurred after two years in remission in the lungs, so he underwent a second operation. At the time of the appointment he was suffering from cancer metastasis in the bones and the brain. He received radiotherapy and a third surgery to excise the tumour in the brain, but the cancer kept colonising his body. Now, he complained ‘the oncologist is giving up on me. I receive the blame of having survived all these years’. The patient and wife’s medical literacy was formidable; in recounting the story, she knew as much as the patient regarding the names of doctors, hospitals, procedures, critical events and the number of cycles he had received of each drug. Dr Y said that he looked very good considering the whole clinical story. He explained that his situation is ‘very difficult; unfortunately, there are only four drugs to treat bowel cancer’, so if they have not worked because the tumours keep growing, the only option is trying to find a clinical trial in the trust or elsewhere. Regrettably, there were no clinical trials that could help the patient at the moment. The only spark of hope came from the suggestion that the patient could go somewhere else to check the ‘mismatch repair status’ of his tumors, a genetic mutation that, if he had it, might have made him eligible to join an immunotherapy trial that the trust will run in the near future. But Dr Y was clear: ‘only 5% of people with bowel cancer carry that mutation, and even if you do, it does not mean that therapy will work’. The consultant examined the patient with the stethoscope and told me indirectly that I could not go in because I was not a medical student. I waited behind the curtain with the wife. Dr Y only asked him to breathe in and out, and he found that everything was okay in his lungs. The patient went to sit again. Basically, there was no way of going back and the doctor was clear in communicating the prognosis. Official options had proven to be inadequate for his type of cancer and no clinical trial will eradicate it, but they could play the odds and test for the genetic mutation. The patient broke down crying, saying sorry and that he had ‘hope again, even if it is a tiny bit’. Dr Y seemed moved; he left the desk and placed his chair closer to the couple. Buried under forms and papers spread on his desk, he took out a box of tissues and offered it to the patient. The wife held the patient’s hand. The room had a very intense atmosphere. I looked at the student of medicine who was sitting next to me, also shadowing the consultant, and became aware of my own emotional display. The couple needed intimacy but we were there. I decided to stare at the floor and avoid crying with them.

While all consultants were engaged as primary investigators in the clinical trials, Dr U (one of the part-time consultants) was the medical director of a private cancer research organisation based further down the road. His involvement enabled this clinic to offer/test a wider portfolio of cytotoxic drugs not available in the NHS, making some patients literally embody the innovation of a potentially life-saving drug, as Kerr and Cunningham-Burley (2015) discuss the work that patients do when participating in clinical trials targeting genetic markers in breast cancer in the UK. However, molecularisation of care does not come without challenges. Day et al. (2017) have analysed women's experiences of the stratification of treatment pathways created by precision medicines in a London hospital. They describe how the quest for treatments targeting biological features not only causes stratification of the workforce, as it must specialise its expertise continuously, but also leaves patients feeling that the care they receive is less rather than more personal. The authors argue that, in those scenarios, patients are asked to navigate complex and fragmented pathways that do not fulfil their needs for assistance. Building on this research, I am interested in the experience of stratification that trials produce due to their inclusion and exclusion criteria. Anthropologist Camilo Sanz writes about the relevance of synchronising care, diagnostic tests, bureaucratic processes of insurance companies, and tumour progression in cancer care in Colombia (Sanz, 2017). In his ethnography, he documents the experience of a contradictory temporality that economically deprived patients face when seeking to obtain chemotherapy treatments in the city of Cali. The tension occurs between 'the imagined time of biomedicine – broadly understood in terms of clinical protocols [...] and the treatment time when accessing chemotherapy would be "beneficial" for the patients' (p. 188). Such contradiction, he argues, occurs due to the process of deferral that insurance companies create, which produces a 'therapeutic disjuncture' (ibid) in which patients who do not have recourse to savings must wait for treatments to be approved, but by the time that happens, their medical condition has already worsened, making the treatment ineffective. Following Povinelli (2011), Sanz understands such disjuncture as a process of 'getting burnt out' by the healthcare system (and the bureaucratic indifference of insurance companies). Like the situation described by Sanz, it seems that, in the clinic, the arbitrariness of drug trials was a question of contemporaneity or synchronisation. To be enrolled, patients must suffer from a cancer that has developed to the right stage (but no more) with the right amount of toxicities in the body (to be fit for treatment) at the right time (when the trial is actually recruiting).

Probably one of the most important treatment trials for metastatic colorectal cancer in patients with specific tumour gene mutations is in immunotherapy today. Using a humanised antibody (manufactured in mice's ovaries) that has been previously

tested for melanoma with positive benefit, the trial of ‘Pembrolizumab’ for colorectal cancer is led by one of the clinic’s consultants. The design of the study aims to measure the efficacy of the biological against standard treatment. Several patients with non-refractory advanced conditions were in need of treatment, yet the trial was approved in the UK only a month after I left the clinic in September 2016. While there, I met a young Londoner who was by then a patient with stage IV colon cancer. After 18 cycles of chemotherapy and a major surgery, he had run out of treatment options just before the trial would have been approved in the NHS to be tested in solid tumours. His treating team in the clinic applied for an individual drug request to the CDF, and to the compassionate scheme of the pharmaceutical company that manufactures the drug with no positive outcomes in either case. So he crowdfunded £170,000 on the internet to obtain Pembrolizumab treatment in a private clinic, with one of the part-time hospital consultants treating him privately upstairs. And he made it. With the support of his local MP, and his network of family and friends, he was able to afford the treatment for a year. At the moment of writing this paper, after 16 cycles of immunotherapy received in 15 months and colitis and arthritis as side-effects, this man reports on his personal website that he has a stable clinical condition for over a year. He also reports that he is writing a memoir of his experience with cancer, and has become a media figure campaigning as ambassador for a national bowel cancer charity.

Cancer is about time. Writing about the paradox of clinical cancer research, Jain (2013) argues that randomised control trials, when exclusively relying on the report of the number of people who survived and died during the study, produce evidence of scientific progress by eliding other forms of suffering. The ‘mortality effect’ signals how the robustness and worth of a trial is built upon the gap between those who received treatment and survived (for longer) and those who were aleatory allocated in a control group. She criticises the use of disembodied results that fuel the promise and hope of trials for people who do not find any other resource, in a US context where enrolment in trials generates financial and symbolic gains for the private scientific and medical industries. She asserts that randomised control trials, whereas providing gold-standard evidence for the scientific progress of cancer care, not only depersonalise death (reducing individual mortality to a statistic), but also create a ‘temporal hierarchy in which the mortality of some props up, or allows, the immortality of the others’ (Jain, 2013, p. 120). In contrast to the bleak picture depicted by Jain (2013), my ethnography evidences that, even though clinical research trials may present a strictly regulated regime of care (for patients, but also for clinicians), the drug regimes that are offered in the GI clinic do not let people die as a product of the randomisation process. Most of the protocols with which I

became acquainted used the gold-standard treatment for the control group, or ‘best supportive care’ when patients were facing end of life and there was actually no other treatment option for them. More importantly, all the consultants showed great care when choosing participants to be recruited, not only because they had to strictly fit the inclusion criteria, but also because they thought about patients’ prognoses. So, for example, consultants would not recommend a patient to enrol in a trial if they truly believed that randomisation could be detrimental for them. Their clinical condition had to be stable. And in any case, they reassured patients that they would need to ‘get off’ the trial in cases where the patient’s condition deteriorated (i.e. the drug was ineffective or toxicity was too high), and they of course would try and treat the patient with the best available drug. The dilemma arose when there was no last resort. In one way or another, I heard Dr Z, Dr Y and Dr W say phrases such as: ‘it is difficult to look at the patient in the eyes and recognise that there are no more options’. Clearly, the whole point for them was to increase the patient’s chances of survival, maintaining their quality of life as long as possible. Therefore, Jain’s argument – even if it is logically plausible – misses the point that clinical professionals do have ethical and professional values that protect patients’ wellbeing, which offset at least some of the crudest contradictions of experimental research in cancer care.

In the clinic, if the Pembrolizumab trial had opened up a few months earlier, not only would the London public male figure mentioned earlier have benefited from the same drug provided free at the point of care, but also Ruth, one of my research participants, might have been offered the possibility to remain alive for more months (I describe her situation in detail in Chapter 8). In Sanz’s descriptions of the dynamics in cancer care for GI cancers in Colombia, becoming out of sync equals death. Such equivalence also applies in the case of the immunotherapy trial I am describing. However, the equivalence stems from different causes. Sanz sees the bureaucracy of a healthcare system as responsible for being purely incentivised by economic gains, letting patients without private healthcare policies use their time doing paperwork and waiting for its results instead of being treated. Fortunately for NHS patients, such as my participants in England, waiting times are regulated and sanctioned (NHS England, 2015), at least for the beginning of treatment; at the same time, patients do not require private medical insurance to afford treatment. Nevertheless, out of sync still equals a hastening of the dying experience. With no resource to any trial, Ruth died at 38 in 2016, as many other bowel cancer patients with refractory metastatic cancer who could not keep waiting. The fact that some people die because there is no treatment that can stop the deterioration of human health is just the reality of advanced cancer. It is obvious and it is impossible to take

it personally. But because cancer is about time, this is also the reason to continue overcoming social and institutional barriers to diagnose cancer earlier. Colorectal cancer is already curable (measured by five or more years free of recurrence) for almost 60% of the population affected by it in the UK, but only when diagnosed early.

4.4 Discussion

In this chapter, I have discussed how an ethnographic approach to health inequalities and other forms of differentiation illuminate the ways in which asymmetries between hospitals are experienced by patients, carers and practitioners. In doing so, I looked at the uneven distributions of health, quality of life and survival not (only) from the political economy that underpins those differences within a developed country that is continuously modernising, but from the point of view of people embodying an arbitrary advantage depending on the criteria they matched: be that living in a territory with a productive and caring CCG in England, or receiving treatment in a good hospital trust, or being affected by cancer with the right genetic mutation at the right time. Considering that the NHS trust in which I did my fieldwork presented one of the best rated levels of care and investment in the country but many patients in my sample were nevertheless seriously struggling economically to afford living in London, I asked: How does it feel to receive cancer treatment in a hospital that, although it enjoys good reputation, is part of an unequal system? How do patients articulate/acknowledge the privilege in juxtaposition to the economic struggles they face in their everyday lives? I wanted to engage in the debates that examine the way in which we can theorise the dynamics between felt positions of advantage and disadvantage in the everyday, and the various resources patients and carers draw upon to navigate those dynamics when seeking cancer care.

Combining a structural approach to understanding the stratification of colorectal cancer outcomes in England and the ways in which my research participants made sense of the treatment they received in the clinic, I showed how patients also contribute to constructing the reputation of the clinic, praising the team of health professionals who are part of an institution striving for innovation and excellence. The reputation of the clinic, I argued, stood in contrast to the performance of other specialist services and was furthermore orchestrated by the clinical team itself, reproducing the idea that it was a kind of privilege to be looked after there. Embodying the privilege shows that the subject's positions are not static but fluid across the city and throughout people's lives. A rich ethnographic description of the fluid positions of privilege that people might occupy in their lives also bears the potential to enrich

an understanding of the conditions and dynamics that might create the possibility of life-giving projects of care.

However, if the clinic is seen as an exception to the rule in terms of the quality of care that is expected for a person affected by cancer in England, efforts to achieve better health must move upstream so that it is reachable for everybody. My experience in the field taught me that the current approach of encouraging patients to take responsibility for their own health is not enough. In a context marked by attempts to roll back the state and hence increase the efficiency of healthcare to reduce the economic burden of cancer care, medical and epidemiological literature increasingly points to the idea that new risk factors associated with our lifestyle appear to be responsible for higher cancer incidence, especially among residents who are living in economically deprived areas. Such discourses persuade patients to bear responsibility for cancer prevention and the management of the condition to improve their personal prognosis through the modification of diet, exercise, and drinking and smoking habits – in other words, their lifestyles ². However, I witnessed that those same people might not necessarily been able to afford luxuries such as a diet rich in fibre or time to engage in meaningful physical activity. They face barriers to adhere to public health interventions that seek to change people's 'unhealthy' behaviours (NCSI, 2013). Widely used behaviour-change campaigns to increase the bowel screening uptake (Von Wagner et al., 2009) or prevent deleterious health conditions are oblivious to the macro-structural determinants of health, with every effort being proportionally most productive for people who have more advantageous socio-economic circumstances (Smith, Bambra, et al., 2015). The individual is not the only one responsible for his/her own health, for an important role in reducing health gaps belongs to social care policies (Marmot et al., 2010; Smith and Anderson, 2018; Smith, Bambra, et al., 2015). Understanding the distribution of the burden of disease in cancer requires looking at both the structural and individual contexts in which people commit to their own health. In the next chapter, I look at the salience of access to material conditions for the everyday management of a surgically modified body.

²see Bell (2017) for a critical discussion of the concept of lifestyle in cancer prevention

Chapter 5

Bowel control: Achieving the everyday

5.1 An unproblematic surgical procedure

Planned bowel surgery to resect a malignant tumour requires patients to physically, emotionally and intellectually prepare for it. A surgeon met Jay, a 35-year-old British man of Indian background affected with stage III rectal cancer, to explain the procedure. He would undergo a colectomy – that is, the ‘en bloc resection’ of a large area of the large intestine where the tumour sits, which includes its vascular and lymphatic structures, and cancer-free tissue margins. Due to the site and stage of his cancer, measured via scans and colonoscopies at the moment of diagnosis, the multidisciplinary team that oversees patients’ treatments suggested that Jay should have a permanent colostomy – that is, the diversion of the bowel towards a surgical opening on the abdominal wall, where the upper end of the bowel is sewn forming a stoma. Plastic surgery was then performed to close his excised rectum and anus. All three aspects of the body – function, sensation and image – would permanently change after the stoma formation.

After discussing with the surgeon the main risks of the procedure and fertility preservation options, Jay was given homework to do: he was invited to meet a former patient treated by the same surgeon for the same condition. This way, Jay could see first-hand how someone with a colostomy could get on with life, and understand that regardless of how gruesome the stoma formation might initially feel, people manage to adapt to it over time. Jay was also invited to talk with a bowel cancer specialist nurse, from whom he learnt how to look after his stoma, and what to expect from his bowel function after surgery. Jay’s faecal waste was to be collected in a plastic pouch attached to the left lower side of his abdomen. However, as a large part of the bowel

had been resected, bowel outputs would change consistency considerably towards more liquid states. ‘The large intestine is the part of the body that drinks water for us’, the stoma nurse explained to another patient I was following. That means that without big sections of the large bowel, water and mineral absorption processes that started in the small intestine could not be completed before they are evacuated.

A week before surgery, Jay underwent a clinical pre-assessment, in which a staff nurse interviewed him to determine his physical and psychological fitness for surgery and successful recovery. The nurse wrote by hand on his medical file answers to questions related to frequency of alcohol consumption, current medication regime (including chemotherapy), allergies to anaesthetics, medical history of the heart and lung problems, fitness to do physical exercise, weight, blood pressure and height, among other aspects of Jay’s overall fitness. Three days before surgery, Jay received a ‘bowel preparation package’ by post, containing laxative sachets to consume over a few days, on top of the requirement to drastically eliminate fibre intake before surgery. The aim was to get his intestines as clean and empty as possible in order to make things easier for the surgeon, and to minimise the risk of infection from faecal matter soiling the peritoneum during surgery.

As he was undergoing ‘elective’ (pre-booked) rather than emergency surgery to repair an obstructed or perforated intestine, the surgeons were able to use the keyhole technique. Instead of a long abdominal cut, only small incisions were made through which surgical instruments, including a miniature camera/lantern, were inserted. Everything went according to plan and Jay recovered in hospital until he could eat a soft diet and pass faecal waste without complications or debilitating pain. Jay’s successful experience of laparoscopic surgery confirmed the shorter recovery period it afforded in comparison to laparotomy (open surgery), also minimising post-surgical pain and infection risk (Vennix et al., 2014). Just a few hours after he fully woke up from the general anaesthetics, a stoma nurse visited him on the ward to teach him how to clean his stoma in practice. His concentration was low and his mind still foggy, so he could not absorb all the information provided, but he had all his life to become acquainted with his new body part and to improve his cleaning technique. Just before getting discharged from hospital, Jay received all the supplies he might need for his stoma free of charge. An order was placed to his general practitioner (GP) to provide supplies from then on. He has a stoma case in the bathroom at home and another smaller one that he carries with him everywhere.

Jay’s case is straightforward, almost unproblematic – although the ‘adjustment’ to the stoma did not happen overnight for him. Bowel motility became erratic and sometimes explosive during chemotherapy. Yet Jay was resolved to keep a positive frame of mind and deal with the stoma and the cancer pragmatically rather than

emotionally. As he used to tell me, ‘the stoma would not prevent me from enjoying life’. He learnt to plan his nights out in quiet places with good and clean toilets, to take Imodium whenever and as much as necessary to thicken bowel outputs, and to master the skill of changing stoma bags standing in front of any toilet. Beyond stoma care, he told me that ‘the cancer diagnosis taught him to appreciate life more’ and so he went off with his recently married wife to visit other countries and live new experiences, including sessions of scuba diving around a Mexican coral reef once he finished the course of chemotherapy. Bowel surgery was only the first surgical procedure he underwent to stave off cancer. When the tumours spread, I followed him through two other visits to the theatre to receive radio-frequency ablation on his liver, and a few months later on his left lung. Jay knew that he might not be able to get rid of his cancer completely; however, he chose to make the most of life with his family while he was fit enough.

The creation of the artificial anus on one side of the abdominal wall is, from the patient’s point of view, one of the most important features of their treatment experience. The bowel takes some time to relearn the original rhythm of peristaltic movements that it enjoyed before the resection. Moreover, the stoma does not have a sphincter and without it, defecation occurs beyond the individual’s control. As colectomies are usually performed before the start of chemotherapy, the combination of circumstances requires people to deal with a metabolic rhythm and a material messiness that all colorectal cancer patients experience but might only appreciate if their intestines get obstructed. Even though the relevance of stoma formations has been well researched by scholars working on psycho-oncology, and matters of defecation in and out of place has become an interesting topic for anthropology, this chapter seeks to offer an analysis at the interface of both disciplines by looking at the materiality that enables my research participants to achieve bowel control in the everyday. Instead of focusing on self-image and social integration, two of the main concerns shared by psycho-oncology studies on ‘adjustment to stoma formations’ (more of this below) and the symbolic analysis of defecation carried out by anthropologists, my ethnography highlights the importance of what comes before self-image.

Re-gaining bowel control is an essential task for my research participants as they seek to carry on with their lives during and despite treatment. Yet the challenge, I would like to argue, relates to our understanding of what diverted bowels and ostomy pouches allow the person to do, analysing the material conditions that enable cancer patients to be in control of their bowel outputs. Practically managing bowel motility makes it possible to present an anatomically different body to oneself and to the world. I suggest that our understanding of the challenges that people with

stomas face could incorporate the analysis of the multiple materialities at play that pre-condition the articulation of such relationship. At the same time, I wish to complement the picture that is created about defecation and body image from a symbolic point of view. In the next section, I briefly review how matters out of place have permeated anthropological understandings of (in)continence and defecation practices.

5.2 Self-image of the unbounded body: Just one side of the story

The symbolism of dirt out of place has been well researched in anthropology. It started with Mary Douglas's now classic analysis of the ways in which categories and taboos related to pollution help us reproduce and purify a deodorised social order. Drawing on her fieldwork experience among the Lele population in the Congo, Douglas (1994) develops the idea that elements that could not be classified within local cognitive categories were conceived as anomalous and posing a threat to the moral order. Importantly for this thesis, human excreta, among other bodily products, fitted with this schema, making its visible appearance a reason not only to refuse contact, but also motivate a cleansing ritual. Such response to matters out of place, the author argues, was due to the fact that:

We cannot possibly interpret rituals concerning excreta, breast milk, saliva and the rest unless we are prepared to see in the body a symbol of society, and to see the powers and dangers credited to social structure reproduced in small on the human body (Douglas, 1994, p. 166)

Because the human body is conceived as a natural symbol – that is, a structure of representation of the social order – the argument follows that visible excreta would threaten the moral categories that people hold relevant to keep their sense of worldly or cosmological coherence. As Lawton affirms in her research on hospice care in England, Douglas is relevant to understand how cultural distinctions of pollution and defilement are mapped onto and experienced within the body, reflecting the value of self-control that has historically evolved since the Middle Ages (see also Elias, 1978). Nowadays, Lawton suggests, self-control embodies as self-containment in places like Britain, and people suffering from bodily incontinence are sequestered in spaces where physical walls replace body barriers. The unbounded body threatens the social order as soon as it breaches the sanitised social space and seeps into the porous boundaries of the other (Lawton, 1998, p. 134).

A similar idea is reinforced by anthropologist Rachel Lea, who argues that defecation in England, as in many other places in the world, is a rite that defines a spatial-temporality; it has to be private, intimate. This definition of the rite assumes continence, the ability to control the sphincter. As such, it is not the ability to keep bodily products out of sight and hidden per se that defines appropriate defecation practices, but the capacity to control how and when they are released and contained (Lea, 2001, p. 38). However, as I will later discuss, the performance of continence is an achievement for people with bowel cancer, which triggers relief when it works well but also anxiety and embarrassment when materiality fails them. Van der Geest (2007), following Douglas as well, writes that emotional reactions to faeces out of place point to a cultural boundary that defines what we consider pleasant and comfortable living. The author also suggests that our language to describe dirt assumes multiple meanings, which are metaphorically applied to social, moral and aesthetic phenomena. Hence, dirt assists us in creating binaries between what is good, beautiful and clean in opposition to what is wrong, ugly and dirty (van der Geest, 2003). This dynamic, in turn, not only signals the cultural construction of boundaries about sociality and intimacy according to the values we historically attach to body fluids, as argued by Thompson (1979) in his analysis of the way in which materials earn and lose symbolic value in England, but it is also informative of the process of identity construction for people undergoing stoma formations, for they may be infantilised when they cannot keep control of their bowel movements.

Undoubtedly, the symbolic aspects that connote matters out of place are relevant to understanding the practices of stoma's concealment/visibility and its consequences that my research participants employ in their effort to maintain a self-image before others. This is particularly evident in their minimum use of infrastructure for people with disabilities. In an effort to facilitate the accessibility of public spaces for all shapes of bodies, bowel cancer patients receive a universal key to allow for priority of access to public toilets designed for people with disabilities. Local authorities have adopted the scheme and 'Radar toilets' can now be found in shopping centres, pubs, stores, bus and train stations and other locations nationwide. However, even if most of my research participants with stomas had this key and could have used it in their daily routines, they would rather not do that, sometimes even offering it to me. Jay illuminates the resistance to using Radar keys:

- **Jay:** I sometimes worry that I would enter a coffee shop, I would ask for the toilet, and the person will ask me whether I am a customer or not.
- **Ignacia:** Then you show the [radar] key.

- **Jay:** I don't like to use toilets for disabled people; I have never used the key in three years. I think the toilets are more spacious, but really, so far, I am still fit enough to do all the manoeuvres in the normal toilet.

For my research participants, using the Radar key was acknowledging their stoma as a disabling condition. They wanted to demonstrate to themselves and others that they could get on with their lives using the mainstream infrastructure for waste management. In the same way, avoiding getting dressed in communal changing rooms in the gym, or not going to the beach showing the stoma, were also important practices of concealment. Elizabeth, one of my research participants who had a temporary stoma for over a year, had planned to go to Colombia to visit her mum and her siblings after two surgeries and 12 cycles of chemotherapy. She wanted to 'to celebrate her survival', as she put it. However, she was afraid of the weather and of the fact that she should wear light clothing. The town where her siblings lived was too hot, and the skin around her stoma could start sweating, so the bag could come off. Knowing from others' experiences, I suggested that she could ask the stoma nurse for a 'super glue' to attach the stoma while she is at the beach, but she did not like to use it. She had tried it already, 'but it really burnt her skin leaving it brownish', she told me. And she continued: 'And it is difficult to clean it afterwards too'. She was frustrated. 'Now, with this thing [*pointing to her stoma*], I can't go anywhere', she explained to me. Elizabeth did not want to wear a bathing suit because she was self-conscious of the bag, which she saw as 'unattractive', 'ugly', and moreover unreliable.

Even though symbolic aspects might contribute to our understanding of the reasons why people with stoma formations sometimes prefer to conceal their 'abject' body parts (cf. Kristeva, 1982), I would like to stress that symbolic approaches to dirt miss the perspectives of people with stomas and make the experience of incontinence something deviant. Writing from the third person point of view, as these anthropologists do, obscures the struggle of those who are actually breaching the symbolic boundary. An exclusive consideration of the generalised other's view – the other with a normative body, the other that acts according to what is desirable – re-victimises the person who suffers from faecal incontinence. By doing this, symbolic analyses do not only reproduce a sanitised anthropological practice (Loudon, 1975). They also neglect the fact that producing the distinction requires symmetry in the analysis. In other words, the matter out of place is not only an experience for the one who perceives it scandalously, but also for the one who produces it and gets defined as 'dirty'.

Instead of focusing on the symbolic aspects of living with stomas, I propose to look at the interface that makes bowel control possible for my research participants. I would like to offer an alternative view of stoma care that foregrounds the materiality of the body in its engagement with the physical and social surroundings. Following anthropologist Chris Tilley (2007), I understand materiality as not only incorporating the world of ‘brute’ objects that are oblivious to human actions (such as a standard ostomy pouch), but also the ‘processual significance’ of those materials and their properties for the ‘socio-political relationships between people’. Tilley proposes a shift from consideration of the raw material to its social significance, for materials are implicated in people’s experiences of the world, ‘providing affordances for thought and action’ (pp. 17–19). Following this approach, I would like to examine the material properties of intestines at their interface with ostomy bags in order to tease out the modes through which material adjustment (dis)enable my research participants in their quest for achieving normal routines. Going beyond the body as representation to understand how it is made to work in practice, I would like to suggest that the ability to manage the stoma depends, in great part, on the possibility of access to material devices and infrastructures tightly related to the social and economic support available to the person. Through the analysis of three different ethnographic cases, I aim to shed light on two related questions: (1) how do material techniques and infrastructures afford liveable stoma management routines and (2) how do those practices afford different emotional states for the person with a body with stoma? My argument is that a fine-tuned understanding of both questions might contribute to demystifying the process through which clinical professionals assess and support people’s relations with their stoma.

5.3 Colostomies and accidents

Four years after the first cancer diagnosis, three surgeries, a course of chemotherapy and fertility treatment, Jay is hitting his 40s being the father of a little daughter, the landlord of a flat in London, and the founder of his own estates company. Jay’s ability to get to this point was not only because of his attitude and the loving support of his wife and father, but also because of a techno-scientific achievement. Colectomy is a surgical technique to resect a faulty, in this case cancerous, part of the large intestine. In order to give the anastomosis – intestinal joining – time to heal, the surgeon exteriorises a bowel loop through an abdominal incision at one of the sides of the inguinal area and stitches it to the surface: the stoma. On it, one or two openings in the bowel are created for the necessary evacuation of faeces. However, anastomosis is not always possible because, depending on the length of

resected bowel, joining both ends after a period of time (what is known as ‘stoma reversal’) may not be practicable. That is the case when a permanent colostomy is created. In *The Evolution of Colostomy*, surgeon Colin Cromar (1968) discusses the evolution of surgical procedures to create an artificial anus from the time he found historical records. Congenital obstruction of infants with imperforate anus and acquired obstruction in adults were the two main causes for surgical operation. But in the 1700, lethality was high. Diagnostic techniques were more than rudimentary: difficulty in understanding the cause of the definitive constipation associated with the impending pain and abdominal distension (the reason was that all types of acquired obstructions were called ‘*iliac passion*’) and difficulty in locating the bowel and the lesion were important setbacks. Purgatives and enemas were administered by physicians instead. Medical literature was only able to illustrate anatomical configurations and to describe pathological causes in major detail when access to post-mortem bodies was socially approved in 1600. A better diagnostic technique was afforded only then, enabling the medieval surgeon (or barber) to answer with some certainty two questions: where the bowel is, and what he would find in it/how he would find it. Nevertheless, the opening of the abdomen was condemned by surgeons until mid-19th century (Cromar, 1968, p. 259). Minimal chances of recovery deterred surgical practitioners.

In 1706, the first surgical case of colostomy was recorded by Vater on a soldier who got his bowel perforated at a battle, but this was not a purposeful procedure. The colostomy had almost happened spontaneously. Then, in 1710, the first premeditated colostomy was conceived (but not practised) by Littre on a three-day-old child with an imperforate anus. It was in 1776 that Pillore performed a colostomy in France. The patient was a merchant suffering from a bowel obstruction that had lasted days due to digitally palpable rectal cancer. Even though the patient died after 28 days from the operation, this is the first dated surgery published by the surgeon’s son in 1840. Interestingly, the case asserts that it was the ingestion of two pounds of mercury to alleviate the obstruction, rather than the surgery, that was the asserted cause of death for the merchant. Due to the delayed publication of this case, there is some controversy as other surgeons were claiming to be the pioneers of the surgical technique. Moreover, Cromar (1968) notes that there was considerable discussion about the location of the stoma, originally set to be in the inguinal area, and then approached from the lumbar area (mainly to avoid damaging or soiling the peritoneum and causing a life-threatening infection with no antibiotics available at the time). In England, Dr Freer was the first surgeon to perform a colostomy in 1815, attending to a child with no anus. The child unfortunately died from marasmus (malnutrition due to lack of protein intake) and, in 1817, Freer did it again to a

47-year-old man obstructed by cancer. He also died at the 10th day after surgery, yet relatives denied the possibility of a post-mortem examination to understand the causes. Nevertheless, the technique started enjoying some value among the surgical community.

Securing antisepsis was then still paramount, and the use of double-barrel colostomies for the resection of rectal tumours grew in popularity from 1891 onwards, for it would allow the drainage of both intestinal sections outside the abdominal wall, to which the use of clamps to contain faecal matter in the cut sections of the bowel followed. The creation of ‘enterotomies’ or surgical clamps around 1824 made possible the closure of what is known now as temporal colostomies. It was Lembert (until today alive in surgery handbooks for medical students as the creator of the Lembert’s stitch) who suggested then that the surgical clamps could be used for end-to-end anastomosis if following the guiding principle of connecting serous with serous surfaces of the linen of the bowel first, to prevent leakages that could cause soiling in the peritoneum with faecal matter and its bacteria.

Discussion of the merits of colostomy was overshadowed by the gruesome image portrayed by incontinent patients, and the thought of such a diminished quality of life. Some conservative surgeons considered in the early 1900s that performing a colostomy was equivalent to ‘make the patient invalid’ (Cromar, 1968, p. 277), even though invalidism claims were proved wrong by some clinical examples recorded in archives of patients with lumbar colostomies riding horses, going back to work and household chores, and working as prostitutes. Wound infection might have been frequent but was not considered a serious complication, being prevented by the delayed opening of the artificial anus once the inner wound had had enough time to heal (Cromar, 1968, p. 277). However, surgeons supporting the manoeuvre started to argue that bowel habits would be formed again after surgery, and patients’ acceptance of their anatomically modified bodies would follow. Like modern surgeons, the supporters claimed that it was better to be alive even with some impediments than not to be at all. Sponges, tightened with bandages, were used to allow the passing of wind but to stop motions until the person could relieve himself/herself.

A century after its original inception, one important technological innovation transformed how colostomies can be performed: the laparoscope. Adapted in 1930 for human use but lacking visual equipment and further developed around the 1970s by a gynaecologist in Germany, it was finally equipped with a small but high-resolution video camera by an Iranian obstetric resident in the US (Kelley Jr, 2008). From laparotomy, an open surgery carried out by the direct contact of the surgeons’ hands with patients’ viscera, to a video-endoscopic procedure only requiring small incisions for the introduction of specially adapted surgical instruments, the laparoscopy was

used for the first time in 1991 to perform a colectomy (Jacobs et al., 1991). Even though the long-term benefits of laparoscopy versus laparotomy in terms of overall cancer survival rates and cancer recurrence are still contested, there is considerable evidence regarding the ability of laparoscopy to achieve lower recovery times, better pain management, and shorter hospital stays for patients in comparison to the use of laparotomy to resect tumours in the large intestine (Kuhry et al., 2008; Vennix et al., 2014).

The current practice of oncological care for intestinal cancer in London is based on colectomies with or without colostomies, standing as the most effective treatment with curative intent (NICE, 2011). Complete surgical excision of the cancer growth, cancer-free tissue margins together with its vascular and lymphatic structures, offers the possibility to some people affected by colorectal cancer to eradicate the disease from their lives. This depends on whether patients meet the eligibility criteria: their fitness for surgery, when considering frailty and co-morbidities, is analysed in conjunction with the progression stage with which the tumour is labelled during diagnosis. During my 17-month ethnographic field research on the experiences of colorectal cancer treatments in London, I quickly realised that, as an important milestone, surgical findings and outcomes do more than structure consecutive procedures. The procedure, its preparation and aftermath were also vividly narrated by many patients as the single cause for their continued life, notwithstanding the complications they might have endured on the way. I met Elizabeth sitting in a wheelchair and talking in Spanish with her sister while she was waiting for her appointment with the medical oncologist. It was her sixth cycle of chemotherapy after bowel surgery. In a loud tone of voice that used to disturb the constrained atmosphere of the clinic, she consented to participate in my research and told me the beginning of her cancer journey. The tumour in the bowel was resected only at the third surgical attempt. The first time, Elizabeth suffered a severe reaction to the anaesthesia that caused her life-threatening breathing difficulties, known as anaphylaxis. The second time, exactly one month after the first attempt, she haemorrhaged while undergoing laparoscopic surgery. This constituted a second medical emergency that required the surgeons to cut her abdominal area open to find and stop the internal bleeding. The team induced a comma and provided blood transfusions to stabilise her. She stayed for four days in the intensive care unit, until the surgeons were able to resume the operation on the third attempt. A stoma was created to facilitate an optimum recovery, which caused her a great shock. In her words:

Elizabeth: The stoma nurse came everyday to the ward to help me with the stoma. In the beginning I did not want to know about it, I did not

want to see it. It was horrendous, much bigger! I cried a lot, but the nurse comforted me saying that it would get better, that I would learn how to manage it. She taught me and my children how it works, so they could support me. In my family, we call my stoma ‘the baby’ and the case in which I carry supplies to control it ‘the diaper bag’.

Despite the fright that Elizabeth’s children felt in between surgical attempts, their mother no longer had tumours in her bowel. With a clear histological margin around the area, the operation had been eventually successful to eradicate the cancer. Elizabeth was emphatic in showing her appreciation for the surgeon’s capabilities. Even though she went through severe complications, developing later a voluminous abdominal hernia around the site of the stoma, and a long-standing pain in her legs because of nerve damage, she was quick to tell everyone that ‘Dr O saved my life twice’ – first by managing the anaphylaxis and second by completely resecting the tumour. I followed her through seven out of twelve chemotherapy cycles, a partial liver resection, and the reversal of her colostomy after a year from initial surgery. After multiple cases of deep wound infections that afflicted her after every intestinal surgery, she started recovering at home. Working to feel physically and emotionally fit, she just wanted to go back to work in the catering industry where her boss was waiting for her arrival. Before the stoma reversal, she did not feel able to go to work due to the possibility of leakages from her stoma.

Accidents, the emic concept for leakages, are a common and powerful experience during treatment. Together with her children and a close friend, Elizabeth and I were celebrating that she had received the 12th and last cycle of chemotherapy after two surgical operations in a coffee shop nearby the hospital. Discussing her follow-up plan, she seamlessly started a story about an accident she suffered because of her stoma, with her children already laughing about it in anticipation. Elizabeth, instead, wanted to convey her frustration to me:

Elizabeth: It was the Saturday after chemotherapy [and I had diarrhoea]. I went to celebrate [my daughter] Sandra’s birthday to a Chinese restaurant with my family. The stoma bag blew up while sitting on the table. I got the tablecloth dirty together with all my clothes. I went to the toilets area, crying from embarrassment, until one became available. I used wipes to clean myself and took off one of the t-shirts I was wearing too. Once in the bus back home, I was smelling the stinky odour of my faeces again, but my son-in-law convinced me that it was only my mind playing games with me, that he could only smell the lotion I used after changing the bag. Yet Sandra realised that it was not a mind game. The

bag was leaking again, the diarrhoea was like water, non-stop! [*Elizabeth exclaimed in the middle of the coffee shop while her children and friend openly laughed*]. As soon as we got home, I went to the shower, taking everything off once I was inside the shower.

Although her children did not think of this accident as a serious matter for concern, for it was not the first or last time it would happen to their mum, Elizabeth was certainly worried. I tried to calm her down, and repeated what I had learnt from the specialist nurses and oncologists during the 15 months I had already been in the gastro-intestinal (GI) cancer clinic: ‘After chemo, you will not have so much diarrhoea, so it will become more controllable’, I said. She instead replied to me that she is afraid to go back to work. ‘Just thinking of the probability of the accident, even if it is less likely [after chemo] makes me panic.’ Joseph, her son, supported her: ‘It is about the possibility, even if the probability is low’. Defecation can be considered as a cleansing ritual that is essential for any living organism. Yet, it seems evident that its positive power is only conferred to those who are in control of the act, who can manage the spatio-temporality of its occurrence, as Lea (2001) suggests. What happens when there is no control of the sphincters any more? Following Thompson (1979), it is possible to think that, in order to keep themselves ‘purified’ from the accident, Elizabeth’s caregivers dealt with the event as something funny. I am interested in exploring the productivity of accidents to understand how people with stomas cope with their threats and remake their bodies through ordinary practices of care. In the next section, I will describe the material properties of the ostomy bag, the single most important material device to achieve bowel continence.

5.4 The humble but powerful pouch

As I introduced before, colostomies did not enjoy professional or public approval well until the end of the 20th century, first because of the risk of sepsis but once that was better controlled, for its visual and practical consequences. ‘Disgusting’ was how surgeons qualified the concern about the quality of life of the incontinent person with a stoma. Resonating with this perspective, Elizabeth’s account of the workings of her stoma and the fear of having accidents points to the relevance of nicely fitting ostomy bags to secure an emotional state that enables people with stoma to go on with their lives. Faecal incontinence is an issue that was professionally taken up by the incipient training of specialist stoma nurses in the UK back in 1980 (Lewis, 1999; White, 2017). Historically, people with stomas relied on cotton pads and collecting devices made of tin and silver to stop faecal leakage. Only in 1940

did people with faecal incontinence start using a washable, smell-absorbing and skin irritant rubber bag tied to the body with strings, yet they caused intestinal prolapses (protrusion of the bowel through the stoma) and excessive excoriation. When plastic started to be industrially manufactured and used for stoma care in 1960, people could resort to disposable pouches. That invention was coupled with the creation of protective barriers for the skin to prevent dermatitis, and hypo-allergenic adhesives were invented for dentistry were now used for skincare (Lewis, 1999). The intestinal stoma was then protected by natural and synthetic materials.

While people undergoing colostomies might recover the bowel habits they enjoyed before surgery, chemotherapy abruptly increases bowel motility so accidents happen with frequency. With regard to chemotherapy, clinical professionals recommend not using intestinal irrigation techniques to manage cancer patients' bowel outputs, being otherwise a commonly home-based technique that offers the person between 12 to 24 hours of intestinal emptiness. Instead, my research participants must resort to the continuous use of ostomy bags, which sometimes fill up in a matter of minutes. Ostomy bags delivered by the NHS to my informants are beige, approaching 30 centimetres length and 5 centimetres in width for an adult size. They hold a maximum of 400–500 millimetres of faecal waste before overflowing. Plastic, flexible and waterproof, the pouch is attached to the skin around the stoma with a flange. Red-like in colour, without innervation, and of variable diameter but usually round, the stoma is the measure against which the inner circle of the pouch flange is frequently measured by the person to prevent the strangulation of the stoma. The flexibility of the flange not only offers support to the wall, but it also affords a tight fitting on the belly irrespective of the shape of the abdomen. Such flexibility is essential, as people like Elizabeth develop hernias around the stoma, changing in turn the topography of the abdomen. Adhesive removers, wipes and skin protectors are used to avoid dermatitis or excoriation on the site in which the flange is glued. In cases of high-output colostomies, such as while the person is on chemotherapy, drainable stoma bags come in handy, so watery waste is emptied without the need to detach the bag from the body (you just open the lock and roll closure mechanism at the bottom of the pouch). Internally, the ostomy bag is coated with an odour-barrier film and contains a charcoal filter to deodorise and allow the escape of gas. However, filters sometimes get blocked with moisture from the faecal output, leading the ostomy bag to 'balloon' and even blow up. Attention to diet, slow and mindful chewing, and avoidance of raw vegetables and fizzy drinks that cause bloating are some recommendations for the person.

Ruth, a 38-year-old research participant who was going through treatment for rectal cancer and had a permanent colostomy, used to know quite exactly what

had caused her stoma bag to balloon. In the chemotherapy suite and while having chemotherapy, she once ate a jacket potato with beans for lunch. We said goodbye after the infusion had finished and, on her way home, she had an accident on the bus. The trade-off between adhering to a constipating diet and enjoying the food one eats is a constant tension that does not have stable values. On the opposite side, lack of air and constipation may cause ‘pancaking’, which accounts for a second cause of leakages. It happens when the consistency of stools is more solid and the matter sits at the entrance of the bag, collecting around the flange, instead of sliding towards the bottom of the pouch. Unlike ballooning, pancaking is a common occurrence for people with stomas enjoying a more stable bowel function, who are likely to be off chemotherapy. My research participants who were wearing ostomy pouches while on chemotherapy would always carry a case with few spares of each appliance in case they find that they had to relieve themselves on the go. The NHS delivers colostomy appliances free of charge to every patient via the general practice in which the patient is registered. As the picture below shows, a basic stoma kit contains between five bags, skin protection lotions or spray, waffles, plastic flanges (in case it is a two-piece ostomy bag), adhesive removal wipes, a sealed collection bag, small stickers to filter the gas, and scissors to cut the flanges as and when required.

Having described the main features of the surgical procedure and the material qualities inbuilt in ostomy bags, I would like to focus on the ways in which it is possible to understand uncontrolled bowel motility for people with stomas in their daily lives. In the following section, I will turn to a discussion of the practices that make up stoma care among the research participants in my study. Three cases – Jay’s, Elizabeth’s and Simon’s – would help me in foregrounding the relevance of the socio-material conditions that allow people with stomas to achieve a sense of normalcy in their lives after surgery, by enacting a body that synthesises other material elements. Understanding to what extent stoma care is about nicely fitting material arrangements that allow patients to achieve bowel continence or mitigate the consequence of leakages during cancer treatment, rather than, say, psychological strength or sense of control only, provides an important point to complement current clinical professionals’ efforts to support colorectal cancer patients. I would like to argue that psychological adjustment comes only after, not before, physical adjustment: a well-fitting stoma bag over healthy skin might indeed solve most of the problem, if conditions are provided.

5.5 Coping: Coordinating a larger body

When I was just starting my PhD fieldwork in 2015, I was kindly received by two bowel cancer support groups in South England (outside London) to discuss how they could help me improve the design of my study. This type of consultation is called Patient Participant Involvement. In different formats, it is currently considered good practice in healthcare research in the UK, and it was promoted by research ethics committees like the one that approved this project. After negotiating access via e-mail, I went to meet with approximately 30 people affected by bowel cancer: they were either bowel cancer patients, people who had gone through bowel cancer treatments, or significant others that accompanied bowel cancer patients until they passed away. I met 8 participants in one group in a common space of a local cancer charity. Together, their average age would have been around 50 years old. The second group was considerably bigger and was holding its regular meeting in the spare room of a local pub. I counted at least 20 smiling but relatively older faces (as a group, they were in average 65 years old). In both groups, almost everybody except me was British, and most of them were women (even though the second group was relatively more mixed). Seemingly used to receiving researchers, they welcomed my request to approach them. However, as people who have learnt to manage their stomas for years, they thought it was more useful for me to understand the ways in which they were navigating the rhythms of daily life with a changed bowel function, rather than just making comments on a study design in which they would not be able to participate. Knowing what bowel cancer patienthood (and survivorship) looked like in practice, they seemed to suggest, would help me in improving the design of my research project. After realising that the practices that members of both these groups mentioned were very similar to the type of actions and behaviours my research participants used to successfully deal with the effects of surgery, I took wisdom they shared with me and transformed it in a decalogue.¹

1. One's body will never be the same and it is important to accept that, for even as we ask why this happen to us, we must get on with life, for us and for the ones we care about.
2. One plans for trips with stops in which a toilet in good conditions is hopefully available.
3. One experiments with the design and the opening of the pouch until finding the right one.

¹On top of these two meetings with bowel cancer support groups, an invitation to comment on the study design of my research project was uploaded on an ad-hoc online platform that one of the main cancer charities in London manages.

4. One learns to eat again; low-fibre diets and little alcohol are the best to slow down peristalsis.
5. One makes sure not to lift anything heavy and only do gentle exercise not to cause hernias and stoma prolapses.
6. One finds the daily balance between having diarrhoea or constipation, depending on how much loperamide – thickening tablets – one takes.
7. One washes the skin around the stoma with soap and warm water thoroughly to prevent excoriation.
8. One reaches out to others in off-line or on-line support groups, for their members will understand what one is going through.
9. One reads ‘Tidings’ the magazine for people with ostomies to find more tips.
10. One carries a change of clothes together with the stoma case, especially while on chemotherapy cycles.

The members of the support groups I attended were emphatic when explaining that the fear of accidents initially seems to take one’s life away, restricting one’s ability to go about with life until one finds balance amid the unpredictability of one’s bowel movements. As the decalogue shows, balancing here means tinkering with different material elements over time, such as food intake, their own bodies, public infrastructure, thickening tablets, bowel movement consistencies, clothes and ostomy bags. Adjusting to the stoma is premised on the coordination of socio-material practices that can make bowel motility occur in a controlled way. In other words, by tinkering or experimenting (cf. Mol, 2008) with the materiality of one’s own body and its surroundings, one would not only gradually learn how to deal with an erratic and sometimes explosive bowel function during cancer treatments, but will also slowly accept one’s body after surgery. In an enlightening essay that attempts to move away from the dualism between the body as an object of the clinical gaze and the body as subjectively felt by the individual, anthropologist Annemarie Mol and sociologist John Law (2004) ask: ‘what is a body in the conditions of possibility at the beginning of the 21st century?’ (2004, p. 45). Through the analysis of the modes of knowing about the body, the authors explore the ways in which people affected by diabetes *practically* get acquainted with ‘the bodies they have’ when they suffer an episode of hypoglycaemia (in lay terms, a drop in the levels of blood sugar). Mol and Law argue that managing hypoglycaemia is not only about measuring blood sugar with a machine, but also ‘feeling from inside’ what is going on and coordinating

a permeable body with material elements such as food intake and other everyday commitments. Hence, by coordinating all these practices that sometimes appear to be in tension, the bodies of people with hypoglycaemia are momentarily ‘enacted’ as a coherent whole by the individuals. This body that is ‘done’ is an achievement that occurs in particular ways. Following this argument, it is possible to say that the way in which my research participants aim to continue with their lives despite and beyond cancer treatment depends on the enactment of a different and larger body, a body with stoma. Instead of focusing on ‘the body we have’ or ‘the body we are’, the authors suggest, understanding how people cope with body parts has to attend to ‘the body we do’. In other words, it is through the productive coordination of different material practices that one produces a body that is substantially different from both the anatomical body that is objectified by the medical gaze, and from our own representation of it as a component of our self-image. Undoubtedly, producing ‘the body we do’ requires work, constituting an achievement when we are successful in keeping it coherent because gaining coherence between materials and actions enables one’s bowel function and the inherent tensions of its management not to rule one’s life.

Assorting different materialities in the construction of the body with stoma requires time and I would suggest that only after such coordination is achieved does acceptance of the body occur. Similar to Mol and Law’s understanding of the ‘body we do’, French anthropologist Jean Pierre Warnier conceptualises the body as a heterogeneous material synthesis. In a more psychological endeavour, Warnier suggests that the subject incorporates experiences arising from its engagement with its material world through sensori-motor practices. Sensori-motricity, together with speech and images, are mediums through which the new (material) experiences of the world are internalised by the subject. This process of domestication of varying material experiences is what Warnier understands as ‘symbolization’ (Warnier, 2001, p. 14), a process that enables the subject to find meaning in events that are unruly or misaligned from the stereotypical ordinariness of the day-to-day. In other words, because temporality is an important feature implicit in this process of symbolisation that aims at normalising experiences that would otherwise have unexpected consequences, by means of reproducing and, at the same time, reshaping sensori-motor engagements, Warnier proposes that the practice acquires meaning for the subject and can be incorporated into a normal sequence of events. Stoma management for my participants is exactly this kind of repetitive and creative process of material tinkering that enlarges the body. Highlighting the materiality that is coordinated in this process bears, for me, important implications about our understanding of adaptation or behaviour change in people who have gone through

stoma formations. In the next section, I would like to unpack the contribution that a materialist approach offers to our understanding of the ways in which people with stomas adjust to their anatomically transformed body.

5.6 The idealism behind the concept of adjustment: Material constraints before attitudes

According to research carried out by clinical psychologists, stoma nurses and surgeons, post-surgical stress after the stoma responds to both the perceived lack of control regarding the containment of bowel outputs (and cancer in general) and the perceived difficulties people find when trying to resume their everyday activities (Tao et al., 2014; Thorpe et al., 2009). People with stomas not only go through the struggle of maintaining a sense of self while their bodies are unbounded, but they also must learn and get acquainted with the dynamics surrounding faecal incontinence while trying to go on with their lives. Both aspects are said to affect the emotional response that patients develop to the stoma post-surgery – the perceived lack of control or lack of acceptance triggering maladaptive practices that cause emotional distress (Ranchor et al., 2010). The degree of stress that living with diverted bowels generates in the person is what clinical psychologists understand as ‘adjustment to stoma formation’ (Simmons et al., 2007). Adjustment is operationalised as a concept concerned primarily with the measurement of ‘quality of life’ for people with stomas. Using standardised metrics to understand the psychosocial burden imposed by the stoma formation, patients are rated on a scale that looks more normative than descriptive but has become essential to understanding patients’ needs and how nurses and other professionals can support people struggling to become a coherent ‘person-with-stoma’. Hence, the scholarship aims to establish the factors that are at least co-related to different levels of adjustment to inform clinical recommendations. The key explanatory variable usually incorporated is ‘coping’, which in turn depends on two stages of cognitive appraisal. The first is about the nature of the stress, while the second is about what the individual thinks can be done (Moorey and Greer, 2011), which is understood as ‘self-efficacy’. Proponents from health psychology suggest that self-efficacy predicts health behaviours (Ashford et al., 2010) but it is a mental construct that is not so easy to modify, as it crystallises through the individual’s previous experiences in life and is affected not only by external sources of motivation (available for modification), but also enduring affective states and physiological conditions (Bandura, 1978). Therefore, it is possible to say that cognitive models of adjustment to stoma formations assume that the individual’s reaction to estranged

body parts depends on the interpretations s/he makes based on the information that is available, and the extent in which s/he believes s/he has the skills to produce the effects (on the body) that are desired. The appraisal process, shaped by one's self-belief, explains how the individual responds to the stoma and its consequences.

The clinical promotion of adjustment is then predicated upon the transference of control from surgeons and nurse specialists to patients through the clear and compassionate provision of information so that they can 'self-manage', a concept that underpins the responsibility of the individual to take care of their own health, which is currently gaining much currency in the NHS in the face of an increasing demand for healthcare services and high work pressure on clinical teams (Foster, Calman et al., 2018). The premise is that patients will feel confident enough to manage the consequences of cancer and its treatment if they acquire the relevant knowledge to cope with the disease. Practical knowledge will enable patients to change their behaviours as needed and to make sense of the body with stoma as the 'new normal' (Allison et al., 2013; McVey et al., 2001; Thorpe et al., 2014). From this perspective, Jay was able to adjust to the stoma formation, partly because his own belief about himself and the skills necessary to achieve bowel control, while Elizabeth found it more problematic as she did not feel confident about what her own body could do then and in the future. Through this lens, the achievement of coordinating 'the body we do' through the habituation of embodied skills draws from the absorption and sense-making of information that in turn inform practical skills and changes in behaviour. The challenge then is that struggling to manage the stoma practically reinforced in Elizabeth the feeling of being out of control. For the colleagues that follow psycho-social understandings of bowel cancer survivorship (Foster, Breckons et al., 2015; Foster, Haviland et al., 2016; Grimmett et al., 2017), the problem in Elizabeth's case was one of self-efficacy: she was finding it difficult to self-manage her stoma because she did not believe whether and how she could do it.

While I understand the relevance of psychological traits to understand how people cope with stoma formations, I would like to argue that adjustment, as defined here, must be complicated for an analysis that takes people's struggles seriously. Enacting 'the body we do' demands the consideration of the ways in which practices employed to cope with daily life are situated in a context that is shaped by material living conditions and by the support that other people can offer to the patient. Against an ideal of the self-managed patient who is proactive and knowledgeable despite the socioeconomic context in which they live, my ethnography evidences that, before attitudes, there is materiality. Thus, I argue that in order to support the self-management of people affected by cancer, attempts to understand individuals' 'self-efficacy' to manage the consequences of cancer treatments must acknowledge

the centrality of access to infrastructure and economic means, regardless of the psychological constructs of the person. Having described in the previous chapters the unequal living conditions and economic resources that my research participants enjoyed, in this chapter, I suggest that we must interrogate the material affordances; namely, the possibilities for action through which materials allow a successful process of bodily synthesis for the management of stomas. Simon's story is illustrative in making this point.

After the second cycle of chemotherapy to treat a non-resectable advanced sigmoid cancer with liver metastasis, a bout of pain and projectile vomiting overwhelmed Simon: his bowel had perforated and emergency surgery was the only way to keep him alive. The procedure resulted in the formation of a temporal colostomy, so like Jay and Elizabeth, he had to learn to live with that. However, unlike Jay and Elizabeth, he did not enjoy the same material conditions or social support. Threatened to be made homeless by members of his family with whom he lived and having lost his zero-hour contract job after the cancer diagnosis, he was left between a rock and a hard place. The flat in which he was living with his close family belonged to his deceased father, but it had become the main source of family conflict. The dispute over the father's inheritance reached the county court. Until the judge could decide, his mother and sibling determined that Simon was not allowed to use the kitchen for cooking or the washing machine to do the laundry, and he was prevented from using the toilet from midnight to 7:00 AM. His relatives did not care that Simon had to deal with a stoma and chemotherapy at the same time, challenging him to contain the faecal waste by other means. Simon was living under a curfew at his 50 years and, as the flat is locked from the inside by his mother at night, he feared that the ambulance could not reach him should he ever require medical attention during an emergency. His relatives observed strict silence with him, so he thought that his mother simply did not want him to feel as if that flat was also his house. Using the toilet, the kitchen, or the laundry was entitling him to feel ownership of something that was in dispute. He repeatedly told me something like:

Simon: I have been called to a hearing in the court, because the family of my father wants to take all the money I have before I die. They [mother and elder sibling] thought I would not be able to appeal for the case, because of the cancer and my financial difficulties, but I have managed to answer 72 pages report to the court without a lawyer, so the judge decided to give me a hearing... What my family is doing is worse than the cancer itself.

Simon considered his stoma to be the worst part of the cancer – with the non-stop leaking, without being able to do the laundry, changing his stoma bag at night or preparing more suitable food at home. Moreover, he was suffering from an intestinal prolapse occasioned by lifting his heavy backpack every day, because he did not trust his relatives at home to leave his laptop, all the hospital letters or his medical appliances there. It was clear that he would have loved to have a stoma reversal, but he was afraid that he could miss the case in court in September if there were any complications during surgery. The problem in the meantime was that he had been in constant pain around the opening made for the stoma bag, and, lastly, it had been bleeding. He was just afraid that the stoma got damaged without him realising due to the lack of innervation. He also complained that the pouch kept coming off, even if he secured it with surgical tape to his belly. ‘Two days ago (he told me) I was in the library in Victoria, and needed to take a hour long bus to go home, but the stoma was leaking, so I spent the whole hour holding the bag in place with a free newspaper that I shovelled under my trousers’.

In an appointment with the stoma nurse to which both of us went, we found out that his stoma had indeed prolapsed due to the heavy weight he was carrying with him everyday and that he was strangulating it because he was not measuring the stoma bags correctly. He was not registered with the GP because his social situation prevented him from having an established proof of address, so he found himself recycling the stoma bags that the hospital had given him months ago. The pain, the nurse suggested, was due to the petroleum-based cream he was using to heal the skin around the stoma, which in turn provoked an allergic reaction and excoriation so that the bag was not able to stick properly. When she suggested that he use a stoma belt to prevent the ongoing prolapse, Simon was staring at the floor. I could only guess what the problem was: he could not afford something like that when he was not even able to make ends meet every month. A year later, the material constraint kept oppressing him, as Simon lost the case in the court and he found himself in an even more precarious position. Unlike Jay and Elizabeth, who fortunately did not face serious material constraints and enjoyed the support of their families, Simon was not always able to produce the larger body with stoma and secure its optimum management due to the lack of access to basic infrastructure.

5.7 Discussion

This chapter has tried to unpack the socio-material practices that make up the body with stoma in order to complement academic perspectives than understand the challenge of faecal incontinence from the point of view of its effects on the individual’s

self-image and confidence in terms of integrating in social dynamics. Drawing on three main ethnographic cases from colorectal cancer patients undergoing treatment in a teaching hospital in London, a rendering of stoma management has been offered that highlights its material aspects, proposing an analysis that sheds light on the preconditions of bowel control for people with stomas in the everyday. Hence, this approach has been developed to contribute to clinical understandings of processes of adjustment that otherwise tend to idealise proactive attitudes to stoma management under the possible slogan: ‘more and better information for a supportive process of behaviour change’. Such an approach, currently used by stoma nurses in the clinical team, transfers responsibility from the clinic to patients irrespective of the material and economic support they have available. Interested in patients’ quality of life, clinical professionals aim to give compassionate and informative advice. However, I have argued that the tensions that arise in the enactment of a body with stoma must pay attention to the material surroundings that enable colorectal cancer patients to live their lives despite and beyond treatment. Instead of focusing on patients’ perceptions of lack of control or their disregard for the recommendations they receive from clinical professionals, my ethnography shows that ‘maladaptive’ behaviours are not only a consequence of individual attitudes or lack of understanding. I have argued that well-fitting stoma bags over healthy skin solve most of the struggle if basic infrastructure is provided.

Chapter 6

Adjuvant chemotherapy as insurance policy: Cancer risk, anticipation and incommensurable values

6.1 The post-cancerous body

There are three groups of people affected by cancer: (1) the ones who will survive more than 10 years after the cancer, (2) the ones who have less than a year to live and will soon submit to the palliative care pathway, and (3) the ones who face a prognosis of 1 to 5 years survival as the cancer is not curable and have to engage with difficult treatment decisions. Jean is a British woman in her late 30s. Her tumour in the rectum became surgically resectable after a month of daily chemo-radiotherapy that downsized the mass. During bowel surgery, the team removed a section of her rectum, some lymphatic nodules, and created a temporal opening on the abdominal wall so she could discharge faecal waste. A few weeks later, Jean had an MRI scan and a battery of blood tests to check for possible traces of tumour activity and cancer bio-markers respectively. Because there was no evidence of the disease, and the histological samples collected from the resected tissue showed that the margins of the surgical resection were clear, the medical oncologist told her that ‘she *might* be cured’.

Although the worst had already happened, Jean had mixed feelings about the consultant’s statement. This could be explained in relation to two temporal orientations. On the one hand, and looking back, Jean thought that the process could have been less harsh on her body if the GPs to whom she complained about rectal

bleeding had not dismissed her symptoms for so many months. She was bitterly disappointed with the healthcare system for this reason. On the other hand, and this time looking ahead, there was still more treatment to do. Epidemiological statistics constructed Jean as a subject 'at risk of cancer recurrence'.

I stressed that Jean *might* be cured because the consultants in the oncology clinic in which I did my fieldwork in London were very careful in managing patients' expectations about the future. They were fully aware of the uncertainty patients and healthcare professionals face at the time of engaging in the 'prognosis chat'. As a consultant used to say to the patients he treated, 'we are not clever enough', referring to their ability to foresee how cancer would develop in their bodies. The imaging technologies available are currently unable to show malignant cells in the very early stages of their growth and carcinogenesis, the process of tumour development, continues to surprise researchers as it can take different paths based on genetic variations that are not yet fully mapped. So, despite the fact that Jean got her tumour in the rectum fully resected, available diagnostic tests were not able to affirm with certainty that there were no mutated cells around the site of the surgery or somewhere else in her body. Anthropologist Lochlain Jain brilliantly describes this situation as follows:

Cancer is creepy. After it shows up one realizes that it must have been there for a while, growing, dispersing, scattering, sending out feelers and fragments. After the treatments, often one hasn't any idea if it is still there, slinking about in organs or through the lymph system – those parts of the body you can't really even visualize. (Jain, 2007, p. 80)

Faced with the uncertainty, conversations about prognosis for people who might be cured are framed in terms of risk, accounting for the observed probabilities that a given *population* has of witnessing cancer cells growing in their bodies again, this time 'stronger and smarter', as a specialist nurse once explained to a patient considering chemoprevention regimes. Depending on the likelihood of this outcome, there are formally three options to deal with the ontological uncertainty of cancer: to not do anything, to 'watch and wait' hoping to catch any growing malignancy as early as possible, or to go through 12 cycles of adjuvant chemotherapy to arrest the progression of the disease (an option also called chemoprevention).

In the following section, I will briefly map out how accounts in medical anthropology have framed the issue of cancer risk and the moral responsibility to not only ascertain its extent but also to minimise it. As will become clear, different practices and bodies of knowledge separate 'risk estimation' from 'risk prevention'. However, because of the morality inbuilt in knowing one's own cancer risk, the

distinction between ‘knowing’ and ‘treating’ the risk is fluid in practice. Making sense of such an endeavour not only requires that healthcare professionals, patients and caregivers communicate specific sets of beliefs and values in order to create provisional understandings, but it also requires that all stakeholders juggle various temporal regimes.

6.2 Cancer risk, a scientific and moral issue

In parallel to the increasing knowledge about environmental carcinogens (Auyero and Swistun, 2009; Lora-Wainwright, 2009) and lifestyle risk factors that may help in explaining the onset of cancer in certain populations (Schottenfeld et al., 2013),¹ historical advances in both techniques of molecular biology and the mechanisms through which various genetic mutations shape the cell cycle (‘onco-genes’) have enabled a better understanding of cancer occurrence in humans through the geneticisation of cancer research (Angier, 1999; Fujimura, 1996; Mukherjee, 2010). The relentless scientific enterprise continuously maps genetic mutations that eventually are translated into screening tests for hereditary variants of cancer conditions, which have been progressively and eagerly rolled out in affluent countries, while less affluent societies resort to international collaborations to access to such developments (Gibbon, Joseph, et al., 2014). Not willing to be left behind in its scientific curiosity, anthropological research has highlighted the importance of looking at how people with cancer make sense of the screening practices, diagnostic outcomes and different therapeutic options to manage cancer risk. Medical technologies translating scientific developments in cancer for the benefit of the population, anthropology suggests, opens up new possibilities for the understanding of biosocial identities through the molecularisation of medical research (Gibbon and Novas, 2007; Rose, 2001), of kinship dynamics (Konrad, 2003), and of moral economies of risk marked by notions of ‘genetic responsibility’ (Hallowell, 1999). In that way, research in medical anthropology has devoted considerable attention to exploring questions that could be framed in terms of the constitution of the cancer pathway, expanding its known span as it sheds light on the dynamics occurring before diagnosis, as well as on the epistemological dynamics that rule the futures of post-cancerous bodies.

In opposition to the bright narratives that celebrate science’s progress in ‘beating cancer’, anthropologists have shown that the personal experience of survivorship is everything except cheerful (Bell and Ristovski-Slijepcevic, 2013; Jain, 2013; Stacey, 2013; Stoller, 2004). Living in prognosis causes an affective response marked by terror

¹For a critical analysis of the concept of ‘lifestyle’ mobilised in Public Health campaigns, see Bell (2010).

and the feeling of lost opportunities. To avoid further regret, the prognosis produces a normative 'opportunity' for the individual to manage it (Bell, 2017). Patient responsibility here means that the person at risk has to become affected by the threat and find resolution amid the fear simultaneously. This temporal complexity not only gives rise to the understanding of cancer as a chronic condition (Aronowitz, 2009; Ristovski-Slijepcevic and Bell, 2014), but it also cements the expectation among health professionals that they will meet with a vigilant patient (Armstrong, 2012).

The responsible patient is one who manages a statistical risk as a personal destiny, benefiting from the fruits of a provident self but experientially enduring the iatrogenic consequences of such interventions in the present. This experiential dimension of risk is what Woodward (2008) discusses as 'statistical panic'. As the discourse of probabilities is incorporated to reflect one's own future, one triggers an affective response marked by the feeling of urgency that propels us to consume therapeutic goods. In this way, managing the risk that one's body harbours colonises the temporal experience of becoming (as if there is no alternative future to the forecast by science (Finkler, 2003). As sociologist Beck put it 20 years ago: risk colonises the future, for 'events that do not exist (yet) strongly influence our present affairs and activities' (Beck, 1998, p. 11). In this vein, it is possible to say that risk is manipulated, objectified and charged with an affective response.

From these accounts, one learns that cancer risk is articulated not only in scientific terms, but also as a moral danger (Lupton, 1993). In other words, understandings of cancer risk are imbued in a moral economy that invites patients to not only disclose such probabilities, but moreover take them personally in an effort to control what seems to be their *predestined*, rather than *probabilistic*, health future. Cancer risk management distributes value in the form of appreciation to the asymptomatic or pre-symptomatic individuals who show wilful vigilance, providence and responsibility. Distribution of blame, therefore, goes directly to the person who, knowing that she or he embodies a high risk of developing cancer, stays passive and neglectful over time. Social science research in cancer care has shown that scientific practices, and the medico-commercial industries behind them, transform risk control into a collective desire framed in terms of the individual responsibility to be situated in different temporal plots, gauging efforts in deciding how to act today to prevent something from happening in the future.

The moralisation that is inbuilt into the medical discourse in cancer care is pervasive in the UK. Yet, I feel uneasy about depicting Jean, or any other person affected by cancer that I met in the clinic, as a subject that is so constrained by this that she does not find room to navigate it on her own terms. The ongoing sociological critique that demonises the medico-commercial industry behind tertiary prevention,

because it profits from the ‘statistical panic’ that cancer causes and thus offers an ‘illusion of control’ regardless of the complex aetiology of the disease, only tells one part of the story. In the UK, healthcare provision is not an unregulated private enterprise exclusively guided by commercial gains. Moreover, the responsabilisation discourse leaves untouched the ways in which health practitioners may well be cautious about the risks of over-treatment, and patients are an important party when negotiating how to personally approach the management of their cancer risk. It is in this context that analysing both the negotiation of epistemological and ethical values that organise treatment in cancer clinics vis-à-vis the moralisation discourse becomes necessary for anthropology. In the next section, I consider the two-fold affective dynamic of cancer risk through the lens of chemoprevention as an anticipatory regime.

6.3 Anticipatory regimes

Responsible patienthood is closely tied to the working of anticipatory dynamics. Adams, Murphy and Clark (2009) define ‘anticipation’ as an affective state that helps us to orient ourselves temporally, inhabiting degrees of uncertainty and producing material trajectories according to hypothetical visions of the future that are ‘lived as inevitable present’ (Adams et al., 2009, p. 248). Focusing on the temporal complex of cancer risk, Jain (2007) offers a critical discussion on the relationship between ‘prognostic subject’ and time in cultural accounts of cancer. She unpacks the counter-factual past and future as temporal articulations that shape the subjectivity of the person living in prognosis. The prognostic subject has to negotiate how the very truth of her body has been revealed by the unfolding of her medical condition, while she simultaneously negotiates alternative futures. Un-knowledgeability of what the body holds from the past suggests tireless surveillance of what could have been an alternative pathway; maybe possibilities of detecting cancer would not have been missed otherwise. At the same time, uncertainty about the future contradictorily paralyses and propels the patient to the future. Thus, prognostic time constantly anticipates a future that is impossible to grasp, and the risk of cancer recurrence for an abstract population becomes particularised and totalising: the person inhabiting a post-cancerous body will not be 60% alive or 40% dead; instead, the prognostic subject will be either inhabiting one state or the other. The management of such prognostic time, Jain points out, requires the subject to embrace a ‘preposterous viewpoint: one in which the end, or posterior, seems to precede the story’ (Jain, 2007, p. 81). Essential for this discussion is that anticipation creates a moral economy through which it distributes value in relation to the modes in which we engage in responding to such probabilistic futures: vigilance and providence are most welcome

in order to *urgently* optimise what is in one's control (and within one's understanding) to achieve the best possible scenario. Such moral economy, then, contributes to fuelling the drive that creates the material conditions for the future just anticipated. The use of chemoprevention in state-funded cancer care in the UK provides an excellent case to illustrate this point.

According to clinical evidence, the survival rate of patients affected by bowel cancer who have been surgically treated with curative intent varies proportionally in relation to the staging of the cancer at presentation. Cancer stages are retrieved from imaging techniques and histological samples with standard labelling techniques that include three main components: size of the tumour, nodule involvement and degree of metastasis (or whether the cancer has spread to other organs). Stages range from stage 0 to stage IV, which are then used to discern the appropriate clinical management of the condition and its prognosis in terms of the numbers of years of disease-free survival. Of relevance for this chapter, patients whose tumour activity has been graded stage III (any T, N1-N2, M0) face a five-year survival rate of 30%/60% (Labianca et al., 2013). In other words, between 30% to 60% of people affected by bowel cancer who have had surgery with curative intent aimed at resecting a tumour graded stage III are statistically expected to live five years or more *on average*. Clinical evidence thus creates a probabilistic future, even though cancer prognosis is evidently much more complex than just staging, because uncertainty remains paramount to account for the challenges in predicting the evolution of carcinogenesis in individual patients. In short, prognosis is, at best, a very 'educated guess', as consultants excused themselves in front of disappointed and sometimes angry patients whose tumours had come back once in remission. Yet, prognostic statistics, along with other clinical outcomes, account for the widespread and mobilised fear of cancer recurrence.

In the oncology clinic where I carried out research in London, as well as in other public hospitals that follow the same clinical guidelines, patients whose tumour activity is graded as stage III are offered 12 cycles of adjuvant chemotherapy.² The aim is to reduce the risk of cancer recurrence in the future, which is known to be the main cause of death among this patient population. Thus, cancer risk is medicalised in anticipation of what might happen otherwise. This is also called tertiary prevention (Armstrong, 2012); the medical oncologists I met in my research translated this offer of adjuvant chemotherapy as an '*insurance policy*'. The caveat of

²Adjuvant chemotherapy is also offered to patients whose tumour activity is graded as stage II, but that are considered at high risk of recurrence. According to the European Society for Medical Oncology (ESMO) guidelines for colorectal cancer: 'The general consensus suggests that patients with stage II are considered at high risk if they present at least one of the following clinical characteristics: lymph nodes sampling bigger than 12; poorly differentiated tumour; vascular or lymphatic or peri-neural invasion; tumour presentation with obstruction or tumour perforation and pT4 stage [II]' (Labianca et al., 2013).

the offer, though, is that neither the patient nor the clinical professionals are able to determine whether the benefit of more years of cancer-free survival are a result of six months of toxic treatment or a result of the surgical resection achieved in the first place (before chemoprevention regime has even started). An informative registrar explained this to me:

Registrar: The way I say it is: ‘your cancer has been taken away by the surgeons. At this moment, you are sitting in front of me, you have no detectable cancer by imaging. But we don’t know what will happen in the future. There is a percentage of people to whom this cancer will cause trouble in the future, and there is percentage of people that it isn’t gonna do anything and they will be completely cured from this moment onwards’. And we try to say that ‘we will give you chemotherapy, but we don’t know, we don’t know what route you are in’. That it is a very difficult concept for people to understand.

Understanding chemotherapy as an insurance policy reveals that risk, toxicity and quality of life are interwoven in the temporal complex of cancer care. Predicated upon a possible undesirable future, the burden must be borne in the present, with no guarantees. The transmogrification of population statistic risk into affective orientations to the future that takes shape in the form of offering and gaining consent to receive chemotherapy as an ‘insurance policy’ requires an ongoing negotiation of epistemic and ethical values by clinicians and patients alike. In the next sections, I will describe a careful and ongoing trade-off between the toxicity and the efficacy of treatments vis-à-vis subjective understandings of quality of life. Since Dr Z was the consultant medical oncologist who most frequently oversaw my research participants’ chemotherapy treatments, his voice appears prominently in this chapter.

6.4 ‘It is your choice’

Jean is nervously playing with her hair and her rings while listening to Dr Z explain that he would like her to give consent to receiving 12 cycles of chemotherapy to reduce the risk of recurrence. Dr Z, noticing Jean’s restlessness, says that he understands that she wants ‘to hit all the milestones very hard and get over the cancer, even if it is just an insurance policy as it does not mean that it will prevent the recurrence’. This is the reason why Dr Z plans to start chemotherapy in a few weeks’ time. She will get an appointment to get the portacath or implanted venous access in the next two weeks (shown in Figure 6.1). Dr Z suggests she starts treatment soon

with only Fluorouracil (5FU), ‘which will offer most of the benefit, and would not cause neutropenia or other important side effects’. He would give her prophylactic antibiotics with every chemotherapy session to prevent recurring septicaemia after the infection that she suffered as a post-surgery complication. She could take 5FU for three, four or six cycles and then see: ‘if it turns to be a walk in the park and everything is going without complication, you could continue with the same drug, or topping up with Oxaliplatin, the other agent, which is a bit worse in terms of side effects’, Dr Z explains. However, Jean could also stop after cycle number four and have the stoma reversal after four weeks of rest. ‘It is your choice’, he finalises.



Figure 6.1 Jean's portacath

The previous vignette shows that adjuvant chemotherapy requires the patients to consider several bits of information: risk of recurrence, procedures for the preparation of the body (including self-administered antiseptic injections, and the professional insertion of a portacath), drug regimes with different toxic profiles, and the management of the side effects. Importantly, all these tasks must be carried out on top of the management of Jean's ileostomy (a surgical operation equivalent to the colectomy explained in Chapter 5, but performed in the ileum) and its overwhelming leaking potential. Temporary or permanent ileostomies are a likely outcome of curative rectal surgeries, as seen in the profiles of rectal patients that participated in this study (see Table 2.4 in Chapter 2).

Adjuvant chemotherapy is an insurance policy for the uncertainty that stems from the risk of recurrence that cannot be fully modelled for a specific patient. There is an intangible form of accumulation – in this case, toxicity with a hopeful therapeutic

value – that aims to produce another kind of value: the efficacy measured in the number of years of disease-free survival. Viviana Zelizer’s now classic study of the origins of life insurance in the US (1979) helps to deepen the moral contours of adopting the analogy of an insurance policy when offering adjuvant chemotherapy to people who might be already cured. In *Morals and Markets*, Zelizer historically looks at the inclusion of non-economic factors in economic values through the lens of the changes in values produced by the introduction of death in the economic market (through the advertisement and sale of life insurance policies). She argues that life insurance requires a specific set of values towards death that allows the development of such social innovation. The main values she teases out involve people’s (un)easiness about making financial evaluations of human life, and the historical development of a non-fatalistic attitude towards death. Such orientations nicely fit with the ideology promoted by life insurance as a commodity, as the latter celebrates the rise of the idea of exerting ‘human control over the conditional elements of life’ (Zelizer, 1979, p. 52). At the same time, Zelizer argues, the introduction of death to the market precipitated changes in prevailing cultural values held by the US American public opinion. Two of the four changes that Zelizer elucidates are relevant for the current argument. First, life insurance started to work as a secular ritual that would not only secure economic aid for the relatives left behind the deceased breadwinner (the one who would need an insurance policy in the first place), but would also help people to emotionally come to terms with the death of the policyholder. Second, the adoption of life insurance started to influence ideas of what it meant to be a responsible father. Not being insured would stand for selfishness and neglect, as the dying person would not have ensured that there were provisions for his dependants left behind.

The parallels between Zelizer’s historical account of the development of the insurance market in the US and the ideology underpinning the phrasing of adjuvant chemotherapy as an insurance policy in the oncology clinic are striking. In terms of understanding how adjuvant chemotherapy mitigates the risks of cancer recurrence with the analogy of an insurance policy, on the one hand, it marks the whole clinical endeavour as the entrepreneurship of those who are willing to personally tackle the risks and assume a *premium* – in this case, not economic but physiological (more of this to follow in the next section). On the other hand, insurance policies as risk-management technologies of loss modify values and sort them in novel ways. Now the ‘cancer survivor’ is more responsible than ever for keeping the cancer at bay, as it is his/her choice to continue treatment after getting familiarised with the risk. Nevertheless, the value of a disease-free life sits eye to eye with the values comprising people’s understandings of quality of life. Managing the post-cancerous body through the continuation of chemoprevention regimes after treatment, then,

means juggling toxicity and the safety of chemotherapy drugs with the value we give to a life worth living. In short, chemotherapy as insurance policy opens up a moral landscape in which different sorts of incommensurable values are put in relation to one another, which requires ongoing negotiation and moral judgement. Consultants such as Dr Z must then adjust their mode of decision-making by counting not only on clinical evidence about what is safe and effective, but also on situational judgement. This is what Dr Z calls ‘the safe and sensible thing to do’, that he explained to me by taking as an example how he decided to push for Jean’s ileostomy reversal before giving her chemotherapy, as she was not coping well with the stoma.

Dr Z: As an oncologist, you need to do what I call safe and sensible decision-making. From the safety point of view, she [Jean] is young, fit, her blood levels are ok, there is no issue of safety. It would not have been sensible to give her chemo while she still had the stoma because she wasn’t mentally well. We give chemotherapy to a lot of people with ileotomies, so it is safe. But it is not sensible [in this case]. Then I have to go very much with the patient [and she wants].

In the remainder of the chapter, I will unpack some of the main aspects that inform the practice of medical oncology in the GI clinic. Within the constraints of healthcare and bioethical regulations, consultants integrate the principles of evidence-based medicine with situational forms of decision-making when offering patients to commit to chemotherapy as an ‘insurance policy’. In the next section, I look at the negotiation of epistemic values offered by chemotherapy as an insurance policy.

6.5 Embedding epistemic values

Important anthropological work has teased out the co-constitution of economic value and biomedicine (Cooper, 2008; Dumit, 2012; Rajan, 2006). Yet, less has been said about the negotiations taking place to find out the therapeutic value of given chemotherapies for actual people. Chemotherapy is an arena in which multiple values are enacted, contested and transmuted. Decisions are made along the line of production, prescription and delivery of the treatment across different places. Clinical trials strive to find a compromise between safety, tolerability and efficacy. The National Institute for Care Excellence (NICE) will then assess drugs’ efficacy against the economic cost of funding them for residents in Great Britain. Once approved to be given for free at the point of access, clinical professionals will discuss the efficacy of the approved drugs, always known in hindsight of when it prevented cancer from progressing inside patients’ bodies.

The cancer pathway is a nationally standardised intervention protocol drafted by NICE with specifications and time targets to be followed by all hospital trusts treating NHS patients. In the gastro-intestinal (GI) cancer clinic, there are two weekly lunchtime opportunities in which such protocol is made particular to patients' current situations. The first is the multidisciplinary team meeting (MDT), an hour long gathering led by a specialist nurse in which the radiologist, the histologist, surgeons, medical oncologists, and clinical oncologists discuss treatment options for around 30 patients who are either recently diagnosed, had gone through bowel surgery, or have had follow-up scans. After a brief introduction to the patient's case made by the specialist nurse, images of patients' bowels in indistinguishable shades of grey are projected onto a screen. The images hypnotise most of the people in the room. The radiologist comments on the location and approximate size of the tumours, any noticeable nodule involvement, and any changes from one scan to another when comparable images exist. If tissue samples are available, the histologist will quickly present a report. He shows a picture of the resected sample, a microscopic image of the tissue in which darker colours mark cancer cells, to then conclude by stating the precise stage of the tumour and its molecular phenotype. Through my attendance to those meetings over a year, I learnt that, whereas scans can only suggest visual resemblances of different morphologies in people's anatomies, histological samples are more definitive proofs of cancer existence.

The orientation towards the screen is at the expense of face-to-face discussion, reproducing the power hierarchy of the field in the room. It is as if the MDT could be done with the people sitting in the first two rows: consultants who are either surgeons or medical oncologists, the ones who have to record their attendance. The vast majority of decisions will be made between them, the people closer to the medical evidence presented on the screens. After initial discussion of the diagnostic tests, the question to be answered by the doctors (consultant oncologists and surgeons mainly) is what the best treatment option for the patient is. In this quick medical discussion, clinical protocols are negotiated, either by the specialist nurses stating the patient's preferences, personal situation or co-morbidities in order to inform the consultants ('we can't do this, the patient has mental health problems') or by medical oncologists (who ask the nurses in return, 'did you get the RAS status?', which is the main bio-marker used at the time I was in the clinic to predict what is known of the cellular make-up of bowel cancer, as it is a protein that activates genetic mutations at the cellular level and is therefore useful to decide for targeted therapies).³ Sometimes, updated images are necessary to decide further steps, as

³In line with the clinical practice guidelines of the European Society for Medical Oncology (ESMO), patients with metastatic colorectal cancer must be screened for RAS mutations before initiating any anti-EGFR therapy

previous details quickly become outdated when cancer rapidly progresses, so the specialist nurses would book appointments for the patient and will always inform patients of the results if no appointment with a consultant has been made. With all information available, the answer includes several combinations of surgery and anti-cancer treatments (chemotherapy, radiotherapy, biological therapies). The three consultants of my team work together, and one of the older ones usually challenges the lead surgeon and clinical oncologists if in disagreement. After encouraging the team to obtain a treatment resolution for each patient, sometimes asking specific colleagues sitting in the room what to do next, the specialist nurses write down the decisions made in the meeting.

Treatment decisions are further particularised during weekly pre-clinic meetings. In 40 minutes, the team goes through the specific chemotherapy decisions for the 60-70 patients attending the clinic that day. For the 10-20 odd new patients every week, consultants in medical oncology will discuss with each other the clinical evidence that supports their decisions – what does a diagnostic category mean, how should they treat a specific diagnosis, what should they do with difficult cases in which patients are finishing treatment but the cancer keeps growing? – and any new trial in which they could be enrolled. The older consultants Dr Y and Dr W, who also do research and teach students at the medical school, are constantly citing published papers to argue for one regime rather than another, presenting information about the efficacy and toxicity of different drug regimes as obtained in recent clinical research trials (with one consultant even doing this at no one's request while the team tries to move on along a seemingly endless list of patients to be discussed before 1 pm). Evidence-based medicine in the shape of trial research outcomes comes to the foreground of the discussion, only to then be integrated with patients' preferences and the clinical situation that the patient is facing. It is this process of retrieving, negotiating and integrating diverse results from scans, histology samples and clinical examinations that I understand as epistemological value.

Throughout the year I attended those meetings, I learnt in the field that only consultants would create epistemological value or negotiate the value that is already implicit in treatment protocols, whereas the rest of the team would tend to reproduce it, following the indications set by the consultants when meeting the patients. Registrars would rarely challenge consultants' decisions, and would mainly ask the young consultant privately to go over the rationale for the clinical decision, so as not to be potentially embarrassed by the older consultants. Specialist nurses only talk with regard to the clinical story of a patient that the consultants do

since the ineffectiveness of these treatments in metastatic colorectal cancer harbouring any RAS mutation has been widely demonstrated; it also would avoid drug-induced toxicity and unnecessary cost expenses. Available at: <http://oncologypro.esmo.org/EducationLibrary/Factsheets-on-Biomarkers/RAS-in-Colorectal-Cancer>.

not remember. Trial managers, also present, will only have a say about what the trials' protocol determines if the patient is on a trial (including, importantly, the inclusion/exclusion criteria of the trial). Pharmacists, on their end, would also rarely publicly challenge what the consultants have decided, even though they are trusted with the authorisation of every chemotherapy cycle. Thus, the hierarchy between members of the clinical team is an important feature to understand how epistemological values are created in the clinic.

For patients receiving adjuvant chemotherapy, age, stage of cancer, number of cycles received and medically relevant side effects are important. Once already enrolled, less time will be spent in the description of their clinical cases, and the registrar or young consultant running the meeting will just update the team about: site(s) of the cancer, number of cycles that the person has received, and whether there is any test coming up in the treatment protocol. With this information in mind, the clinical team goes to meet patients waiting for them and offers them pre-decided treatment options for their consideration. In the consultation, epistemological values are negotiated vis-à-vis toxic responses and people's preferences. As Dr Z would often say 'I will ask the patient what s/he wants'.

6.6 Drawing therapeutic thresholds

In the consultation rooms, epistemological values are negotiated vis-à-vis toxic responses and people's preferences. Together, the treating doctor, patient and sometimes a relative, draw a fine line between toxicity and quality of life, considering first 'what is the safe and sensible thing to do?', as Dr Z put it, in line with how the patient feels and what s/he wants.

This therapeutic threshold is experienced by patients at home, who, in between cycles, look at toxicity from the experience of what it takes to manage but eventually endure the treatment side effects. Ninety minutes having passed after the original time of the appointment, Elizabeth – another patient being treated with curative intent – her daughter, granddaughter and I go to sit upstairs in the follow-up clinic. We sit in a row, a bit tired of waiting. Trying to fill the time, I ask about Sandra's birthday celebration the week before. Elizabeth tells me instead about the last accident she had with her stoma in the house of Sandra's mother-in-law while they were celebrating Sandra's birthday. It was the first week after a cycle of adjuvant chemotherapy and she had had diarrhoea for the first days: her stoma bag was suddenly bursting. She managed to leave it on the sink and empty it, but by doing that, she clogged the pipeline of the sink. Trying to unclog it with a toothbrush, she took out more solid waste stuck in the pipeline Sandra's mother-in-law, in return,

thanked her for unclogging the sink. I laugh all the way through the end of the story together with Sandra. After the laugh, I become serious and ask about side effects from the last cycle of chemotherapy, one of the main empirical questions I pursued throughout the fieldwork in order to understand what chemotherapy does to people and how people cope with it. She tells me that she has been very tired, so she either stayed in bed or went to sleep to feel better. She also experienced diarrhoea for the first two days and an awful metallic taste in her mouth. She tells me that she eats because she has to do it, but everything smells and tastes very bitter for her. Having said that, she re-assures me that most of the side effects fade away in the second week, when she ‘bounces back’.

After a two-hour delay, Dr Z eventually calls her in. He looks tired after a whole afternoon of working non-stop in a busy clinic, but he remains friendly with us. After having gone through six cycles of chemotherapy, Elizabeth knows the gist of the consultation and explains to the doctor that she has had headaches, tiredness, cramps, body aches and some diarrhoea, so she stayed in bed during the first week after the last chemo cycle. Dr Z asks whether she is feeling as tired as she was before the liver surgery (carried out after the 6th cycle of chemotherapy). She thinks it is different; she is not suffering from pain in the leg any more after receiving an injection on the spine and she has already recovered from the (eventful) bowel surgery. Acknowledging her tiredness, Dr Z lays out the options for her.

- **First option:** She can decide to drop the Oxaliplatin and therefore she does not compromise the opportunity of getting all the cycles of Fluorouracil (5FU). He explains to us that Fluorouracil gives two thirds of the expected benefit, and she has already taken seven cycles of Oxaliplatin, so she has also absorbed half of its potential benefit. Dr Z reminds her that this chemotherapy ‘is just an insurance policy’.
- **Second option:** Elizabeth could also reduce the Oxaliplatin that causes the tiredness and aches another 10% to a final 60%. Further down, it is better to drop it altogether. He then goes on to warn: ‘I do not want to make you think that you should have taken all the cycles of both drugs if the cancer comes back. I am just concerned that you will need to go through three more months of tiredness’.

Elizabeth struggles to understand the scenario and asks in Spanish for an explanation. After Sandra and I explained the situation in her own language, she looks at me emotionally and says, still in Spanish, that she wants to keep going, but answers in English to the consultant: ‘You are the doctor and I trust you, I follow whatever

your decision is.’ Dr Z reflects on the trade-off: ‘From the quality of life point of view, it is not good to be tired; nevertheless, from the safety point of view, you are doing well’. He would like to see her continuing treatment, but he will drop the Oxaliplatin if she starts having tingling because that is the onset of neuropathy, long-term damage to the peripheral nerves. However, for him, it is good to know that she currently bounces back in the second week of the cycle, so now Elizabeth should just adjust to the expectation that in the first week of the cycle she will need to have a lot of rest. That will be for the next three months.

Over the course of treatment, patients like Elizabeth learnt to read the performance of their bodies in relation to the side effects that chemotherapy causes. She developed what anthropologist Thomas Csordas (1993) coined as a ‘somatic mode of attention’, which enabled her to discriminate bodily sensations that might be related to the workings of the drug from other somatic experiences stemming from, for example, the complications during surgery. Such embodied knowledge is incorporated through weekly interactions with the clinical team over the period of six months every time patients (and relatives) report side effects of chemotherapy to the doctor and to the pharmacist, who acknowledge the symptoms and not only suggest pharmacological measures to ameliorate nausea and diarrhoea, but also give room to the patient to find out what best works for them. In such interactions, there are two movements at stake. First, the symptom report creates an interpretative space in which Elizabeth’s subjective experience is portrayed. Analogous to Shapiro’s work with US American residents who have been exposed to Formaldehyde in their residences, toxic treatments could be understood in terms of the process of ‘bodily reasoning’: a concept with phenomenological purchase that shows how bodies are not only the materials that become wounded or healed by chemical potency, but they are also the instruments to measure the properties of toxic treatments creating bodily knowledge (Shapiro, 2015). Thus, on a second move, the symptoms experienced by patients are incorporated into a standardised toxicity form that the doctor fills for the pharmacist. In such translation, bodily knowledge becomes numerical. In this green form, toxicity is constructed as a matter of degrees that point to the extent to which the patient’s body is tolerating the chemotherapy during cycles, from 0 (no effect) to 5 (death because of effect). A simplified form is also provided to patients in their chemotherapy notebooks for their own guidance at home.

As seen in Figure 6.2, degrees of toxicity are presented in the notebook form of a traffic light tool with the aim of setting the expectations regarding what is normal to occur (green light) in opposition to what requires seeking urgent medical care (red light). It is a material used to inform patients about the extent to which bodily damage is acceptable for the sake of therapy – the extent to which chemotherapy

Abnormal temperature Is your temperature above 37.5°C or below 36°C?	Normal temperature and feeling well	Low or high temperature	
Generally unwell Are you feeling generally unwell? For example flu-like symptoms, shivers, chills? (even if you have a normal temperature)	Feeling generally well	Generally unwell	
Chest pain Chest pain of any type must be treated as an emergency!	No chest pain and feeling well	Chest pain Seek urgent advice telephone 999	
Infection Do you have a sore throat, a cough or shortness of breath, discomfort or burning when you pass urine, diarrhoea, a rash, bruising or bleeding for no apparent reason? Do you have a high or low temperature? Do you feel generally unwell? Has there been any shivering, chills or shaking episodes?	Generally well, but worried about the possibility of an infection	Generally unwell with some sign of infection	
Numbness/pins and needles, weakness in limbs When did the problem start? Is it continuous? Is it getting worse? Is it affecting activity/function? Any constipation or urinary incontinence?	Mild numbness, pins and needles occasionally. No loss of function. No weakness	Mild or moderate numbness pins and needles often or for long periods. Mild weakness with no loss of function	Severe numbness or weakness that interferes with normal movement or functions
Activity levels/tiredness Has there been a recent change in activity or energy levels?	Shows symptoms of treatment but does not need to spend time in bed during the day	Spends some time in bed during the day, but less than 50%	Bed Bound or Severe loss of ability to perform some activities
Bleeding or Bruising You should be concerned if this is a new problem or an old problem getting worse. Is the bleeding easily controlled? Has there been an injury?	None or slight bleeding or bruising following injury	Bleeding easily controlled- small amount. Bruising or a reddish or purplish rash in one small area.	Uncontrollable bleeding- telephone 999. Reddish or purplish rash or bruising increasing in size or in more than one area
Diarrhoea You need to measure any increase in your normal bowel movements (before you started treatment). Do you have any abdominal pain or discomfort?	Only one extra episode in the last 24 hours	Between 2 to 6 extra episodes in the last 24 hours.	Increase to 7 or more episodes a day or incontinence with or without abdominal pain or bloody diarrhoea

Figure 6.2 Side-effects 'traffic light'

still holds therapeutic value. However, the ideal situation that patients and clinicians seek is to give the full course of chemotherapy, so most of the appointments with doctors and pharmacists are around negotiating the right prescription of medications to mitigate the effects of chemotherapy and therefore support patients in attaining more quality time at home. As Elizabeth's case demonstrates, that the distinction between toxicity and quality of life is basically determined by the clinical judgement of safety, but only when personal preferences remain constant. Dr Z explained this to me during an interview in terms of safety and morbidity:

- **Dr Z:** Of course there are other toxicities, diarrhoea, sore mouth, fatigue, low blood count, but then I think neuropathy is the main thing I am worried about because it is much more morbid. 5FU diarrhoea, 5FU low blood counts, they would resolve when you stop chemo. Neuropathy goes on and on. [He continues...] Six months of adjuvant chemotherapy is not too much [for a person], but in terms of side effects clearly
- **Ignacia:** You over-treat them.
- **Dr Z:** We already say we are over-treating you because 75% or 70% of the time you are already cured. But once you have signed up for that, I will give you six months of chemotherapy and once you hit the halfway mark, I do say: 'you have done extremely well to get to the halfway [mark] and every cycle now is, you just tell me when it gets too much'. Particularly with neuropathy, the conversation changes. I say: 'Look, if you start having prolonged neuropathy we will start the dose reduction or we will stop it completely'. And then, there is a tipping point when the clinician has to step in and say, because there are people who just say 'I want 12 cycles, I am fine, I am fine, I am fine'. I say 'no, you are not fine, because you are telling me this, you have been honest with me'. And then I go through that scenario, it is all about going back to the beginning and say, 'look, what we have been trying to achieve is a 10% reduction' and then you go really into the figures and you say: 'You have already gone half way through, if you can just finish the 5FU – which I am trying to advocate for most patients – two thirds of the benefit on that, one third is on Oxali'. Then you can really go into the figures and say, 'look, we have already said there is only 4% benefit for Oxali and you had three quarters of it, so the extra 1% of benefit means that really? That means that by finishing this off, you might improve by 1% or you will get life-long neuropathy?' [...] Usually, at that point, the patient agrees. But then you have heard me saying 'I don't think that is a problem because I discharge you, but my CNS nurses tell me

that there a number of patients with terrible neuropathy six months or a year later, and that is not what we want'. So that is the balance.

As the consultant's words attest, patient morbidity is understood as an effect of the cumulative effects of chemotherapy. This is the reason to be mindful about the number of cycles that any patient going through adjuvant chemotherapy receives, so that the potential benefit of the drug is not offset by its consequences. Temporalising adjuvant treatment as a rhythm punctuated by fortnightly cycles is then not only a social form that expresses the power of treatment to control daily life affairs when patients commit to that, but it is also a form of disciplining the body in what the anthropologist Nancy Munn understands as 'body-time'. Body-time is particularly relevant in relation to the assessment of the cumulative effects of toxicity, and the ways in which the clinical team tackles the risks and side effects triggered by the potency of the drug. Chemotherapy cycles become reference points for the duration of the agency of the drug on the body, and of the expected time in which the body 'bounces back'. At the same time, cycles act as forms of orientation to decide the future clinical management of the patient undergoing chemotherapy, as Elizabeth's routine exemplifies. Therefore, talking and measuring treatment in terms of 'cycles' could be understood as a form of time-reckoning through which clinicians and patients articulate 'reference points as part of a project that engages the past and the future in the present' (Munn, 1992, p. 104). Using cycles as a time-reckoning technique is articulated in relation to the knowledge that clinicians have about the particular dynamics of cancer in specific bodies (whether it has been resected or is slow growing or is advancing rapidly), the way in which patients are currently experiencing chemotherapy, and the professionals' clinical judgement based on what they have seen in other patients. Neuropathy is an icon of the last case, as shown in reference to the CNS nurses' comments about patients still in pain months after treatment. However, as is apparent, what for the consultant is chemotherapy's *duration* is *endurance* for the patient.

6.7 Enduring treatment

Chemotherapy was received by the whole sample of my research participants, even if they had different intents (not always curative). And on top of diarrhoea, fatigue was something that patients had to endure, adjusting personal and colleagues' expectations of how productive they can be at work. It was experienced physically, in terms of stamina, but also mentally in terms of what researchers call *chemotherapy brain fog*, a mild and non-permanent cognitive impairment that affects short-term

memory, that makes concentration essentially difficult by turning thoughts ‘foggy’. Jean explained to me the relationship between chemotherapy-induced fatigue and low moods. She said:

Jean: I find it difficult to keep a steady pace at work. I can’t work the whole day because I get exhausted and cannot go in the next day. My focus is improving, but it is not the same as before. The problem of being constantly tired is that I stay in bed, and then in bed, I cannot separate what is depression from fatigue and do not find purpose to get up.

For many of my research participants, receiving chemotherapy for 6 months sat at odds with their financial circumstances, which is the reason why some kept working full-time. Not because they just wanted to get on with life, but because cancer treatments did not happen to them in between brackets. Instead, chemotherapy had to be absorbed in everyday routines. Holidays run out and sick leave is not always possible, especially considering cases such as Leia’s, someone who spent all her statutory paid sick days trying to find a reason for her symptoms and pain, which eventually were put together under a diagnosis of locally advanced cancer. So when chemotherapy treatment was offered after surgery, she took it, but she couldn’t spare more days without working. She had financial commitments to honour, and not being eligible for economic aid, struggled with neuropathy and fatigue at work. Eventually, these side effects made her and her consultant jointly decide to stop treatment after 8 instead of 12 cycles of chemotherapy.

With most of the oncologists being aware of this context, while the cancer remained absent from patients’ bodies, the balance between toxicity in relation to quality of life become pivotal for the clinical relationship. How well is the patient tolerating the treatment? How far have we got in the treatment protocol? The balance is not always easy, especially because the clinical team is aware of the frustration that reducing dose triggers for many patients. Patients often experience disconcert. This was Britta’s case, a 75-year-old British woman who just wanted to finish 12 cycles of chemotherapy non-stop as any other patient. However, Dr Y gave her a week off so that her bone marrow could catch up in terms of producing more neutrophils when her blood tests showed that she was neutropenic. Moreover, as was discussed in Elizabeth’s case (and also happened to Jean), clinicians also may reduce the dose of chemotherapy so as to avoid causing more harm than benefit when fatigue and diarrhoea do not allow patients to get out of bed (the reduction occurs in a range that varies between 10% and 40% of the dose, for a dose lower than 60% does not make sense any more in terms of its cost-effectiveness). Oxaliplatin is the first drug to be dropped from the regime in case of neuropathy. However, sometimes,

the only option is stopping the chemotherapy altogether. Such cases happen either because of an absolute breach on the safety threshold (chemotherapy almost killed the patient) or because of patients' preferences, which the clinic calls 'chemo breaks' and arise out of multiple personal circumstances, such as holidays and important dates but also bereavement and relevant work commitments.

Following Munn (1986), it is possible to understand toxicity as a negative value that must be managed by patients and clinicians, for it not only undermines the effort to obtain the drug's dubious efficacy, but also might jeopardise patients' quality of life. As the specialist nurse explained to Jean when she experienced a drug reduction she also did not want to have: 'We want to treat you, but we don't want you to be incapacitated for life'. So even if chemoprevention side effects are approached by clinicians as 'rigours of treatment [that are] the sacrificial bargain through which one earns back life', as Steinberg (2015, p. 133) put it, the same clinicians are open to negotiating whether and how to finish treatment considering patients' quality of life and what they consider worth doing in terms of treatment.

6.8 Discussion: Ethical values

This chapter has elaborated an ethnographic account of chemoprevention articulated as a regime of anticipation that is organised by the negotiation of incommensurable values. Patients negotiate the trade-off between those values, adjusting to the difficulties of anatomically different bodies at the same time that they manage the side effects of toxic treatments on a day-to-day basis. And the efficacy of treatment remains uncertain. Narrativising such experiences might help to un-silence the suffering felt by 'cancer survivors' and to understand the vicissitudes of the subject that continues feeling pain, disruption and uncertainty in a chronic manner (Manderson and Smith-Morris, 2010). Following Povinelli (2011), I have tried to describe an experience of endurance that is marked by the continuous (self) management of bodily, emotional and social aspects in which the self tries to go beyond the spatial-temporal configuration of the here and now by subjecting itself to chemoprevention as a regime of anticipation. Such an endeavour requires understanding cancer not as an acute condition, but as a disease that might uncannily continue to be present in one's bodies well after it is not possible to visualise it.

Having said that, I would like to underscore that this chapter has not aimed in any sense to undermine the use of adjuvant chemotherapy. How to go through treatment hurdles is what patients and clinicians discern on an ongoing basis, as enduring toxicity is considered more desirable than allowing time to pass without tackling the increased risks of cancer recurrence that could eventually kill the patient.

Going back to the initial discussion, I ask: Is adhering to chemoprevention just the epitome of the prudential patient, the figure mobilised by medical discourse? I would not say so. The possibility of enjoying loving relationships with partners, children and grandchildren while being cancer-free stems from the desire driving my research participants to commit to chemoprevention. Even if constrained in their choices, their will to live is the will to live with loving others (see also Hallowell, 1999). This means that the moralisation of the obligation to prevent risk tacitly suggested by clinicians when offering treatments is only one part of the answer of what motivates patients to undergo chemoprevention. The second part is relational and explicit. Enjoyable relationality, that is, the desire to be there for others and look after them.

This second answer constitutes a kind of ‘ethical value’ (Lambek, 2013) that patients put at the forefront when discerning whether to give consent to go through adjuvant chemotherapy. In ‘The value of performative acts’, anthropologist Michael Lambek (2013) discusses and contrasts ethical to economic values and its modes of objectification and circulation. Making use of the dual nature of the concept, in which value stands for both the material and ideational objectification of two different modes of creation (production and action), Lambek defines the ethical value of acts as means and end in themselves, so that value is co-constituted by meaning and actions, producing incommensurable qualities. As non-exchangeable outcomes generated by performative acts, ethical values are not subjected to choice or calculative reasoning; rather, they are discerned through situational judgement. I find Lambek’s understanding of ethical value useful to explore the production and efficacy of subjecting oneself to chemoprevention, for it might be that undergoing such treatment is not so much about the belief of the drug’s agency to prevent cancer recurrence, but more about demonstrating to oneself and others that, at the very least, one is doing something about the risk, one is managing it for one’s personal survival and to honour the affection one feels for others. Elizabeth did it for her children and her grandchild. Leia did it for her daughters still at university who she did not want to leave alone. Jean did it for the project she envisioned for herself together with her husband. In this line, committing oneself to adjuvant chemotherapy in order to prevent cancer recurrence is a collaborative form of world-making, as enduring the side effects in anticipation of possible unfavourable futures in the form of risk management enables my research participants to work for the relationships they consider essential.

When it comes to clinical professionals, I find it more difficult to talk about ethical values. In a way, their work is regulated by toxicity protocols and clinical guidelines that they must follow. However, I have tried to show that drawing the distinction between survival and survivorship, between life expectancy and quality of

life, presents grey areas that still require an exercise of situational judgement on the part of the medical oncologist. What is important for the patient? How advanced is the cancer? How is the patient coping? How much support does s/he have to deal with the side effects? Would s/he be able to continue working if s/he wants/needs to do it? Hence, within the distinction between ‘the logic of care’ and ‘the logic of choice’ that Annemarie Mol (2008) proposes for the management of diabetes in a Dutch clinic, I would like to suggest that medical oncologists not only aim to share the responsibility of care with the patient by informing them about the risks and benefits so that they can make an informed decision. As Kirsten Bell (2017) lucidly explains, patient choice is a heavily loaded concept developed by bioethics discipline to protect the ‘autonomy’ of the patient, but has been widely criticised as shorthand for assuming that there is a rational person in front of the doctor who is able to understand the scenarios and autonomously make an informed decision. The medical consultants I had the opportunity to learn from carried the responsibility of promoting ‘patient choice’ based on the evidence they amassed while knowing that patients are never fully informed and that patients still seek advice from them.

Oncologists consciously deliberate on ‘what is the safe and sensible thing to do’ by approaching epistemological values hand in hand with the discussion of how patients would fit the chemotherapy regime in their day-to-day life. In this way, when medical oncologists consider chemoprevention options, their rationale includes evidence-based medicine, as well as patients’ obligations and desires. In my view, this brings them closer to the ‘logic of care’ (marked by ongoing adjustments and wider appraisals that bring the patient’s context into the clinic) rather than the ‘logic of choice’ (where the patient is assumed to be a rational actor able to decide for him/herself and therefore the only person responsible for their choice and clinical outcomes). For the medical oncologists I met, thinking in terms of ‘the safe and sensible thing to do’ in scenarios of cancer recurrence stands as one of the markers of what they understand as ‘professionalism’. As an umbrella concept that hints at, at least, one aspect of the moral landscape through which they understand their role, professionalism incorporates compliance with guidelines, practices such as the ritual use of medical education leaflets and forms requiring the informed consent of the patient, as well as the situational judgement exercised in every patient’s case. In the first part of the next chapter, I will discuss a different aspect of professionalism, understood as an ideal moral character, in the context of dealing with the emotional burden of cancer. I will unpack the way in which health professionals cultivate emotional detachment in order to make a comparison with the ways in which informal caregivers negotiate the frustration discharged by cancer treatments.

Chapter 7

Emotion work in cancer care: Silence as a practice of world-making

7.1 Negotiating atmospheres: Committing to the suffering other

Frustration is one of the most common affective experiences that patients and their support networks embody throughout cancer treatment. As stated in previous chapters, the ways in which toxic treatment risks jeopardising patients' quality of life are sources of frustration, as well as the process of learning how to live with a body with stoma. There is a real paradox between the desire to embody cancer treatments and the iatrogenic consequences they may trigger. Anti-cancer treatments may (and do) make people temporarily unable to carry on with their everyday lives; nevertheless, the patients I met committed to treatment, hoping that they will eventually become cancer-free. However, things get increasingly worse when the clinical scenario is no longer curative. In those situations, frustration stems from the failure to control cancer growth. It emerges in the form of disappointment when patients get denied treatments that are clinically approved, supported by the clinicians, but not widely available. Robert, a man in his 70s, complains when a targeted treatment is not made available for him through the Cancer Drug Fund (CDF). Robert asks who the people behind these decisions are, and Dr W explains that 'those are clinical professionals from a committee'. Robert says angrily, staring at the floor, 'faceless bureaucracy' and looking up, sighs and continues: 'Ok, life is life. Here is where we are now.' Dr W, understanding the frustration, tries to offer

support, saying ‘but it is good that you came to clinic, so we could check the pain that you have been feeling around the liver, book a scan to see if it is because of the cancer progression, and sort the right dose of painkillers delivered by the pump’ that Robert got implanted under the skin to manage the cancer-induced increasing pain.

Sudden twists in the treatment plot, created by the abrupt change from ‘a pathway with curative intent’ to a ‘palliative pathway’, generate an important clash in terms of expectations of health recovery. This triggers obvious feelings of unsettlement, as it happened, for example, to a male patient in his 50s who came to the clinic thinking that all the tumours had been resected during surgery. But he was breathless. Dr Y, checking the blood test results of the patient on the computer screen, realised that some cancer markers were very high. His shortness of breath turned out to be a symptom of cancer recurrence. The patient sighed heavily, like he was trying to collect his thoughts and put them into words. He just looked at the wall. He had thought everything was clear-cut in the last clinical intervention some weeks ago. The doctor quickly booked the scan in the online system and invited him to follow him to check his pulmonary function.

Frustration also shapes the atmosphere in the inpatient ward where patients struggle to recover from surgery or to continue receiving treatment. I joined four medical students who were shadowing the consultant and the registrar in several cancer rounds. Dr V, a female consultant that I used to meet in the MDT meetings, and the GI registrar were caring and considerate with patients and their relatives. Nevertheless, the rounds were tough. A young male patient from an African background was pushing for more treatment options, but there was only pain management left to do. He was a thin man with bone metastasis who had a lot of pain in his leg, pain that hadn’t been well managed from his point of view. He wanted more chemotherapy but he wasn’t fit for that, or another surgery that he couldn’t have because the primary tumour in the rectum was inoperable and the bone metastasis was also impossible to resect. So he asked about getting more radiotherapy, but he already had that before and ‘you can’t get it twice in the same area’, Dr V explained. Running out of options and getting a bit exasperated, he opened his eyes widely and enquired about steroids to alleviate the pain, but that would prevent the surgical site from healing, a process that takes two or more weeks. The registrar and Dr V decided that the patient was to be helped to control the pain better and then sent home. The patient remained silent, as did the woman with a long headscarf covering her hair and eating mangoes at his side.

I have purposely used the term ‘frustration’ in a broad sense, as an intensity that is generated at the interaction between people, objects, cancer as patho-physiological growth and place. In that sense, I understand frustration as shaping an affective

atmosphere that is not only socially and culturally manipulated, but also worked upon. Initially coined by geographers (Anderson, 2009), the concept of affective atmosphere is a useful analytical tool through which it is possible to analyse the existential experience of in-betweenness (Bille et al., 2015) articulated by places, subjects and objects dynamically affecting the people who inhabit the space when confronting the temporal proximity of death. Atmospheres provide not only an orientation for behaviour when ‘feeling the air’ (Daniels, 2015), guiding health professionals in what to say to comfort patients, but they also shape space and time (Rutherford, 2016). Atmospheres are not an objective reality out there, neither are they a purely a subjective feeling; they are better understood as multi-modal intensities discharged by the interactions taking place and unevenly affecting people’s sensorial and bodily experience. Socially and culturally constructed in the spaces of biomedicine, understanding frustration as an atmosphere may help us to unpack the potential of caregiving practices in their ability to momentarily stage an experience of emotional containment in relation to our ideas of how the situation is and how the situation should be. Here frustration becomes an ethical substance to be managed. Staged atmospheres (the product of the manufacture of the situation) are therefore the product of situated dynamics guided by moral values.

In this chapter, I would like to further such lines of enquiry and look at the ethical and spatial management of affective intensities in cancer care. Following the lead of my research participants’ and my own embodied experience as a research fellow in the GI cancer clinic, I discuss the dynamics of the cancer clinic as what I came to feel was an arena in which two atmospheres were contested. On the one hand, the clinic was felt as an atmosphere suffused by frustration. In other words, the experience of going to the clinic felt haunted by the deadliness of cancer and the collateral damage that biomedical weaponry uses to annihilate the patho-physiological growth, by the struggles already lived, by patients who passed away despite all therapeutic efforts. On the other hand, health professionals and support networks routinely sought to contain the frustration felt by patients and themselves. Hence, I would like to argue that frustration in my field site was both the atmosphere engulfing the emotional impact of cancer and an ethical substance through which the world-making potential of caregiving happened.

Following Michael Foucault (1990) in his famous historical analysis of sexual pleasure as a domain that required self-reflection and self-regulation in classic Greek thought, I would like to contend that frustration was for health professionals and support networks (relatives and friends) an affective intensity felt as requiring ethical work. The cultivation of a personal character that allows and recognises the frustration triggered by cancer but, at the same time, contains its expression

and impact for the benefit of the patient is what I understand here as emotion work. Crucially, I argue that emotion work in cancer care, at least among my research participants, takes the shape of silence, which I analyse as the practice of world-making: an ethical project through which comfortable environments are staged for the sick. Considering emotion work as an interactional dynamic through which a specific atmosphere of containment or harmony is articulated to care for the relationship with the suffering other, I argue that silence is an active practice that enables professional and informal caregivers to dwell in a moral experience that is suffused by frustration.

In the next sections, I will show that, unlike healthcare professionals who have learnt to deal with this atmosphere by ‘switching off’ after work – a practice of detachment that they consider a sign of professional character – support networks (close friends and relatives) negotiate a complex tension around the repression of their own frustration and tiredness, and the expression of compassion for the benefit of the patient. Moreover, unlike healthcare professionals who perform a delimited and recognisable therapeutic role, close relatives and friends supporting cancer patients feel that they are not protagonists of the story, which blurs any clear delimitation of safe spaces in which they could openly talk about their emotions without experiencing guilt. Therefore, I show how the practice of silence that structures emotion work for caregivers does not occur without challenges. In the next section, I discuss the cultivation of emotional detachment as a feature of a professional character.

7.2 ‘Switching off’ and the construction of professionalism in the clinic

It is Wednesday, a weekly clinic day for the gastro-intestinal (GI) cancer clinic. Consultants, registrars but above all nurses would be always ready to step in and manage the affect that surrounds cancer treatments. While showing empathy, consultants and registrars would mainly offer pragmatic solutions to alleviate symptoms or diminish the distress by explaining again confusing developments of the medical condition. A great deal of emotional support also takes place in the non-space between the lifts, the corridor, the bookshelves with patients’ files, and the reception desk: specialist and support nurses don’t have a room to talk with patients if it is not in a follow-up clinic, so patients meet them in the reception of the first floor while waiting for appointments. They carry out the type of work that Day (2015) understands as ‘informal forms of care embedded in waiting’ (p. 176), which her research participants praise as responsive acts of kindness by the clinical team. With

support nurses squatting in front of patients and their relatives to be able to talk at the same level, and specialist nurses bringing yellow prescription forms authorised by the consultant to palliatively help them with the side effects of treatment, patients' distress is met by attentive and responsive ears that listen to their worries. Specialist and support nurses offer an intimate space that works as a platform for patients and caregivers to debrief their bitter emotions. Similar to the work presented by Livingston (2012) about the moral intimacies of care in the only public cancer clinic of Botswana, the nurses I met do not try to manage those emotions; they simply and powerfully acknowledge them. Cancer – as something that not only happens within the body, but also between people – is painful and devastating. When I asked a nurse how she deals with patients' frustrations during treatment, she told me:

CNS B: We just try to open it up and give them an opportunity to talk about it. It is often letting them be cross, or to be angry, or to be frustrated, because all are logical and normal emotions to have during cancer treatments.

Wondering about how the clinical team would cope with such affective atmosphere in the clinic, I set out to ask every member what their personal strategies were to deal with this. Most of the consultants would answer that such frustration only occasionally gets to them. As Dr Y told me: 'I don't have sleepless nights after working in the clinic. I just switch off'. For him, passion for the basic research in the wet lab of molecular biology they are involved in, combined with the reassurance that patients have plenty of sources of support outside the clinic, prevents him from feeling an emotional burden. Dr Z echoed Dr Y's answer:

Dr Z: If I have to get heavily involved in all emotional aspects of the care of a patient, I can't take it. My mom is a psychiatrist and she is the happiest person on earth outside the clinic, because she doesn't take work home with her. I constantly try to do that.

'Not taking work to home' or 'switching off after work' are strategies through which two consultants in medical oncology coped with the emotional demands of their work. Compared to the type of answers that I collected from consultants who had years of experience in the field, nurses and medical registrars would say to me that the emotional burden of cancer was felt and it is real. To become an oncologist, students must toughen up or leave. As a clinical fellow told me, recounting his experience of working with cancer patients:

Research fellow: I basically got used to it; at the beginning, it was a bit more difficult. Coping can be difficult. There are some medical students who change the discipline to a happier one after three years because of this.

Specialist nurses used to debrief in supervision meetings and with significant others outside the clinic. Staff nurses advocated for patients' well-being at the same time as they tried to achieve an emotional balance that could enable them to continue embodying other roles as mothers, fathers or partners at home. Chemotherapy nurses rotate the patients they intervene, and usually decide not to go to their funerals to prevent creating affective attachments. Despite the variety of mechanisms clinical staff adopt to deal with the suffering cancer poses to patients, they would all agree that they 'have to keep the boundary'. CNS B explained to me: 'It would be horrible if I am upset in front of patients when they are upset'.

As Byron Good (1993) explains at length, healthcare professionals are trained to see the physiological features of the disease and work over them, rather than getting immersed in people's biographical emotional experiences. They need to be able to make a clinical case out of a complex life. In a similar vein, at the GI clinic, health professionals prefer to obtain some distance between them and their patients as their own way of coping with the suffering they see. They articulate this as a matter of being professional, which involves the cultivation of character that includes the fine-tuning of emotional expression. The interview with Registrar C is illuminating in this point, which I here quote at length.

- **Ignacia:** What does it mean to be professional in your job?
- **Registrar C:** You respect your colleagues and your patients, and you have appropriate mannerisms and conversations.
- **Ignacia:** What is appropriate?
- **Registrar C:** I suppose people talk about appropriate boundaries.
- **Ignacia:** What kind of boundaries?
- **Registrar C:** I suppose in the language you use.
- **Ignacia:** So you don't swear?
- **Registrar C:** Exactly, and in terms of physical contact, especially when you are comforting somebody and obviously that sometimes changes according to the patients but you have to always, you know, but you have to always

respect that they are a patient and not your best friend and make sure you communicate and approach them in that way.

- **Ignacia:** This is interesting, I am asking this question precisely because some nurses have told me that being professional means not getting upset in front of the patient. Do you think that emotional management is also part of being professional?
- **Registrar C:** I think it is not inappropriate to show emotions because you know it is an emotional time, and sometimes patients or patients' relatives in a way sometimes appreciate that because they appreciate the fact that you have connected and that they are not just another person especially when things are not going so well. [However] you have to be able to say something, you can't just literally fall apart, but I think showing emotion is ok, I don't think [it] is bad. But if you are in a heap with every patient, that makes you question whether you are in the right profession.

As registrar C's words show, there is a tacit responsibility to not get upset with every piece of bad news, as the clinical team need to be there for the patients to be treated and for the ones who come after. They understand that patients' hope for a cure or a good prognosis depends on them as medical experts, so they need to remain professional when facing the disappointment of an ineffective treatment. Professional competence here is premised on the idea that the clinical team not only has the skills to treat a life-threatening disease such as cancer, but it is also not afraid of death. Understanding how members of the clinical team master those skills requires that we understand the process of medical training and the ways in which it shapes students' relationships to the disease and to the discipline itself (Good, 1993).

When I started fieldwork, my line manager suggested that I read a memoir about an anthropologist undergoing medical training in the US, partly – it seemed – to help me understand the dynamics of the hospital. Effectively introducing me to a specific form of autobiographical storytelling that has now become commonplace to narrate the cultivation of character in the hospital world (see also Kalanithi, 2016; Kay, 2017), Konner (1988) describes that an important challenge for the doctor is to hold in personal emotions and continue working regardless of the contingencies of life. Without this switch, the author suggests, it is impossible to navigate a long line-up of patients seeking care during the day. Konner presents how (male) medical students carefully cultivate skill and character during the medical training, which is equivalent to other sociological studies about the medical profession in the US (Becker et al., 1961) and not too different from the description of the training that

transplant surgeons undergo in the UK (McDonald, 2015). In all those references, the key ability that clinical professionals develop is the one of affective detachment. Anthropologist Maryon McDonald (2015) argues that, in order to retrieve an organ from a dead body to give life to someone else, transplant surgeons cultivate a 'switch' that enables them to change from an understanding of the person lying on the table as a 'social body' (defined by an identity embedded within social networks of obligation and care) to one characterised as an operable body 'composed of spare parts' (p. 35). In order to achieve that, medical students follow a tightly supervised programme of teaching and laboratories where the student learns to see and feel body landmarks only visible to the trained eye. Akin to the social science studies of medical professionalisation, the medical students I met in the clinic were enrolled in teaching programmes through which clinical skills and scientific knowledge are pedagogically paced and combined.

Still, I would like to stress that, contrary to the idea that it is necessary to 'toughen up' in order to work in oncology, an idea of emotional callousness that seems to be hinted by consultants and the clinical fellow when they mention that frustration no longer affects them, the voices of the registrar and the nursing team show that the emotional impact of cancer also reaches them and requires management. Moreover, after a closer look, it is possible to say that frustration was momentarily visible in clinical meetings. I heard chemotherapy consultants sighing when the radiologist read scans showing aggressive progressions in long-term cancer patients. I also witnessed senior consultants explaining to one another how hard it was to break bad news. In one pre-clinic meeting, they were discussing the case of a young woman with bowel cancer, liver and bone metastasis. She was spending all her savings in buying a monoclonal drug no longer available through the CDF to do what looked like buying time to me. With her husband and toddler, she came from another city every two weeks to receive treatment. The couple wanted to remain hopeful that such drug would make the surgeons able to do a resection of her cancerous liver. But the medical oncologists knew that it would not happen. Dr Z tells Dr W : 'You should tell them the truth'. Dr W has already done it, but he recognised that 'it is difficult to look at her in the eyes, a very young girl, and say no'. The patient was asking for a second opinion about her liver to see whether it was amenable to surgery, privately, so Dr W was asking for references to his colleagues. As Dr W put it, they needed to refer her to 'someone who is trustworthy' – otherwise what would happen was the same thing that happened with another patient, who ended up visiting an oncologist who promised everything without any foundation in the evidence. Dr W was afraid that '[the patient] will spend the rest of her savings on something it is not worthwhile'. These examples demonstrate that the switch that

consultants talk about only occurs in front of patients, but it does not prevent them from feeling and voicing patients' despair when they are not in front of them.

So far, I have tried to describe how frustration takes the shape of an affective atmosphere enveloping cancer care in the clinic. It is present in cancer treatments, working on different levels at the interaction between cancer tumours that keep growing, patients who want to be cured and clinical professionals offering their skills and expertise to sensibly intervene. Recognising the disappointment, and sometimes also feeling it, clinical professionals strive to act pragmatically either to try and alleviate the causes that trigger the problem (re-explaining information and envisioning different clinical scenarios) or offering the opportunity to talk about it more openly so that patients' emotions are expressed rather than repressed. I have also shown that professional responses towards the suffering of patients vary, as if the atmosphere of frustration seeps into some people more than others, which seems to be related to different role expectations and tenure in the clinical setting. However, a common understanding in the clinical engagement with frustration is conceived in terms of a professional boundary through which members of the clinical team make sense of their work. Some of their answers thus point to space-temporal delimitations of zones of affection, which would be reinforced by emotional detachment as an expression of their professional value. They will not only endeavour to find a balance that enables them to continue their everyday lives outside the clinic, but they also choose to avoid an overly emotional expression of frustration in front of patients.

7.3 Being there: A constant wave of emotions

A large volume of anthropological literature on caregiving is predicated upon the idea of presence – that looking after others is expressed in the commitment of being alongside the suffering other (see for example: Danely, 2015; Garcia, 2010; Han, 2012; Kleinman, 2010; Livingston, 2012). Nevertheless, I would like to stress that such a presence, in my fieldwork, is felt as needing to be silent. For informal caregivers, this is the figure of the selfless subject who provides compassionate care without limits for the benefit of the other, witnessing the other's suffering and swallowing their own emotional storm. Even though informal caregivers are aware they could talk (and they do) with healthcare professionals who empathetically listen to patients' and relatives' expressions of distress when and if they occur in the clinic, in my fieldwork, it struck me how the normativity of care hinders the possibility for an open engagement in which emotions can be expressed, either because it breaks professionals' understandings of their role or because overwhelmed caregivers may cause an undue burden to the patient. Professional and informal caregivers would

seek not to mirror patients' feelings openly to the one who is moreover suffering physiologically. Ethnographically, the affective atmosphere that cancer as a life-threatening medical condition that requires harsh and sometimes invasive procedures to control is felt by everybody around and must be contained by informal and professional caregivers alike: doctors and nurses don't get upset before patients when they break bad news or give disappointing test results, whereas relatives and friends must get on with the treatment and stop complaining about it, for they are not the patient. Not getting upset in front of patients as a sign of professionalism or containing the carers' struggle within oneself is what I consider in this chapter as silence.

Emotion work at one level aims to contain expressions of frustration within oneself so that its intensity does not reach patients. The expression of frustration and its associated feelings is controlled in order not to harm the already vulnerable cancer patient who is already struggling to navigate the consequences of surgery and chemotherapy on their own. Frustration is then managed spatially, at least partially. In the clinic, the affective atmosphere is confined to the clinical spaces by health professionals, at least for themselves, inside the hospital. At home, nevertheless, the frustration stemming from cancer treatments keeps fogging the space between patients and caregivers. The affect leaks from the hospital and pollutes everyday interactions between patients and informal caregivers even after treatment. So, whereas health professionals will do emotion work with patients in the clinic as part of the professionalism necessary to perform in the field, informal caregivers will need to roll with the charged atmosphere without a safe space in which they could express their burden. For once, there is no backstage to dive into when seeking a respite, or at least not one in which relatives can openly verbalise the toll cancer takes in their own lives.

I remember one of the first times I met Daisy, Jimmy's wife, in the chemotherapy room. I asked her how her weekend was. She was looking for a magazine among the ones that patients bring and are piled up around a white plant bedding at the centre of the room. Between magazines portraying news from a terror attack and *The Housekeeper*, she quickly took the latter. She answered my question as if she had already internalised the patient narrative as the main narrative to be told. 'The weekend was very good indeed because Jimmy was able to do things, so we met [our] four grandchildren and two sons'. She kept telling me about Jimmy's experience of treatment, how difficult it was to get him to do things during chemo, reasons why the children suggested that he could keep his mind busy planning improvements for their new house to which they just moved some weeks before Jimmy got diagnosed: first, a greenhouse that is already built but needs the final touches, then the kitchen

and bathroom that also need some fixing. She thought that keeping him planning was a good idea... But I wanted to know about her. I stopped her and asked: ‘how do *you* feel?’ She got a bit surprised with the question and answered:

Daisy: Oh! My family has helped me a lot: both daughters-in-law took me for lunch during Jimmy’s surgery, and both sons made sure that I did not feel alone while Jimmy was on the ward, so they left a mobile phone next to my bed and told me to call them if I was not feeling well. But I did not call, I did not want to bother them.

Standing in the middle of the chemo room, with the magazine in her hands and tenderly looking at Jimmy who was sitting some steps further away, she started opening up slowly:

Daisy: It has been very difficult and tiring, I cannot have my own life and keep going because everything I want to do clashes with Jimmy’s appointments. I simply gave up with them. During chemo, he is not only tired and with fatigue, he gets very grumpy and sensitive to things and I am the one that receives all that. Sometimes I’m exhausted, but you just need to keep going. I feel guilty of going to [the] hairdresser and annoyed at Jimmy who just had a tantrum while I was running an errand in the bank.

For Daisy, that was a natural end. Perhaps feeling a bit uncomfortable with the conversation, she suggested I go and talk with Jimmy. She sat down around the table, some steps away from us, and started reading the magazine. As Daisy’s words show, cancer treatment is a continuous struggle that carers have to get on with. Patients’ close relatives like Daisy get immersed in the constant waves of emotion, but the impact of those emotions is swallowed rather than expressed. The struggle is silenced. As Daisy later told me, the only way to deal with her husband’s moody temperament caused by the chemotherapy treatment was ‘with difficulty’. She had to deal with his grumpiness and tantrums. Such expressions are something new and mainly unintentional, so Daisy understood that she had to forget those and keep going until treatment is over.

Those difficulties are explicitly acknowledged by Jimmy, Daisy’s husband, the person receiving treatment. Two months had passed since I met Jimmy and Daisy and I had been waiting with them in the reception area of the clinic for more than an hour while doctors came in and out calling patients. Feeling tired, Daisy decided to go and sit down. I stayed with Jimmy, standing at the rear of the room. Because

he felt that I should always be asking questions rather than just hanging out with him, I asked him what was the most challenging thing during treatment, considering that he was about to finish adjuvant chemotherapy in the next cycle. He remarked:

Jimmy: [The most difficult thing] is to see the end, to keep the spirit up. Everybody tells you that you are doing well but there are still nine or six more cycles to go and chemotherapy gets me depressive. I get sensitive about things like driving and very impatient with children and issues about food. I feel miserable many times. The problem is that sometimes I feel constantly miserable during the treatment, which also affects my relationship with Daisy and affects her. I also wake up at night; appointments in the hospital make me very anxious so I cannot sleep. [I keep wondering] what they will say, what will happen.

When addressing this concern with Dr U in the last chemotherapy appointment, Daisy asked about whether Jimmy's temperament will improve since treatment has finished, 'because sometimes [it] is really bad'. Dr Y listened to what they are saying attentively. CNS A, who was there with us, empathetically nodded at Daisy as if to say she knew what she meant. Dr U said: 'now that the pressure of the cancer is off, Jimmy should feel better'. So Daisy, with a fine voice and tears in her eyes, said 'well, so the only other thing to say is thank you'.

The emotional experience of treatment for Jimmy and Daisy was marked by mood swings, low days and the uncertainty of the efficacy of treatment. Adjuvant chemotherapy was given to Jimmy 'as an insurance, to reduce the risk of recurrence' but there was a small probability of still having some cancer cells floating inside the body. In this context, close relatives like Daisy are actively absorbing patients' frustrations at the same time as they deal with their own emotions triggered by the cancer experience of their loved ones. However, they can only get on with treatment, despite its practical difficulties and emotional toll. Carers are the companions who sometimes can help and sometimes just sit empty-handed, not like a passive recipient but as someone watchful and available, ready to 'engage with the stubbornness of things' (Kleinman, 2010, p. 24). Following anthropologist Angela Garcia (2010), who did ethnographic research among heroin users in New Mexico, emotion work for my research participants could be described by what she understands as sociality based on incommensurate experience. Garcia discusses this incommensurate experience as a fragile mode of care based on the acknowledgement of our interdependence as social beings, shared vulnerability, and the intention to remain watchful for the needs of each other over time within our own limitations. As I argued for the health

professionals as well, emotion work requires the acknowledgement of the pain of the other but, I would add, also the silencing of our own pain.

Following anthropologist Robert Desjarlais (2011, pp. 22–28), who carried out an ethnography about the different ways of being in the world for homeless people in Boston, it is possible to say that even though carers like Daisy did not experience treatment first-hand, they struggled along. To ‘struggle along’ becomes an indeterminate temporal parenthesis, a life in brackets experienced as timeless, in which meaning is inchoate and efforts are made to create the sense of an ending of the struggle. Uncertainty is always there and it is one of the features that qualify the affective atmosphere surrounding cancer that people have to navigate. Daisy sometimes felt isolated on this aspect; her partner Jimmy, the one affected by cancer, did not want anybody outside the close family to know about his cancer diagnosis. So, Daisy’s challenge in managing the frustration triggered by treatment was not only about finding the appropriate space to express or debrief frustrations, such as in the clinic, with a group of friends or with the anthropologist who directly asked, but also about getting on with it and keeping life as normal as possible. Coping emotionally gets more complicated when realising that carers or relatives are not the protagonists of any story, so therefore they don’t necessarily have a voice. This is what I will examine in the next section through the experience of Elizabeth’s children.

7.4 The voiceless carer

In June 2016, after eight months of fieldwork and a feeling that I was not able to get many opinions from the informal caregivers I had met, I asked authorisation from my line manager to participate in an open call that the Department of Health had set up to improve the carers’ strategy. The call was established on the realisation that as long as the patient is the protagonist of the cancer story, it was very difficult for carers to feel they could talk about their own experiences. The open call was an opportunity to give a sense of legitimation to hear their voices. I was in the clinic following Elizabeth’s chemotherapy. Matilde, a good friend of hers, was leaving from the chemo room to go to work, so Joseph (Elizabeth’s son) and I stayed with Elizabeth until the delivery of the last bit of chemotherapy finished. Elizabeth went to the toilet with the pole of chemotherapy, telling me how diuretic chemotherapy was for her. In the meantime, Joseph asked me about the interview that I told Elizabeth and Sandra (Elizabeth’s daughter) I would like to have with them some days ago for the carers’ strategy. I explained to him that the ideal situation was to be able to talk without his mother being present. Elizabeth, overhearing part of the

conversation while she was coming back, asked me why, showing clear surprise in her eyes. Joseph reassured her that ‘there is nothing I would say to her [me] that he could not say to you’. I told Elizabeth that if she prefers to stay, it is ok with me, I was only talking about an ideal case, but have had other cases in which carers or patients don’t want to talk in private with me. Anticipating that the issue about ‘feeling like a burden’ could come up from Elizabeth’s point of view, I also explained that the impact of the treatment on relatives is not only or necessarily because of caregiving roles, but also because of the affective experience in the hospital. She looked Joseph in the eyes and said: ‘I don’t think I have been a difficult patient. Sometimes I cry alone in my room not to bother you, I am not complaining all the time’. Joseph looked at her and nodded silently. We arranged to meet the following week at their place.

Feeling the sense of awkwardness of having asked Joseph to talk with me about his experience privately, I confirmed that I was touching upon a sensitive topic rather insensitively by allowing Elizabeth to overhear what I told her son. It also made me realise that having voice entails the possibility of betrayal. Voice and silence in this line can be understood as a product of interpersonal negotiations that eventually become political, about who has the right to say something about cancer. Elizabeth’s case, as well as Daisy’s one, show that cancer patients are the protagonists of the story. During the interview with her children, and with her present, Sandra (her daughter) explained to me in one of the recorded interviews I had with caregivers. Throughout it, we alternatively spoke in Spanish and English:

Sandra: I am not optimistic, rather pessimistic, I would say. And it is not that I expect the worst, but I just know the reality of things, and I am aware that my mom can die, and I really fear that [*sobbing*]. I don’t want to think about that, but I know it is a possibility. I don’t expect that, I only hope she recovers completely.

Asking how she was dealing with this fear, she answered:

Sandra: I am not the kind of person who talks about this, but has been very difficult [*sobs become tears, she gets a tissue to blow her nose*]. Starting with the fact that we have gone through many things in life, my mum has had a hard life. Also with my daughter, because of her own medical issues. [*Crying becomes louder; it interrupts the flow of the conversation*]. It is a very strong [emotional] pain [*un dolor muy fuerte in Spanish*] that you have to bear day to day. But what can one do? One must carry on. It does not mean that the pain is not there, or that

the sorrow is not there. Despite the fact that she can get cured and everything, it hurts to know she has to go through all this and that is not fair.

For Sandra, her mom's treatment has been 'the most difficult thing that has happened in her life'. Still, despite the emotional toll that Sandra felt, she asserted that 'life continues and that you just need to get on with it'. In this scenario, Veena Das's (2007) description of the figure of the witness in contexts of political violence in India is useful to understand Sandra's experiences of caregiving, for she is a witness of the ways in which cancer and its treatments have (temporarily) undermined Elizabeth's quality of life. This probably was the first time that Sandra openly talked about her experience as a caregiver of her mom. Wholeheartedly desiring a full recovery for her mom, she feared the possibility of a grim outcome, which was always at the back of her mind. She believed that she must carry on with life, despite the pain and the sorrow of witnessing her mom suffering once again in her life. Pain and sorrow inhabited her, inside, while she kept on going with her life. In her ethnography in Punjab, India, Das (2007) explores the figure of the female witness of violence as a subject who incorporates poisonous knowledge. Poisonous knowledge is the affect that seeps from pre-existing social relationships and becomes an atmosphere from which the subject cannot get out. Violence becomes rooted in women's subjectivity, incorporated in the everyday. Das shows that poisonous knowledge, the witnessing of violence, presents a temporal projection in which pain is not granular; rather, it extends its impact on the ordinary, inhabiting the person, and is endured after the event. Poisonous knowledge is only appraised through the bearing of suffering, through the emotional work of the self. Here, the acknowledgement of the other's suffering is not done through words, but through the bodies that suffer. So Elizabeth's suffering became Sandra's own suffering, 'a very strong emotional pain', and stayed with her. Like other studies in which some sort of violence must be contained to prevent conflicts from spilling out and generating more damage (Argenti-Pillen, 2013; Gammeltoft, 2016; Han, 2012; Samuels, 2012), Sandra's initial reluctance to talk about this experience can be then understood as a way in which she tried to inhabit the world preserving the relationship with her mother.

7.5 Emotion work

In the last section, I tried to describe one aspect of Sandra's commitment to her mom's wellbeing that is experienced through the incorporation of her mom's suffering as a layer of her own suffering, which is partially noted in the emotional note of the

‘confession’, to use Foucault’s words. I argued that witnessing the suffering of the other caused by cancer can be understood as poisonous knowledge that seeps into relationships, inhabiting Sandra’s subjectivity. Sandra found it difficult to express that suffering, and kept it inside to continue carrying on with her life. This is not only her story.

There is a website that contains a forum in which carers of people affected by cancer can talk with other carers, virtually, about their experiences looking after others. Intelligently, the website’s manager decided to create a private forum for caregivers, so they would feel free to share their emotions without the risk of upsetting patients. The 30 carers or so would introduce themselves with their name, followed by the diagnosis of the patient they look after, updating the progress of their clinical condition on their own profiles. On this platform, most of the carers identify themselves as women and their ages range from early 30s to late 60s in average. In its threads, again, the person entitled to voice the experience of the treatment is the patient, marked first by the biography that every member writes, not about themselves but about the patient. In several posts, caregivers make the point that even though they were having their own peripheral experience of the process and were working very hard to support the patient, they could not express the struggle in front of the patient as it would sound ‘selfish’ and ‘inappropriate’. That is why they cherished the space on the blog because it was only possible to talk about the caregiving burden of cancer (NOT of the patient) with other carers. Nevertheless, the guilt remained. Carers on the blog expressed their feeling of guilt for not being ‘adult enough’. The ethical projection of caregiving on themselves was about ‘putting the big girl pants on’ as one of the threads was titled. In their eyes, saying how difficult and strenuous everything had been for the carer could only be seen as a complaint. In other words, silencing the emotional burden of the treatment as a way to care for the patient is, however, only one side of the story, for relatives – such as the ones using the online forum – would feel guilty of complaining about anything. I propose to consider caregivers’ guilt as both the moral sentiment that marks the domain in which the care for a social relationship is at stake (Zigon and Throop, 2014) and a mark of the limit of the ideal of such selfless care.

In the last conversation I had with Jay, his wife and his father, the following conversation took place:

- **Ignacia:** I feel that society does not let the carer express the burden.
- **Amanda:** [*taking it personally*] I have not been that bad.
- **Jay:** [*trying to help me, knowing that I was interested in his wife’s experience, asks Amanda*] But have you felt that you have been unable to express yourself?

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- **Amanda:** No, I don't have problems expressing my emotions, I would usually meet some friends who have gone through different things and I will be who I am.
 - **Ignacia:** But you won't be who you are before Jay.
 - **Amanda:** [*Looking at Jay while answering me*] We talk a lot, but I would not moan. I think he had enough of me and enough with the cancer as well. It is not fair on him to complain to him, because he is having the cancer not me. I was bad at the beginning, but I have a good friendship support network.
 - **Ignacia:** It is not bad, it is what it is.
 - **Amanda:** [*Looking at me this time*] No, at the beginning, I was bad. Then, we were expecting the lung resection. For me, the worst part was chemotherapy, not the surgery. Being there, seeing him in pain, vomiting a lot, in bed, and not being able to do anything was the worst.

When Amanda repeated that 'she was bad' because she was moaning or expressing herself before Jay about her difficulty in accepting his medical condition and in witnessing how he was suffering because of the treatment, Amanda was not only signalling that she cared for her husband, but she was also negotiating a norm, the expected behaviour of the female caregiver who should 'put her big girl pants on'. In other words, this moral sentiment not only signals a relationship that she constantly tried to cultivate by debriefing with friends and keeping emotionally silent before her husband, but also marks a value of harmony that carers such as Amanda wanted to strive for. Moreover, the sentiment of guilt that female carers expressed either bodily or in words, points to the normative understanding – valued among my research participants – that in order to create harmonious relationships, some of the ragged edges of the cancer experience should not be expressed.

Anthropologist Tine Gammeltoft, in writing about the reasons that could explain why women in Hanoi who are victims of domestic violence stay silent, argues that not talking is a way of cultivating 'fantasy worlds of attachment and integration, worlds that were bearable to them, making it possible for them to go on' (Gammeltoft, 2016, p. 443). Such fantasy, she suggests, informs both the deliberate choice of her female participants to only voice distress with trusted others who were outside the immediate circle, and the unconscious silence of the anxiety that the idea of failing in their efforts to secure their belongings in their husbands' kin networks triggered in them. Gammeltoft traces the fantasy of familial harmony to the ideal of the 'Happy Family', a state-supported vision of family life characterised by 'affectionate, peaceful,

and harmonious communities' (p. 439) that women strive to achieve. Yet, the author argues, that ideal not only conceals the contingent structural position of women in Vietnam, it is also used as a normative yardstick against which women assess themselves. Attaching themselves to this ideal or striving towards its realisation then turns their silences in mechanisms of social reproduction that sediment the position and vulnerability of women in the Vietnamese society. In line with Gammeltoft, caregivers that participated in this research measured their own selves against the ideal of a voiceless, compassionate carer who is selfless in her giving for the benefit of the patient. With such yardstick to measure the success in practices of self-cultivation, Amanda's statement that 'I was bad', meant that initially she was overly emotional in front of Jay. Amanda repeating that 'I was bad' points to the feeling of guilt that was triggered in female caregivers when expressing the emotional demands of being alongside the cancer patient. In this scenario, emotional management can be understood as ethical substance. Swallowing the emotional storm and 'putting the big girl pants on', then, is also instrumental in the carers' efforts to strive in a way that is concordant with historically and culturally approved social forms. However, at the same time that caregiving efforts are embedded in a normative ideal, my ethnographic material indicates that silence, as sought and enacted by my research participants, has world-making potential, even if this does not 'emancipate' women. Silence helps people affected by cancer to accommodate the treatment experience in their everyday lives, preserving the relationships that they care about. Anthropologist Michael Jackson (2004) offers a beautiful argument that helps me unpack the value of silence in *The Prose of Suffering*. In discussing the testimony of a young woman tortured by the militia in one civil war in Sierra Leone, he argues that the Western focus on excessive verbalising goes against Sierra Leone's way of keeping silence as a sign of respect. For Jackson, the fact that the amputee young woman just moved on a few days later, instead of dwelling on the horror she faced together with other relatives and neighbours, stems from a deliberate choice to honour the ineffability and privacy of certain experiences. More importantly, Jackson argues that rather than necessarily understanding silence as evasion or repression, it is possible to conceive of it 'as a way of healing and reconciliation that seek to consummate a form of coexistence' (Jackson, 2004, p. 56). Jackson contributes to my understanding of silence as a practice of world-making through which caregivers seek to restore relationships that have been threatened by cancer treatments. In this vein, understanding care as a world-making project in which different possibilities of experience are crafted, silence is a practice that seeks to preserve a world so that patients and relatives can comfortably dwell within already established relationships in a world filled with frustration.

7.6 Gender and the emotional rollercoaster

The members of the clinical team with whom I talked about the frustration of cancer sought to manage that emotion by carefully calibrating degrees of emotional detachment. Within this group, gender differences are subtle, for emotional detachment is considered by them to be a mark of professionalism. In contrast to this seemingly collected manner of dealing with the frustration triggered by cancer experiences, the emotional stakes of cancer appear to vary according to the gender of the lay caregivers I met. They were people who were sharing most of the experience of treatment as close relatives (partners and children), often living together with the patient. In particular, for men, frustration did not appear readily available as an ethical substance to be managed, and I did not grasp any sort of guilt when speaking to them. They were never ready to expand on their experience of the ‘emotional rollercoaster’ of cancer (a phrase used by Jimmy’s son, a young architect who I briefly met during the last chemotherapy appointment, to describe what he thought was my own, rather than his, experience of the fieldwork). So even though most people I met said that getting emotional was not productive (regardless of gender), women recognised that they may cry in silence, backstage. Men, instead, would consider that getting emotional might be *counterproductive* when caring for someone or that it fogs reason in general. As Joseph, Elizabeth’s son explained:

Joseph: I have tried to deal with it as much as I could. There is no point in me being sad for a very long time if my mum is still around. It’s not gonna help. My aim is for her to get better. If I am strong, she is strong. If I am sad, she is sad.

Joseph’s words describe the form in which he has chosen to do emotion work. Following Thomas et al. (2002, p. 542), who define the concept of emotion work as ‘the continuous effort made by carers and patients to manage their own feeling states and those of others in the everyday’, I understand Joseph as trying to enact a caring atmosphere. However, in the experience of the male caregivers I met, it seems that the enactment of that atmosphere did not necessarily stem from the same internal process of ‘work on the self’. When speaking to them about it, dealing with cancer in a practical, rather than emotional, way provided a strong mechanism to reinforce the role they saw in themselves: rational and practical companions.

Two more examples. Gregory, Leia’s partner, with whom I talked over the phone, did not feel that he had to emotionally cope with Leia’s treatment. ‘She did most of the work. I only had to do what I always do, like cooking and cleaning,’ he answered. Cooking and cleaning were part of his everyday life regardless of cancer, as he was

managing his home on his own in a different city while Leia lived and worked in London. When I met Paul in a café to talk about his experience as the husband and principal caregiver of Jean, he wanted to spend the time with me articulating his concerns regarding the way in which the NHS had looked after Jean. He had never been in one of the consultations in the clinic, as he 'did not want to compromise her autonomy' and, moreover, he was working full time. However, he wanted to comment on the way in which Jean's diagnosis was communicated, the way in which she was approached to participate in a research trial, the way in which her post-surgery infection was treated, the way that the A&E mistreated her in an emergency, and the way in which chemotherapy was offered. He did not want to talk about his emotional experience, even though I could see how him recounting the whole treatment was making him feel frustrated, if not filled with rage. When I prompted him again to talk about his emotional experience, he just said squarely that 'the cancer treatment had made me feel anxious' but he again invited me to talk about the practical side of things.

Considering these three short examples from Joseph, Gregory and Paul, I find that this kind of silence among male caregivers – the silence chosen and articulated by talking with me about the practical side of the treatment experience rather than the emotional – is still meaningful but in a different way. Catherine Lutz (1988) has shown that the Western rhetoric of emotional control reproduces a view of emotion as irrational, weak and dangerous. She argues that placing the emphasis on its control not only defines boundaries of what should be inside and outside, but also suggests a set of roles and hierarchies in which women are irrational, weak and dangerous within the same structural distinctions used to understand emotional expression. So it may be that male caregivers' concern for the practicalities of care instead of the frustration that cancer produces could be understood in terms of the expected roles that they strive to embrace for the care of the patient. The male caregivers I met were practical, and keeping their jobs for the wellbeing of the whole family was an important concern. In contrast, the female caregivers I met, whether they were working or not (Amanda was working full-time at the time of Jay's treatment), did not only support patients in a practical way, but also emotionally. This is not to say that one group of people may be more virtuous than the other, for what informal caregivers deemed as relevant attributes to cultivate were differently situated. The issue is, instead, about where the emphasis is placed. Advocates of the 'ethics of care' – Joan Tronto, Berenice Fisher and Sandra Laugier among others – have discussed for almost three decades how caregiving and gender are historically co-constituted. Defining caregiving as an essential component of human life that enables us to survive individually and collectively, it includes a range of practices that are carried out in

various spheres, be that at home, in the market, or in political arenas. Caregiving practices occur in correspondence with the particularities of people's own situations, which are sometimes challenging and sometimes unpleasant. Nevertheless, they argue, caregiving tends to be unevenly distributed according to dominant power and class conflicts. Women carry the vast majority of the caregiving burden, be this affective or practical, but they are nevertheless invisibilised (Fisher and Tronto, 1990; Laugier, 2015; Tronto, 1993).

The argument of the ethics of care proposed here is clearly a general overview that, even though it has inspired some of my thinking about caregiving, needs to be ethnographically unpacked in order to demonstrate the everyday experiences of the men and women performing it. Within the context of cancer care, this has been one of the aims of my dissertation, and of this chapter specifically. However, the original argument is still relevant to understand that, within a context in which emotion work is belittled and female caregivers feel guilty about expressing how hard it hits them, it is necessary to highlight that women's pseudo-confessional openness about their struggles with the emotional side of anti-cancer treatments does not nullify all the practical care they also give throughout and beyond treatment, regardless of the weight of their own experiences. From driving patients to the hospital, cooking for their whimsical appetites, remembering side effects and questions for the doctors to changing wound bandages, flushing PICC lines and disconnecting pumps, women have mastered care practices throughout – and nevertheless feel some sort of shame when giving an account of what it takes.

Anthropologist Uni Wikan (1990) poses a similar argument that, in broad strokes, refers to the containment of grief and the expression of a 'bright face' as a moral choice for Balinese women, which is necessary for maintaining the social order and avoiding the threat of sorcery. Arguing that 'to brood and persist in sorrow is to declare oneself selfish and insensitive to the wellbeing of others [] Crying exposes despair, opens up a void that might not heal' (Wikan, 1990, p. 146). Together with Wikan's ethnography, anthropologist Lila Abu-Lughod (1986) pioneered an understanding of emotion work tied to intersectional axes, in which age, gender and social position would pattern ways for the expression of emotional experience (Wikan's focus was on grief while Abu-Lughod's focus was on love), sanctioning expected behaviours. The key idea of such understanding would be the desire to avoid harming or offending others, which Abu-Lughod conceptualised as the feminine practice of modesty. In this line, for Wikan as well as for Abu-Lughod, the wilful containment of emotions would be considered a virtue, which could only be understood in relation to the subject position people occupy within existing social structures of Balinese and Beduin societies respectively. I cannot but agree when recognising the relevance of

gender asymmetries to understand the ways in which the lay caregivers I met chose to express or contain their emotions.

7.7 Discussion

Throughout this chapter, I have tried to show how emotion can be understood as having two axes: interiority/exteriority and laterality. On the one hand, emotion work can be understood as an ethical practice, consisting in the constraint of frustration. On the other hand, emotion work is about assessing the impact that the expression of our own emotions causes in others, so it aims to maintain a social world that is cherished. This applies for both health professionals and lay caregivers. Thus, emotion work acts upon ourselves as it acts upon the world, with silence having a performative impact in the staging of what I have called the atmosphere of harmony and containment that seeks to negotiate the frustration atmosphere surrounding cancer and its treatments. In one or another way, professional and lay caregivers' commitment to the suffering other, even though sometimes emotionally ambivalent, staged a possibility of experience in which patients and themselves create liveable lives under difficult circumstances.

Chapter 8

Where there is life there is hope: Narrative emplotment and moral self-fashioning at the end of life

8.1 Introduction

Throughout this thesis, I have looked at the ways in which caregiving as a moral project seeks to stage atmospheres of emotional containment and to repair achy and leaky bodies affected by cancer in London. Such projects, I have suggested, have been collaboratively pursued. Deliberately, I have flattened out some of the power asymmetries that shape the dynamics between clinical professionals and patients and their caregivers. My ethnography indicates that cancer treatments are not battles of ‘you against us’. Rather, they are arenas in which teamwork among people with different kinds of expertise is articulated with the promise of survival. By doing this, I have suggested that despite occasional disjunctures, misunderstandings and complaints that people may have about one another, world-making projects are consciously crafted by patients, caregivers and health professionals *together*. I have shown the many challenges that my research participants encountered when trying to fit treatment routines into the unruliness of their everyday lives. Yet, it has been striking to realise how willing my interlocutors were to follow treatment instructions and put up with the side effects and consequences with the hope of achieving cancer remission. Indeed, most of the care efforts I observed inside and outside the cancer clinic occurred only because patients and their support networks trusted the intentions and knowledge of the health professionals. Trust is essential for creating what Cheryl Mattingly (2010) describes as ‘clinical partnerships’ through

which patients, caregivers and health professionals jointly engage in care tasks, planning and unfolding a therapeutic trajectory.

When patients and caregivers get on with treatment, there is a biomedical narrative that frames, times and gives meaning to a series of therapeutic steps. They learn the colorectal cancer treatment pathway as it unfolds, because the clinical team guides them step by step. First, there is the confirmation of the diagnosis, then surgery (or chemo-radiation if the mass in the rectum needs to be downsized first), then chemotherapy. For every step – with greater or lesser success – the team communicates the rationale and likely scenario to unfold. They explain what is required from patients, what the intervention is about, what their associated risks are, and what patients should expect in terms of treatment consequences. For every intervention, there is a process of consent, and patients and caregivers – informed to various degrees (many of them would seek more information from other sources) – will decide whether they want to commit to treatment. Hence, narratives are powerful tools for fostering collaboration when articulated in practice. In *American Medicine: The Quest for Competence*, Del Vecchio Good (1998) unpacks the clinical narratives through which oncologists combine the worlds of science and therapeutics. Her argument is that professional competence is crafted through these narratives that aim to give shape to patients' experiences of treatment at the same time as they structure the way in which medical information is given. She shows convincingly how oncologists in the US combine the language of statistics and research, along with the use of metaphors that direct the focus of patients to what is happening 'for the moment'. In a way, it is necessary to create a sort of temporal myopia to navigate the risks of treatment and uncertainties of the cancer prognosis in an ever-changing context of technological development and discoveries of genetic mutations. In the words of the anthropologist: clinical narratives seduce patients and clinicians, 'enveloping both in a world of the medical imagination, with a many-possibility regime of truth, with fantastic but apparently purposeful technical acts' (DelVecchio Good, 1998, p. 10).

Clinical narratives have performative effects. They don't only organise and constrain how the disease may be understood by patients and relatives (Miles, 2013); they also contribute to sustaining people's physical, social and emotional efforts during treatment (Mattingly and Garro, 2000). Hope for remission, adherence to treatment and trust in the clinical team were outcomes afforded by therapeutic narratives that not only supported people's long-term painful efforts, but also further motivated me to understand care practices as a world-making project. Embedded in narratives, trust works as the condition for patients and caregivers to create clinical partnerships, which in turn sustains the long-term endeavour in a treatment

pathway undertaken with curative intent. How people navigate treatments to achieve remission was the original focus of my research, and most of my informants followed that path in a historical time that has enabled resourceful healthcare systems, such as the British one, to offer optimistic outcomes and prolonged survival rates. In fact, in 2011, 59% of the population diagnosed with bowel cancer in the UK survived for at least five years since the time of cancer diagnosis. My thesis would have finished in an optimistic portrayal of cancer remission if only colorectal cancer would not kill the other 41% of people who cannot be protagonists of the same story.

In that latter 41%, some people come from the pathway with curative intent ('curative pathway' from now on) but eventually see themselves enrolling in the non-curative one. Those people soon engage in a conversation that is framed by clinicians in terms of the management of 'advanced cancer', after new symptoms of cancer progression appear and, more importantly, scans have confirmed the new status. Advanced cancer means that the original tumours previously treated with the aim of eradication have developed and spread to other organs, either at local or distant sites of the body. How science explains the exact mechanisms through which this shift happens is something that is outside the scope of this thesis. Instead, I would like to unpack the experience of someone who, believing that they would eventually achieve remission, could not follow that path. Due to the unavailability of curative surgical and systemic options, the growth of the cancer tumours in the bodies of patients with advanced cancer is something that is still impossible to stop. Statistics show that when cancer cannot be cured, patients' prognosis is limited to a range of between one and five years. Advanced cancer invariably includes the worsening of the medical condition, which irrevocably changes the dynamics of any care effort. Clinical dynamics only aim to de-accelerate cancer progression and to palliate any relevant symptoms occasioned by this patho-physiological process to preserve patients' quality of life as much as it is possible. However, my ethnography shows that, for cancer patients, such shifts in the clinical narrative are difficult to come to terms with. While cancer progresses, therapeutic narratives get fragmented, undermining patients' trust in health professionals and their efforts to keep adhering to a treatment that seems more and more futile. Ruth, a woman in her late 30s, Christian and mother of two, was affected by an 'aggressive' type of rectal cancer. This is her story.

I met Ruth in March 2016. After her cancer diagnosis in winter of 2015, she was invited to embark on a clinical pathway comprised of chemo-radiation, en bloc resection of the area surrounding the rectal tumour, and 12 cycles of chemotherapy without elective breaks in between treatment options. I followed her to every hospital appointment from her second chemotherapy cycle for over a year until she was

discharged to go home (and die). While she was finishing the course of chemotherapy, we learnt together that even though imaging did not show tumour activity and she was feeling well and ready to go back to work, the cancer would eventually come back. She then realised that her treatment was no longer given with curative intent, that the new monoclonal antibodies offered to her would only work for some time, making remission a frustrating illusion. A bout of debilitating abdominal pain only two months after seeing 'clear scans' was enough to get her admitted onto the ward once again and for last time in her life. She was suffering from an inoperable form of obstruction in the large intestine, a life-threatening condition that impedes bowel motility, which affects a disproportionate number of colorectal cancer patients and, in her case, indicated an aggressive form of cancer recurrence. Drawing on the ethnographic data I collected during her stay in a hospital ward, I would like to look at her experience of palliative care. She perceived the dynamic as an ongoing oscillation punctuated by two seemingly opposite poles: brief moments of technological intervention and long periods of inactivity while the clinical team was limiting the therapeutic effort. This dynamic structured her dying experience. Yet, stuck in hospital for 15 weeks, it made her feel increasingly frustrated and angry. Following Kaufman's work *And a Time to Die*, I am interested in unpacking ethnographically, and from Ruth's point of view, the idea that '[the] switch from curative and palliative activity is often fraught with conflict [...] as comfort care is not really a discrete activity [...] but a matter to be distinguished in kinds and degrees of treatment' (Kaufman, 2005, p. 39). I would like to suggest that Ruth's perception and experience of palliative care could give us insight into the relationship between narrative and trust articulated between patients and clinical teams in resourceful healthcare systems.

In the second part of the chapter, I describe some practices and beliefs that constituted this transformation, as Ruth invested herself in bringing about a different possibility of experience. She embedded her efforts in a different narrative, which, although lacking any scientific foundation, gave her meaning and peace of mind when her new clinical prognosis was written on her medical files. This alternative narrative could be understood by some people as psychological denial caused by the proximity of death. However, I demonstrate that such judgement does not offer any advantage from an anthropological point of view that cares about patients' lived experiences, for labelling certain behaviours under the rubric of denial only helps to make some of the ways in which people cope with death pathological. Rather, I argue that through the remaking of hope or the imagining of alternative futures, patients articulate a heightened form of ethical subjectivity that enables them to approach death in a different way. In other words, I would like to argue that imagining alternative futures

in a situation marked by the certainty of an imminent death in a context of open awareness (Glaser and Strauss, 1966) co-constituted a process of moral self-fashioning through which Ruth worked to develop a partnership with God that resulted in the emergence of a strongly religious, albeit ambivalent, subjectivity.

8.2 A living candidate for pelvic extenteration

It was mid-February 2016, my third month doing fieldwork about what I succinctly explained to the team as ‘patients’ experiences of treatment’. It was surely shorthand, using words that enjoy some degree of appeal in clinical settings that aim for world-class medicine, but it helped me to get the support of a multidisciplinary team looking after bowel cancer patients. Sitting in one corner of the consultation room of a senior consultant in medical oncology, he told me that the next patient was a ‘living candidate for [pelvic] exenteration’. Ruth was a cheerful woman who did not complain about anything other than the skin rash produced as a side effect after two cycles of combined chemotherapy for locally advanced cancer (Folfiri and Cetuximab). Having read a week ago about exenterations after the lead surgeon suggested that option for another patient in the multidisciplinary team meeting, I asked Dr Y how he saw the balance between a disruptive surgery that takes out most of the female organs, bladder and vagina, and quality of life. As a professor deeply committed to research and teaching, he seemed to enjoy answering those questions (time being available). He answered carefully:

Dr Y: Yes, it is not good, but the other option is dying, and sometimes the surgery is curative as those tumours do not spread to other sites; it is not risky, and Ruth has two small children. Her type of cancer only grows in the area, locally, so she would not die from cancer in the liver [a frequent cause of death for bowel cancer patients] before going for this operation.

Before this appointment, Ruth had had one unsuccessful attempt at surgery when doctors realised that her rectal tumour was bigger than what they could see through the scans, so surgery was postponed in order to give her one month of a daily dose of chemo-radiation to shrink the tumour. She went through the kind of marathon-like endeavour described in Chapter 6 to then receive the news that her operation would encompass the creation of a permanent colostomy (as also happened to Jay, described in Chapter 5). Just before Christmas 2015, she underwent such surgery, leaving deep wounds on her back that took some time to properly heal and forcing her to stay as

a hospital inpatient for two weeks until the beginning of January 2016. I followed Ruth's treatment from the first day I met her on her second cycle of chemotherapy. The plan for her was to receive 12 cycles of Folfiri-Cetuximab, a combination drug administered fortnightly, through a mixture of outpatient intravenous infusion that is followed by 48 hours of slow release administration from a portable pump. She would have scans after the 6th and 12th cycles. Depending on her results, they would adjust the plan and see how to move forward, also considering exenteration as a curative option.

Meeting on average two times a week (during consultations and chemotherapy administration), I witnessed what looked like a painful and debilitating process. During interminable hours every second Friday, we would talk about her family and our everyday lives, her plans, the British political situation compared to those in our home countries, and her strong belief in God. In the clinic, and only from time to time, she asked about her chances to undergo exenteration as a last resort. Consistently and following the logic of 'one step at a time' that DelVecchio Good et al explain as a way to structure oncological time in US clinics (DelVecchio Good et al., 1994; more below), the therapeutic narrative crafted by consultants left the big surgery as an option to keep in mind for the future, but not the main point to worry about. As happens in those clinics, focusing on the next immediate clinical task, instead of outlining all possible future scenarios, is one important way through which the clinical team seeks to control the uncertainty of cancer and deal with the clinical situation that they have information about. Always with a cheerful attitude and grateful for life, Ruth came to what seemed the end of treatment just some weeks after her birthday (which we spent in the clinic).

After checking the toxicities of the last chemotherapy cycle, the senior cancer nurse specialist who saw Ruth in the last clinic explained what was to come after this 12th cycle. The session was soon over, and Ruth gave a bottle of sparkling wine and a box of chocolates as presents for the 'end of treatment' to her so that she could share it with the clinical team. Five days later, we met in the waiting room where she was about to get an MRI scan after the 12th cycle, and for the first time I noticed that she was visibly anxious. Understanding such feelings as a normal response of patients before important scans, I offered some warm reassurance. But I had got the reasons wrong. She told me that she had received a letter from another big teaching hospital in London giving her an appointment to do a series of assessments in order to see whether she needed the surgical exenteration. Dr Z and CNS A had arranged this referral for her, but she was concerned about it. She did not want to make that option a reality, telling me that she was praying so that it would not become true. On 13th July, Ruth saw the same specialist nurse to receive the results of the end of

treatment MRI scan in the clinic. CNS A read the results for herself and told Ruth (and me): ‘*There is no evidence of the disease*’. However, Ruth and I understood that despite the cancer inactivity, *it would come back*. The nurse explained:

CNS A: Patients have Cetuximab, a maintenance therapy that does not cause so many side effects, for several months until cancer reappears. At that time we can add another drug or operate [...] Clinical trials show that at some point, the cancer cells discover what has been happening with your body and change their DNA to continue growing. They are very clever.

Mid-September. It had been one year since Ruth’s diagnosis, in which time she had undergone chemo-radiotherapy, rectal surgery, 12 cycles of combined chemotherapy, and 2 cycles of maintenance chemotherapy with little or no breaks in between treatment varieties. She was admitted to the ward that day. The last four weeks of unbearable pain were later found to be signalling the obstruction of her large bowel, a life-threatening condition that impedes digestion. This is a complication that disproportionately affects bowel cancer patients and, in her case, it indicated a quick form of cancer recurrence. Nine days as an inpatient, amid episodes of pain, total parenteral nutrition (TPN) and soft diet, with no surgical options available, she was discharged after managing to ‘open her bowels’ for four consecutive days. She also started combined chemotherapy again ‘for four or six more cycles to see if it is of any help’, Dr Z said. On her last day in hospital, we waited long hours for her discharge. She was full of life. Planning to slowly resume working as assistant accountant, to cherish her children, and to make some changes in her diet, she told me: ‘I don’t ask for much. Just not being admitted to hospital again this year.’

The frustration was great when after four days at home, she called the specialist nurse and asked to be admitted into hospital for what would be the last time of her life. With unbearable pain and uncontrollable sickness, her bowel was obstructed once again. A week after the second admission and she was back on TPN feeding, nil by mouth, and with a nasogastric tube inserted to diminish pressure from her bowels (and to avoid what would be otherwise frequent episodes of projectile vomiting). An experienced surgeon I only saw a couple of times in the MDT meetings came and told her that there was no option to do surgery, for the scans showed that her cancer had spread throughout her bowel and peritoneum; not even an exenteration was possible any more. From now on, Ruth started to struggle to understand the dynamics that made up the palliative pathway that emerged for her. When I went to see her after three weeks on the ward, Ruth was alone. She told me that she had two ‘revelations’. The first was that doctors were only doing ‘educated guess work,

that they were finding [it] difficult to find the balance between not doing anything and watching, and then rushing when starting to feel desperate'. She thought that the specialist registrar was feeling guilty about having rushed her first discharge, and that she did not know what to do any more. That was when the second revelation came: she learnt how to approach the doctors' suggestions: 'is it life threatening? Yes or no. If no: then, what are my options?' So she applied this technique with the registrar when she came to talk about the nephrostomy bags. However, the scenario was uncertain, the urologist did not know if she will need one or two, or whether they would be placed temporally or permanently either. It depended on the results from the physiological assessment of Ruth's kidneys. She told me:

Ruth: I have already one bag, I might have two more. And then, there is still this thing, the nasogastric bag. I can't go home with this, but it seems that doctors refuse to start planning anything to sort it out, and the TPN woman [the dietician] told me that there are options.

Ruth would like to be on the same page with the clinical team, and felt that asking about options was the only way of preventing them from doing something detrimental for her because she believed they were rushing after the inactivity. Anthropologist Sharon Kaufman (2005), writing about the illusion of choice, asserts that technologically driven dynamics in resourceful hospitals shape the form of end of life care and dying experience, posing a false dichotomy to the patient, as options are already constrained by the hospital system and patients not only cannot know what they want technically speaking (if they are not clinically literate enough), but they also do not have all information to make sense of the clinical procedures available to choose the best one. Ruth wanted to be an informed patient and choose as it was expected of her, despite its obvious limitations, as she felt that her involvement in the treatment plan was the only way to ward off the iatrogenic effects of 'doctors' desperation', 'for waiting and then rushing'. However, I would like to suggest that Ruth embraced this logic of choice not as much as an enactment of modern and rational patienthood, but as a proof of her distrust. Ruth had subjected herself to a clinical pathway in which being a 'living candidate for exenteration' meant having the possibility of achieving cancer remission after 15 months of strenuous treatment that produced clear scans. However, all in all, a month of chemo-radiotherapy, open surgery from her backside, 12 cycles of chemotherapy, and 3 cycles of maintenance therapy were just not enough. Her expectations were not fulfilled by embracing the 'medical imaginary' that circulated the hope for remission, and she felt she could no longer rely completely on the competence of the clinical team. The clinical narrative was fragmented and she not longer felt that there was a clear path to follow.

Furthermore, the technological imperative of medicine was changing her body more and more in an effort to stabilise organ failures and stave off death: TPN to feed the patient with a combination of nutrients directed to the blood stream, allowing the digestive system to rest; stoma bags to collect bowel outputs when there is no longer any use of the large bowel and anal sphincter; a nasogastric tube to drain stomach content, and thus diminish the risk of vomit going through the airways and causing lung infections; and nephrostomy bags to drain urine from infected kidneys, thereby preventing kidney failure. Moreover, Ruth was also connected to two drips that enabled her to receive drugs on an ongoing basis: a chemotherapy pump, and a syringe drive that automated the release of painkillers and other medications intravenously, so that she was sedated. It was sadly impressive that medicine has the ability to replace so many physiological functions via external portable bags.

Studies in medical anthropology have shown the usefulness of clinical narratives to structure and sustain patients' efforts during long-lasting treatments (Mattingly and Garro, 2000). Clinical emplotment is one such concept through which clinicians and patients in partnership sort various procedures and give meaning and therapeutic purpose to what would otherwise look like basic pain and inconvenience – in one word: futility. When analysing the economies of hope that medical oncology gives form to in the US, DelVecchio Good et al lucidly explain that a key feature of such narrative emplotment in oncology is the structuring of time (DelVecchio Good et al., 1994). Time horizons are purposefully blurred, and clinicians encourage patients going through cancer treatments to think, plan and act in the short term: what has to happen now. Similarly, in London, the emotional management of the uncertainty of cancer patients' prognosis is realised through the discussion of the pragmatics of treatment. This not only offers some meaning to the patient, but also enables the clinician-patient relationship to adjust the therapeutic effort as the scenario unfolds. However, when the intent of curative health outcomes is no longer pursued, such clinical narrative becomes fragmented and the patient simply 'loses the plot'. It was not that Ruth was unable to understand the medical reasoning, but because the medical reasoning itself started being guided by a different and insufficiently communicated goal, it became confusing for her. From the perspective of the patient, who happens to be in the oncology ward in the weeks before her death, clinical dynamics are understood as an inchoate mixture of 'waiting and rushing' which Ruth cannot trust any more.

8.3 Approaching death in its ambivalence

If one of my roles in the chemotherapy clinic was to offer company and reassurance to patients and caregivers in an atmosphere filled with frustration, the weeks on the ward taught me that soft care could not only be very practical, but also provide a window to understand the ‘intimacies’ through which patients negotiate normative expectations and subjective desires at the end of life. Intimacies can be seen as unstructured and fleeting encounters in which normative, intersubjective and personal dimensions merge. In such fleeting moments, the observer is able to see flashes of others’ subjective self-making. In the next pages, I would like to attend to Ruth’s subjectivity as it emerges and is made visible in intimate moments that she let me participate in. I acknowledge my heavy presence in this chapter as a researcher. However, I understand the incorporation of my voice as an analytical tool through which it is possible to explore intimacies and the interactive and situated process through which subjective changes are made visible.

Ruth’s time on the ward was accompanied by her mobile phone. Despite her husband’s disagreement with the fact that she was always hooked to it – keeping in touch with members of her support network and sharing how she was feeling with them – the mobile phone offered a way ‘to keep herself mentally sane’. More importantly, through her mobile phone, she was enacting her self-in-relation as a mother of two young children who ‘should be living their lives full of laughter and innocence’. Sending good night wishes while checking whether her son did his homework and organising who could go and pick up her daughter from the nursery when her sister-in-law was unavailable, or who could give a lift to her son so that he could play football after school, were specific ways of cultivating those relationships, enabling the kids to continue a normal life that would not be marked by the fact that their mum was in hospital.

One day, while staying with her in a temporary private room while she was infected by MRSA, Ruth was encouraging her friend living in the US on her phone to recognise what she has already achieved and how able she was to take on further professional challenges across the Atlantic. With her permission to stay in the room while she was talking, I commented afterwards on her admirable ability to give courage to others. Pleased, she told me that she knew it was one of her more important gifts, so she consciously tried to support others that way, even from the hospital. As she did with her friend in the US, Ruth encouraged me to further develop my professional skills, which for her were underpinned by the management of my emotions. She wanted me to keep a safe – detached – distance from draining hospital dynamics. She taught me how to react to the emotional ambivalence produced by

life difficulties, and especially when approaching her own death. Probably realising that my emotional strength during fieldwork was wavering from time to time, and especially while witnessing her condition deteriorating, she told me:

Ruth: Emotions make us humans. I let myself cry if I need. But then, I just hand it to God, I tell him that the problem is too much of a burden for me. That is because I am Christian. I always remember when a pastor explained [to] us that people don't have to get on your nerves, you decide how to react to people and situations. That is our gift of discernment.

Her advice was directed as much to me as to herself, for a big task for her in the current process was to exert emotional control over the despairing situation that was yet to come. It had been seven weeks on the ward. She thought she was receiving contradictory information from different clinicians. Moreover, her main point of contact, the cancer nurse specialist, was overwhelmingly busy working in a clinic with just too many patients; and consultants were only coming to see her when important (bad) news needed to be broken. The worst news, given in black and white, was about her prognosis, coming in a letter addressing the insurance company to which she was affiliated so that they would continue supporting her family economically until the end. It painfully read:

Ruth will be on treatment for the rest of her life, unable to work because of the toxicity and debilitating nature of her medical condition. Her prognosis is now limited to less than six months.

On Ruth's request, Dr Z came two days later to talk about the context of this letter with her and her husband (the husband could not come earlier to meet the doctor because of childcare duties). Ruth and her husband understood after the meeting that the clinical team had her consent to write letters about her medical condition to relevant third parties. This was not the first letter written on her behalf. The hospital team had already sent letters supporting visa applications for Blessing, her sister-in-law, and Ruth's mother coming from her home country to look after the children; a letter to the jury service explaining she could not fulfil that responsibility in court; and applications for granting social housing to Ruth and her family since they were living with a friend in a flat where the TPN feeding machine could not fit, making the situation unsafe. Those letters were only some of them. However, the unsolicited one about the, until then, obscure prognosis was the most important letter at that time.

With a letter stating her prognosis, the perception that the clinical team was giving up on her, and in a frequent hallucinatory state due to continuous sedation, Ruth rose to the occasion, building the trust she could no longer find in the clinic in the being who ‘had always got her back’: God.

8.4 Trust as self-making

The day after the conversation with her consultant took place, I went to see Ruth at the ward. I asked how she was feeling after talking with the doctor. She replied thoughtfully:

Ruth: I do not work with prognosis. Those are probabilities, and I don’t fit within them. You need to be able to think outside that box [*pointing up with her index finger to signal God*]. God is in control and I trust him. I see people fighting the cancer until they can’t do anything else, but I am not afraid of death. As Christians, we know the afterlife will be better, and we will be reunited with our relatives and friends. Why people are so scared of death? The only reason why I don’t want to die now is because of my children, they are four and seven years old. I would like to see them at a stage in which they can carry on by their own. That is why I receive the treatment and do what I am asked to do, but I am not afraid of death. Don’t think that death has not crossed my mind, that is why I tried to do the most I could with my children during the summer. Last summer [before diagnosis] I was too weak for anything. I try to teach them and share with them the most that I can, but you can’t ... You can’t cram a whole life in some months. And if I die, I know my husband is a good father. He will take care of the kids. God gave us the free will to decide how to tackle what is on our way. I have decided to look positively at things and get the most out of them.

Although God’s unconditional loving support is asserted, offering a promise of life after death in which Ruth is reunited with her loved ones, the moral struggle of her earthly experience was frequently glimpsed. Ruth’s awareness of leaving her young children behind was sometimes paralysing. Moreover, her experience of relentless pain caused by the unstoppable cancer progression was another earthly reminder of her finishing life in this world, making her daydream for an alternative future. While staying in bed, but not in pain, she would tell me how she would decorate the garden of her new flat and put a little playground for her kids. Other days she

would suggest that we could go to New York to eat pastrami, and when noticing my scepticism, would invite me instead to join her at TGI Fridays where she would like to go with her friends for drinks and food. Frequently, Ruth found herself creating dramatic narratives that could offer a glimpse of emotional excitement, dramatic narratives that I failed miserably to understand at that time, thinking that we were once again engaging in the exercise of mutual pretence that death was not imminent (Glaser and Strauss, 1966).

In those moments, I could only reply with my silence. Now I have come to understand that trusting as a self-making practice through which she was re-asserting her identity as the loving child of God was never complete, for trust achieved by constant prayer was continuously threatened by pain and sorrow. Now I see Ruth's frequent daydreaming as an offer to engage in an emergent narrative (Mattingly and Garro, 2000), which, once improvised, offered the hope of a life through cancer by keeping her identity intact. If daydreaming is a form of denial that takes shape through an exercise of mutual pretence, could we consider that as a form of caring? Ruth did not want to be stripped of her role as mother or friend. She did not want to think that she would ever stop caring about the people she loved. From leaving food and juices for her kids after every meal so that her husband could collect it, to organising who goes and picks up the children from school, to talking on the phone daily and receiving visits from researchers, friends and relatives, she continuously cultivated social relationships. Even before being admitted to the ward, she struggled and put up with the pain in her hands and palms caused by the chemotherapy to continue cooking, telling me that 'My husband likes the way I cook, he does not like how my sister-in-law does it'. Even when sexual intercourse was really painful for her, she tried hard to continue intimate relationships with her husband as a demonstration of love, until it became impossible. By maintaining those interactions, she was warding off cancer's power to take away her identity. Mead (1967) long ago demonstrated the interactive process through which self-identity is constructed. What I find illuminating, though, is to think about Ruth's efforts to engage in mutual pretence with me and her friends visiting her on the ward as not only a way to keep her identity intact, but also to look after others' emotional needs. Even if I failed to buy the daydream, she wanted me and others to detach from the anticipated grief she saw in visitors' faces. Only then could life be lived as normal.

Two months on the ward. The hospital conceded that she could spend her last Christmas at home. Ruth decided to delay chemotherapy in order to feel strong. Accompanied by several relatives from her home country and together with local friends from her community and church, she threw a big dinner party at home. The celebration was organised while her kids were on holidays and she stayed on the

ward. On Christmas Eve, she went to a church service in a white dress and received a one-to-one blessing from her pastor. Her nephrostomy bags and the nasogastric tube were taken out; her TPN bag was only connected at night by a supportive nurse who lived close by and had decided to go the extra mile and look after her during Christmas. For New Year's Eve, Ruth stayed at home, but feeling increasingly weak and sickly, she remained in bed listening to how her relatives and young children danced in the other room. On 1st January, she was voluntarily readmitted to the ward and a catheter was inserted in her urethra to pass urine so that the liquid could stop building pressure in her bladder.

8.5 Life-enhancing death

It was 9th January, three months since Ruth was first admitted. Ruth, with difficulty, lying in bed and covering her body with the blanket, looked at me and told me as a greeting after two weeks without seeing each other:

- **Ruth:** I have been thinking, for first time, what will happen when the doctors tell me that they have used all the resources they had and that there are no more options available. I wonder how I will react because that will happen at some point.
- **Ignacia:** [*Surprised, I try to put myself together and remember the training and the conversations I had overheard from nurses and doctors breaking bad news... Measuring my own words.*] It will happen at some point. There are two things to keep in mind: first is that any reaction you have will be ok, because it is about you. The second is that you can continue praying, so you and your family are ok during that time.

Ruth listened to me with her eyes closed, telling me that she was sure that her family would be all right. She also said that she would be ok, not meaning that she would be cured but that 'God had her back'. Trust as a self-making practice in her case not only required prayers, but also a particular emotional display. Managing the fear of death successfully was used by Ruth to confirm her trust, projecting it outward. As C. Jason Throop (2008) argues for the people from Yap in the Micronesian states, in order to transform pain into a virtue that strengthens the moral character of the person, the process of subjectification includes careful management and concealment of dysphoric sensations; at the same time, they are embedded in a longer cultural narrative that sanctions particular dispositions (being extenuation from work and compassion, in the Yapese case). Working on her trust

in God was therefore happening hand in hand with her work on her emotional reactions that could demonstrate the strength of her beliefs to herself and others. Coincidentally, she had some news to break to me. She looked at me with only one eye open, as the other was hidden by the pillow:

- **Ruth:** I got my last chemo. There is no more. The cancer keeps growing and the drug has not helped. Now I have just to wait. *[She does not smile, but she does not show her sadness that much either. I believe she is just resigned.]*
- **Ignacia:** *[I look at her, then at the floor.]* I don't know what to say.
- **Ruth:** Don't worry. I am in the hands of God.

Realising the inefficacy of cancer treatment invited Ruth to strengthen her trust in God. In *Becoming Sinners*, Robbins (2004) crafts a model of cultural change drawing upon the experiences of a small community in Papua New Guinea, the Urapmin people. Robbins aims to examine Urapmin's lived moral struggle of being caught in between two cultural systems, which he understands is systematically structured in the contradiction between two paramount values: relationism and individualism. Relationism sanctions people's practices in relation to their efforts to construct social relationships on which the Urapmin people depended. Individualism, brought by an individual model of salvation offered by Pentecostal and Charismatic churches – which were increasingly shaping their social life – sanction individual responsibility, replacing wilfulness (for the cultivation in relationships) with lawfulness (in their obedience to God). It is in this process of cultural change brought by Christianity that Robbins shows how the Urapmin people carry out diverse ritual practices that aim to reconcile the contradiction of individual salvation offered by Christianity in a culture that still very much appreciates social relationships as essential to their culture. Moral reasoning, Robbins argues, is the ongoing exercise encouraged by the contradiction between those paramount values, which enables people to navigate the tension in the everyday. Indeed, frequent church services, sin removal prayers, confession rituals and, more importantly, Spirit Diskos are described by the author to exemplify the ways in which the Urapmin people try to come to terms with two different and almost irreconcilable systems of meanings that have not yet been synthesised.

Robbins' ethnography aptly helps me to elucidate the way in which Ruth is caught between two systems of meaning present in her dying experience on the ward. Like the Urapmin people, Ruth endeavoured to become a moral person through her voluntarily and conscious adherence to different forms of subjectification. The proximity of death and lost confidence in the power of biomedical care provoked a

tension. While still a cancer patient in the hospital and receiving the care of the clinical team, she individually worked towards building a closer relationship with God. As previous attempts to cure her cancer or even provide ongoing comfort started vanishing from the horizons of possibility, Ruth concentrated on exercising her own 'gift of discernment', as she put it, blessing God and honouring the freedom He gave her to approach death. As such, that gift can be understood as a form of moral reasoning. Ruth's religious belief sought to remedy a clinical plot that was fragmented and no longer provided guidance. For her, matters of spirituality and biomedicine were interconnected, with doctors being potentially able to act as instruments of God. She decided to cultivate an alternative narrative that offered a different kind of hope, non-referential, that helped her to control uncertainty. 'I am not afraid of death. God has my back,' she repeated.

It was mid-January. I decided to see Ruth who was still on the ward, after a few days without visiting her. After Christmas, I started following a regime of one visit a week, agreed with her, to allow her more time to rest and to interact with an increasing number of people who came to visit her. I texted her to check whether I could go and she told me to please bring an ice-lolly, clear (without cream). I went to the cubicle in which she was with a lollypop, but she explained that she wanted ice cream, something cold for her throat. So I went down again to the kiosk and left her with the pastor who had just come to visit her. When I came back, both were singing a religious song in an African language they both shared. The image was beautiful, probably the most comforting one I experienced during the fieldwork. The blue curtains were closed and the light coming through them made the little space a bit blue. She, lying on the bed, bald from chemo, and wearing her pink pyjamas given by the hospital, was singing softly a song that praised God. She looked radiant in her sickness, lying with her eyes closed, holding the hand of the pastor who was sitting next to her. He was a young man of African background, tall and smiley. While they sang, I sat at the bedside and stared at the gadget that was disconnected. I didn't want to interrupt that moment in which Ruth's pain seemed not to exist. She smiled, relieved, and while keeping her eyes closed, praised God.

A few days later, Ruth's pain was getting worse and she received a new injection after the nurses heard her complaining. But the pain was increasing, the moaning getting louder, and her poor face was showing it. She kept changing positions, rubbing her belly, until she suddenly sat up in the bed. We stayed in silence while I gently caressed her arm. An abrupt change happened. 'I am sick,' she told me. I quickly gave her one bowl and closed the curtains upon her signal. She was not eating, only drinking water, so she did not have much to vomit anyway. She was sitting there, waiting, holding the bowl, shivering. Ruth's medical condition worsened

more and more over the coming days; she was hallucinating from medication and moaning with pain. Her pastor and friends from church were fortunately able to offer some momentary relief again. Two weeks after, her lungs became compromised by an infection that the team thought would not clear up. She was finding it very difficult to breathe. In the third week of January 2017, connected to her many bags and also to the oxygen cylinder, Ruth was facing serious difficulties in moving her body and finding relief from her then-compromised lungs. She told me when I arrived in an almost aggressive tone:

- **Ruth:** Now they say that they will not take off the catheter and I feel they are being dishonest with me. They told me that they would put it at the side of my leg and nobody would notice. Why do they do this to me? Every time we get to a point in the negotiation, they come up with silly ideas.
- **Ignacia:** [*I keep to myself all possible answers I could give.*] Yes, it is frustrating.
- **Ruth:** I have started to think that my condition has worsened so much because of the choices the doctors have made. I still don't understand how the cancer spread if I had radiotherapy. I had radiotherapy, then surgery, and chemotherapy and I was doing well. But then they told me it spread. How?
- **Ignacia:** [*I keep silent, looking at her. I am determined to just listen to her, attentively and compassionately.*]
- **Ruth:** And my friend came and asked me if I have thought about the eventuality of death! I don't want to entertain the idea! [*Staring at me.*] I am not afraid of death. The only sad thing is that I will leave my children behind! [*After some seconds of silence, resigned*] Anyway, there is no point in worrying for [that] which is not under my control. I pray so God sees me through.

This was the last conversation we had. I left the ward as the young pastor arrived, seeing that she was noticeably agitated. I said goodbye, troubled by the scene. Over the last week, she had had two respiratory arrests, which made her 'feel like someone was stabbing me', she told me. The nurses rang Ruth's husband both times to come immediately in the middle of his work shift. A few days after we had seen each other, she sent me a text message saying 'thank you for all your help, I am due to go home now'. She was discharged from hospital to live (and die) in her new flat, in the company of her relatives and friends. Until the last day, and despite all troubled emotions near the end of life, Ruth taught me that hope dies last.

8.6 Discussion

In this chapter, I have looked at the end of life of a young cancer patient who was receiving palliative care in a hospital ward in London. To do so, I have crafted a story that allowed for the lived experience of Ruth in its ambivalence, as her body deteriorated and her faith was strengthened. In such a narrative, some elements of Ruth's clinical experience were connected, seeking to make sense of unfortunate and abrupt happenings and their complexities. I have sought to accommodate particular events as they unfolded in a narrative, in hindsight, foregrounding an element of Ruth's identity that remained stable in the chaos: her religious belief. Being Christian was a truly pivotal element that kept her going despite the despair. Hope based on the idea that God had her back not only enabled her to continue adhering to more and more invasive procedures, but also to stay calm and not fret over the situation. I have shown that, initially, she was only left with distrust and frustration, which endured until the last day I saw her. By cultivating a relationship of trust with God, she tried to navigate a clash between two systems of meaning and, more importantly, craft some type of hope that could cushion her throughout the dying process. Ruth freely engaged in prayer and emotion management, thus becoming an ethical subject who not only praised God, but also demonstrated that there might be something else beyond the technological biomedical limits.

Building trust was an essential practice to understand Ruth's subjectivity at the end of life, when advanced cancer relentlessly conquered her body parts and truncated her opportunities for survival. Ruth's subjectivity was characterised by her devotion to God and his causes at the same time as she embraced treatment. There were never guarantees that the last available treatment would eventually work and yet Ruth embraced the contingency of the results knowingly, that results were dependent on something else (Crapanzano, 2003). However, the difference is that, through the trust-building process, Ruth endeavoured to work on her relationships with that 'third party' that might harbour the success of the actual treatment regime. Thus, following Roberts (2012), who carried out ethnographic research in fertility clinics in Ecuador, we could understand Ruth's moral landscape of the treatment as characterised by a combination of science and religious tradition. Similar to the way in which fertilisation techniques were sought in the Ecuadorian clinic – where clinical protocols were methodically followed at the same time as faith was placed in God as a life provider – spiritual and scientific practices coexisted in Ruth's interpretation of clinical practice in the hospital in London. Still receiving the last chemotherapeutic option, Ruth considered that clinical professionals, and even myself in my soft-care role during treatment, were God's instruments. This is to say that Ruth did not shift

her trust from the clinical profession to her spiritual resources in a zero-sum game. Rather, with both elements constituting her moral landscape of treatment, she saw the need to strengthen this relationship with her spiritual roots as the situation demanded.

However, this argument should not only be read in religious terms. By acknowledging how Ruth's belief specifically worked as a resource to confront death, a larger argument that I aimed to show in this chapter is that once biomedicine stops offering its own resources to cope with cancer, people like Ruth may swiftly change the focus of their attention. In Ruth's case, she sought to strengthen a relationship of trust in God, as one way of cultivating forms of subjectivity marked by non-referential types of hope. As such, hope was a social practice that Ruth worked upon to counteract the uncertainty of her condition and truncated future. It worked in a double temporal horizon: on the one hand, it helped her to endure a day-to-day experience filled with pain, toxic drugs and frustration; on the other hand, it nurtured her efforts so that her family could lead a relatively normal life. Rather than underpinning hope in her own medical recovery, Ruth's hope advanced a different possibility of experience for her children. Her labour of hope was made on the ward so that her children could be supported by caring people and could live a joyful life. In fact, against all odds, Ruth convinced her husband to bring their families from her home country under the same roof for the first time in their lives. The occasion: 'To celebrate a big Christmas together.' Before the end of the year, Ruth and her side of the family, who had already arrived, were busy on the ward preparing the party they would throw, with the ethnographer also taking part in the organisation by transporting long tablecloths to the ward and briefly minding the children while they discussed the details. Ruth's hope, albeit sometimes tricky to decipher by me, made her dying experience on the ward a process of 'reaffirmation of life' (Kellehear, 2014) through the protection of people and values she cherished and the creation of loving and intimate moments with them.

Chapter 9

Conclusion

9.1 Understanding patient experiences of treatment

Policy efforts have put patient experience at the heart of healthcare improvement plans. A better understanding of patient experiences of treatment allows healthcare providers to further improve a patient-centred approach in medicine, through which the healthcare system can monitor performance and improve services, gain contextualised feedback, be held accountable to their users, and strive for quality improvement that is responsive of patient needs (Coulter, 2011). Moreover, holistic approaches to patients that are aware of the diversity of needs and multi-layered effects that interventions make on people's lives offer the opportunity to foster therapeutic alliances and shared decision-making, as well as attune clinical practices to maximise the potential for symptom control, adherence to lengthy treatments, and the improvement of clinical outcomes (Retzer et al., 2018). A holistic approach can assist patients and carers in feeling that healthcare practitioners approach them in a compassionate and respectful way that acknowledges life projects and the relevance of regaining quality of life through the support they can offer if needed (Ziebland et al., 2013). Yet, the collection of patient-reported outcomes is sometimes inconsistent, with research indicating that procedures may be creating a potential source of bias in the resulting data (Glaser et al., 2015; Kyte et al., 2013; Retzer et al., 2018) as non-white ethnic groups, older people and people living in more economically deprived areas tend to participate in these reports with less frequency. Even more importantly, in studies of patient experiences of treatment, it is not explicit what 'experience' actually means.

Patient experience is a construct often operationalised in terms of reported perceptions of care received by patients, without considering the vast amount of

labour that patients and support networks do as well, even before self-management strategies are considered. In their effort to produce statistical and standardised results that can be used to make horizontal comparisons, metrics of patient experience such as the *National Cancer Patient Experience Survey*¹ have been paramount in health research at the expense of arbitrarily fixing ‘what counts’ depending on the questions and categories deployed. Following Adams (2016), who discusses the production, circulation and use of ‘evidence’ of global health interventions across the different geographic contexts of the world, it is possible to say that what counts as evidence in patient experience reports may not only function as the gold standard for demonstrating the value, both clinical and economic, of cancer interventions; the use of such evidence has vast implications for the discussion about what counts as efficacy in health interventions. Because of the embeddedness of patient experience metrics in an audit culture that only funds interventions that are proven in impact and cost-effectiveness, deciding what to include in the metrics may indeed change how patients are supported.

This poses the question of how to listen to patients’ needs better to support their quality of life during and beyond treatment. Experiences of treatment are temporal and individual. On the one hand, they are not only created along the pathway by the interaction between patients and health professionals (Mattingly, 1998), but they also change over time as the meaning and urgency of clinical interventions are appraised differently by patients while the progression of the disease unfolds (Pols and Limburg, 2016). On the other hand, they depend on the particular values that the respondents cherish. This is an important reason to critically examine the concept of quality of life of cancer patients throughout treatment, not as a status achieved once and for all, but as a process of continuous accommodation in relation to both the moral economy of surveillance and responsibility that organises certain biomedical discourses, and the ethical values people hold relevant in their lives. Moreover, understanding quality of life as a concrete and personal composite of ethical values complicates the understanding of the ways in which people strive and struggle to achieve a life with others.

Producing knowledge about patients’ quality of life while receiving anti-cancer treatments is therefore complicated by several reasons. As Warren and Manderson (2013) argue, current quantitative measures on quality of life used by oncology clinics are based on assumptions about how people must experience and value different situations, and how those experiences are measurable to produce stable and comparable results. Moreover, this psychometric instrumentation currently

¹Surveys are designed, implemented and analysed by Quality Health, the largest provider of patient and staff surveys to the NHS that works for 360 trusts in the UK

used in cancer care often fails to capture underlying inequalities that exist between people, as it does not always account for the attitudinal, political, and material contexts in which medical conditions are lived. Moreover, the authors suggest that producing reported outcomes is in itself an intervention. The concept of quality of life is always the product of a comparison that the respondent makes in relation to previous experiences, how s/he sees other people in similar situations, and how s/he understands what s/he is 'expected' to feel. In that sense, accounts of quality of life are not only embedded in deep contextual nuances that refer to society, memory and history, but they are also shaped by power dynamics that define normative responses and shape what is appropriate to answer to the nurse specialist (or researcher) asking the questions. Writing about patients' experiences of hospitalisation in a referral cancer hospital in Nairobi, Kenya, anthropologist Benson Mulemi highlights the value of hospital ethnography in this regard:

The patients' current hospital stays in this study reveal only a small part of their long and cumulative experiences of life interrupted. Serious illness disrupts the normal rhythm of life, thereby threatening patients' lifeworld (Good 1994). Their lifeworlds entail a daily struggle for a quality life. However, wider socioeconomic issues outside the hospital also have a bearing on the struggle for wellbeing in the hospital. This ethnography shows that a hospital ward may conceal most patients' livelihood and treatment backgrounds – backgrounds that shape their hospitalisation experiences. Both objective and subjective factors within and outside the medical setting shape patients' interaction and satisfaction with biomedicine. Hospital ethnography therefore facilitates an understanding of an array of patient care issues that other kinds of hospital research may fail to reveal (Mulemi, 2010, p.199).

Hence, understandings achieved through quantitative analysis (e.g. national questionnaires and patient-reported outcomes) are strengthened when coupled with qualitative understanding of the treatment pathways in patients' own terms. Following this line of enquiry, this thesis has aimed to unpack what 'experience' during cancer treatments is composed of for the patients and their caregivers, by examining the complex, small and silent practices that people carry out along the pathway and that nobody asks about. As the historian Julie Livingston argues, the experience of suffering cancer is composed by details. Foregrounding those details 'help to establish the stakes of illness and medical care' (2012, p. 28). In this context, Livingston argues that 'one strength of ethnography as a mode of writing lies in its ability to

communicate these details as they are emplotted in experiences of illness and care' (ibid).

This research project explored the everyday experiences of colorectal cancer treatments of patients and their support networks. The aim was to look at the myriad practices that patients and support networks articulate to navigate treatment and live with and despite cancer. Significantly, this was done from the perspective of what matters to them. The initial assumption, based on the literature review on qualitative approaches to illness experiences of cancer, was that colorectal cancer is not only a physiological/somatic experience, but also a social, emotional and moral one in which the self and self-other relationships were re-articulated to continue living. I asked: how do patients and support networks navigate the requirements, side effects and consequences of colorectal cancer treatments in London? Their answers pointed to the relevance of creating possibilities of experience where they could meaningfully and comfortably dwell throughout treatment. This is what I have described as the potential of caregiving as a world-making project.

I have argued that caregiving has the potential to create possibilities of experience for people affected by cancer that are other than death. However, I have been careful in not essentialising the ways in which those phenomenological worlds exist (or appear to the consciousness), or providing a normative account of how worlds *should* look. Instead, I have aimed to let them emerge through the development of the ethnography. Thus, this thesis does not attempt to suggest a hierarchy that sorts into preferred ways of coping with treatment. Rather, it aims to unpack the ways through which my participants made sense of cancer and were committed to treatment, navigating the disruptions that the condition (still) poses for their everyday lives by sticking to what they considered worth living for. This had methodological implications. A guiding concern that I sought to explore throughout is how one can give an account of the dynamics that make up the ethical projects of caregiving and what is the role of the researcher in supporting or advocating for those worlds? I asked: what does it take to use an ethnographic approach to look at the values that make the social worlds of patients affected by cancer? In the next section, I offer a reflection on the 'ethics of engagement' in fieldwork, exploring soft roles of research and the responsibilities that lie therein. As it will become soon clear, ethical guidelines regulating healthcare research become essential, but not enough, to guide the ethnographic research efforts with vulnerable populations.

9.2 Ethics of engagement

Carrying out research requires a rigorous process of ethical clearance in the UK. Organisationally, the National Health Research Authority was created in 2014 to protect the interests of patients and the wider public through the implementation of research regulations that guarantee the safety and quality of the studies authorised. All health research involving the participation of vulnerable patients must obtain ethical clearance from one of the 80 expert committees that are overseen by the National Research Ethics Service (NRES). Study protocols, including those of qualitative nature, are encouraged to put mechanisms in place in order ‘to safeguard the rights, safety, dignity and well-being of research participants’, which are in turn discussed by the expert panel. As I explained in the methodological chapter (Chapter 2), my research project successfully navigated this terrain before the commencement of fieldwork, which included: patient participant involvement to improve the design of the study, on-site supervision by a supportive clinical line manager, multiple forms of immunisation, and the design and use of approved patient information sheets and informed consent forms.

Hence, I obtained approval to carry out 12 months of non-participant observations of ‘naturally’ occurring interactions in the GI cancer clinic, where I first shadowed some of the members of the clinical team for three months, and then the sample of 10 patients in their treatment and follow-up consultations with clinical oncologists, nurses and pharmacists. Always framed as an invitation, shadowing patients also included being present in waiting rooms and for pre-assessments for surgery, post-surgery and chemotherapy cycles. I accompanied some of my participants who were there either recovering from surgery or who were admitted due to medical complications triggered by the fast progression of the cancer. As is apparent throughout the thesis, my fieldwork had two sides: the patients and their support networks, and the clinical team. With the clinical team, I joined consultant-led medical rounds on the wards, multidisciplinary team meetings and pre-clinic meetings to which patients or their support networks are not invited, in order to understand the nature of the disease and the way in which the clinical team negotiated its treatment. At the same time, I obtained narrative interviews from 10 patients and 9 of their caregivers, and 8 semi-structured interviews from health professionals providing direct care to patients in my sample. The ethics committee also approved that, after a year in the clinic, I spent six months paying visits to a subsample of participants and their support networks, only if and when – and as long as – they showed interested in meeting with me. The aim was to understand how they carried on with their everyday lives outside (or inside) hospital settings. Besides the inherent problems and the assumptions

that social scientists have criticised regarding the use of informed consent forms as a proxy of patient autonomy (Bell, 2016), here I would like to explore a different area of concern. Since no amount of research regulations could foresee the grey areas of ethical decision-making that ethnographers face when doing research with people who have life-threatening diseases, how do we approach and reflect on the ethical dilemmas that arise and what does that say about the nature of ethnographic research?

In the clinics, many patients looked to me to get answers about the gravity of the situation. I did my best not to communicate anything with my own expressions, and thus really be in the role of the (silent) observer, until I developed trust with a Latin American patient and all my distancing got screwed. I translated what Dr Z was explaining to her, as she was not understanding and growing very agitated by the possibility of having her treatment suspended. In that type of situation, I saw my role as the one who mediates, and Dr Z seemed to understand that. The bigger challenge was when there was information that you should not mediate: the prognosis of a patient was poor, the treatment plan for another patient was longer than expected. In those cases, my role was to use common sense and not to mediate: I was not there to break bad news, I did not know, with complete certainty, what exactly all the jargon I heard in the clinical meetings really meant, and I was not there to communicate frustrating news. Nevertheless, I was always facing grey areas of discernment. Dr Z told me at the end of the fieldwork (when I was not following more patients in the clinic): ‘You have to be careful with what you hear in these meetings.’ By then, that had been a clear concern for a year.

9.2.1 The second appointment

There were patients who came to the clinic accompanied (like Jimmy, Jay, Elizabeth, Robert) and others who did not (like Seaus, Jean, Ruth and Britta). Elizabeth was a woman who fitted into the first class of people; I always met her in the hospital with one or more of her close relatives. She would come with others because then the waiting is easier and, more importantly, because there are more pairs of ears to listen to what the doctors or nurses will say. With English as her adopted language, the communication of accurate symptoms and side effects, and the recounting of important questions she wanted to ask, went smoother in company of others who were sometimes more fluent in English than her. Bringing others to the clinic became more and more important to Elizabeth as she went along the treatment pathway. As any other patient of my research group, she was engaging in a constant process of sense-making in partnership with the clinical staff. What was going on in her body?

What was coming next? How long would all of this last? Those were the main questions that doctors and nurses would answer every fortnight for her, answers that she would go over again with her children and me later. It was as if she was having two appointments: the first with the doctor and the second, usually tearful, with us in the waiting room to understand what the doctor said and whether that was good or bad news. The exercise of interpretation was necessary for her. She feared that the doctors were hiding something from her, that they were not telling her the whole truth. After two complicated instances of the same surgery, one marked by an anaphylactic reaction to the anaesthetic and a second one (few months later) where she was literally at risk of dying due to haemorrhagic bleeding ‘from damaging a branch of internal iliac vein’ (as stated in the patient’s letter), her sense of trust in the clinical team had changed, and suspicion abounded. Elizabeth would tell me from time to time ‘why are they hiding information [from] me? I am not afraid of dying’.

What I understand as a second appointment took place not only to make sense of things, but also as an opportunity to do emotion work in which her children would listen to her attentively, wipe her tears and hold her hands, talk about the information that was given and explain how it would affect her. My position there was always challenging, but I clearly became an authorised translator for them, as I would understand the treatment pathway better than them (due to my experience following other patients and because I was attending clinical meetings). In fact, during that time, I carried out non-participant observations of 32 weekly meetings restricted to the clinical staff where treatment decisions were made: those were the pre-clinic meetings taking place before the chemotherapy clinic, and the multidisciplinary team meetings. In those meetings, I made sure that any bit of information I learnt about the conditions of my research participants was kept to myself, as it was clearly inadequate for me to break any news, not having the expertise or the authority to do that. But the fact that the patients knew I attended these meetings made them also doubt whether the team was hiding something from them, and they voiced their suspicions to me, for me then to provide reassurance or to invite them to talk again with the CNS or the treating doctor.

Elizabeth’s changing view about the way in which members of the clinical team were communicating with her resonates with anthropologist Sylvie Fainzang’s analysis of clinical interactions in cancer clinics. Drawing on individual interviews with patients and doctors, and non-participant observations of clinical consultations in a set of unnamed hospitals in France, Fainzang (2016) analyses the interactions of doctors providing care to 80 patients, among which 60 are affected by cancer. Immersed in those interactions, the author describes consultations characterised by

the incomplete provision of information, concealments and lies from patients and doctors, which are partially counterbalanced with non-verbal mechanisms through which both sides try to approximate the meaning of the other's message. On this basis, the author questions the assumption that patients are now fully informed (and therefore empowered). In terms of the processes used to gain patient consent to administer different therapeutic treatments, Fainzang focuses exclusively on those that turned into misunderstandings. She unearths some roots that might cause those clashes, encompassing cognitive frictions that are not only associated with the lack of a common vocabulary between patients and doctors, but also related to different ways of making sense of medical conditions (for example, patients think in particularistic terms in relation to their own bodies, while doctors think in terms of statistical cases and available evidence). Fainzang asserts that the asymmetrical nature of the clinical relationship is further revealed in those misunderstandings, concluding that, rather than informed consent, what she observed in clinical relationships could be better understood as resigned consent – that is, the asymmetry of the relationship tends to make patients surrender their power to decide to the medical authority (Fainzang, 2016).

I tend to disagree with this approach that places an undue contrast between the parties at stake: on the one hand, doctors, and on the other hand, vulnerable patients. There are resonances between Fainzang's understanding of clinical interactions and the concept of medicalisation and the view that places exclusive power on the side of the medical profession, a strand that started with Foucault's seminal understanding of the power of the clinical gaze to shape 'docile bodies' for the social control of the population that hardly holds true anymore (Conrad, 1992; Lupton, 1997). Biomedicine is not a monolithic enterprise (Van Der Geest and Finkler, 2004; Livingston, 2012), healthcare workers are not the bad guys, and patients are not void recipients of medical power. Importantly, Fainzang fails to capture the moral landscape in which clinical professionals work and ends up demonising them. My ethnography shows that what for Fainzang is a lie, could be better understood as the pacing of information. Breaking news step by step is seen by the clinical team as necessary for the patients' own emotional well-being, as it does not make sense to worry them with possible future situations for which there are no guarantees. Although it could be seen as a paternalistic attitude in some degree, this view corresponds to the idea of a clinic that is open but does not necessarily overwhelm the patient. Indeed, pacing information is necessary to cultivate hope for recovery, as Elizabeth did. In *American Medicine: The Quest for Competence*, DelVecchio Good (1998) unpacks the clinical narratives through which oncologists combine the worlds of science and therapeutics in the US. This anthropologist's argument is that

professional competence is crafted through clinical narratives that aim to give shape to patients' experiences of treatment at the same time as they structure the way in which medical information is given. In my own research, I have taken those clinical narratives as a departing point to understand how doctor-patient interaction was structured in the clinic. However, clinical narratives also may fail and may change the ethnographer's role, as happened with Ruth when she embarked on the palliative pathway.

9.2.2 Soft roles: 'I am her masterpiece'

Although I thought I had already got to know Ruth well as I accompanied her throughout her chemotherapy treatment for almost a year, the following 15 weeks on the ward enabled me to gain a much deeper insight into her cancer experience and way of life, affording me to learn from intimate moments that she generously shared with me. At the beginning of her stay, she would introduce me to the various friends, colleagues and relatives that visited her as '*Maria, a researcher; I am her guinea pig*'. After three times in which I respectfully explained that I did not consider that our relationship could be described in those terms, as I didn't think ours was a relationship marked by instrumentalisation nor was I trying new interventions on her, she told a new friend coming that '*She is Maria, she is following my treatment and how I react to it. She doesn't like when I say that I am her guinea pig, but I am her masterpiece [laughing]*'. We had good rapport by then – going to see her on the ward once or twice a week, always asking by text beforehand whether I could pay her a visit, smuggling drinks or ice-cream for her on request, leaving when most of the visitors came, or impotently seeing her moaning with pain and trying to get her mind off it by talking about life outside the hospital (something that some palliative care nurses I met in the clinic called 'the recreation of the mind').

My role on the ward evolved during these weeks. In the short time I stayed with her, I started being her advocate and bed assistant: bringing ice and water to relieve her sore throat after weeks using a nasogastric tube; going to ask pain-management nurses for more painkillers to top up with in an endless effort to get her on top of the pain; asking nurse assistants to come to see Ruth to help her drain one of her many bags (from the stomach, the bowel, and later on from her kidneys); closing her curtains when the projectile vomiting started; trying to get a charger for the chemotherapy device that was beeping incessantly; and, more importantly, tidying up her small cubicle and crowded bedside table from the bowls with tissues and spit water before visitors arrived (a role shared with her husband and sister-in-law who

came to visit her on a daily basis). One day, she graciously and gratefully told me that I had got ‘a masters in bed assistance’.

These modes of participation in fieldwork are a common thread in long-term anthropological projects. During the 18-month fieldwork in New Mexico, Angela Garcia volunteered in a publicly funded but economically constrained detox facility, and offered human contact, emotional containment and acknowledgement of the pain of those users who were suffering severe symptoms of heroin withdrawal (2010, p. 28–38). Livingston, in Botswana, acted as the chaperone, driver, advocate, translator and sounding board for the cancer patients of the ward (p. 24). Following Livingston, care practices occurring on the ward are not only situated within a bureaucratic field that allocates responsibilities and expected roles. The ward is also an existential space in which improvisation occurs. Livingston writes ‘[patients] recognised that I, unlike the busy staff, was someone who had more time to answer questions, to listen to their existential angst, and to provide encouragement or at least recognition of the challenges of their predicament’ (2012, p. 24). Both, Livingston (2012) and Garcia (2010) helped me to understand that ethnography (with cancer patients) is a mode of participation in the life of others; even if this mode of participation is clearly incomplete, it keeps something of this incommensurate experience of suffering. Although avenues to really feel what the other feels are clearly diluted and partial, there is still a consideration about how time, vulnerability and openness towards the other makes the researcher and the researched mutually implicated. Eliding any definition of research ethics, remaining watchful and attentive to the needs of others is the minimum that anyone can do, but our ability to fully empathise has painful limits.

9.2.3 On the powers and limits of friendship

Just as cancer care has limits, so do world-making projects. Attempts to create other possibilities of experience sometimes fall short, so it is fundamental to highlight those aspects. I have tried to show that caregiving understood as a world-making project is not only about wilful perseverance to make things better or at least be able to endure them; world-making faces material and affective constraints. In short, caregiving is precarious, and so is the world that is created out of its potential. There is an autobiographical story that just happened when I was finishing writing this thesis in 2018. I entered the church where Simon’s funeral was taking place. One of his friends had reached out to me to break the bad news about Simon’s painful death. Shyly, my eyes met the evasive looks of others who recognised me there, but did not want to interact with me. I also met a few friendly faces. It had been 13

months since I had finished the fieldwork and had given Simon an ‘end of study’ letter while he was receiving chemotherapy for a refractory metastatic sigmoid cancer that was slowly conquering his liver. In the written letter, I formally thanked him (and all other participants) on behalf of the hospital for his generosity in sharing his experience with me. We had met because of the research, but he expected that I would stay the same after it finished. He considered me ‘a good friend’. Facing complex social, economic and emotional needs, for exactly 12 months, he welcomed me into his social world, introduced me to his closest friends from church and invited me to monthly events that he and his community were running where I helped as much as I could. Simon let me enter at a time in which he was seriously vulnerable. At risk of being made homeless by his family, he invited me to the hearing in court in which the judge decided in favour of the relatives who initiated the legal procedure. Without a job and living out of the generosity of his friends from church, he was penniless, depressed and usually hungry. Throughout the process, Virgin Mary was his most powerful advocate and his consolation was that he had been blessed by becoming friends with members of the church.

The day I gave him the letter notifying the end of the fieldwork was no surprise for him. We had talked about me leaving London for the last three months on several occasions. The fact that I was leaving my research position at the hospital motivated me to try to put him on social security. We had agreed that he was desperate for money as he was going hungry, with his safety at risk because of the place in which he was still living at that time. At that time, he asked me not to tell the clinical team about his needs, and because the safeguarding team of the hospital was already aware of his situation, I accepted. Eventually, a specialist nurse and support nurse came to understand the situation from his own accord, which did not make any difference (good or bad) as his situation sat besides the scope of what a hospital can do. During the final months, the atmosphere of our (research) relationship grew increasingly toxic for me. I felt as if Simon was trying to manipulate me through an emotional dynamic that depicted him as powerless and vulnerable, while I was a traitor who was betraying him in the same way that so many others had done in his life. With all that he had given me! (he appeared to say). Assuming that everything he said was right, I could not stand it for much longer. So the day I said goodbye, I did not only give him the end of study letter; I also gave him an envelope with a flashcard for the Macmillan Cancer Support phone line and the printed forms necessary to claim social benefits, for he continuously complained about his inability to access the internet. There were few text messages in between from him inviting me to do things and me refusing because I was living in a different city and trying to move on, still thinking everyday about my research participants as I had started

writing the thesis. The next time I saw him, he was inside a coffin in the catholic church in West London where a funeral mass was taking place. There, his friends from church and I recited the prayers and sung the hymns that he had once taught me, for his ability to eternally rest in peace.

I am telling this story not to redeem myself, but to highlight the fragility of world-making. The guilt of feeling a traitor is a common experience among some of the caregivers I met. Paraphrasing Malkki, the feeling of ethical inadequacy is paramount to understanding the delicate balance between proximity and distance in the field (Malkki, 2015). Such scalar impossibility stems from what Mattingly, Dyring, et al. (2018) understand as phenomenological excess that is experienced by caregivers (and researchers) as an ethical demand. Such experience asks you to be responsive, and the research participants from whom I learnt were resourceful in answering such requests, emotionally and practically. However, there are moments in which people run out of those resources. My role as researcher prepared me to support some of my research participants in making sense of their circumstances when they were feeling lost throughout the process, but I had not been allowed by anyone else to get as close as Simon allowed me to. Having done research for several years among vulnerable groups since I got into university 11 years ago, I was not prepared to deal with the existential drama that Simon was experiencing, and I felt unable to respond. How is it possible to be deeply intrigued by the potential of caregiving to create comfortable experiences for the ill, and, at the same time, fail in actualising its possibility? Was it that I was preaching what I did not practice? Some anthropologists, and many other scientists, would suggest that it is not my role to advocate for others' worlds – simply understanding them would suffice. For them, the role of the ethnographer includes emotional (and moral) detachment in order to gain an objective view. I disagree with this, and would argue that it does not make the analysis of this thesis less valid. As Sharon Kaufman (2005) put it:

[Our] emotions about patient and family suffering were inseparable from [our] emotions about being careful researchers, constantly on guard about the impact of [our] intrusion on staff routines and into patient and family privacy (Kaufman, 2005, p. 16).

Ethnography does not happen behind a glass barrier – the incommensurate experience of witnessing cancer as an existential space also gets to you as an ethnographer (even though some ethnographers may sanitise their view when publishing). Ethnography has never been pure, but rather an extremely embedded practice in which we constantly engage with the unfolding of the worlds of our research participants, entangled with our own. I have said in Chapter 2 that the ethnographic material

that gave form to this argument has been filtered, first by my own position within the interactions in the field, and then by the analytic categories that seemed relevant by my participants (and the growing scholarship in the field) to explain patient experience. Along this line, the only provisional and unsuccessful answer to my own dilemma is that I got caught in my own game; doing research trying to understand my participants' ethical values and supporting them in the realisation of them made me embody how it feels when it fails.

Perhaps if I had looked at caregiving as a routine in which intentions and dispositions do not matter, this would not have happened. Simon's commitment to and reliance on his friends from church could have been only seen from the perspectives of the reality effects it created, not the values that put such practices forward. Simon cherished friendship, in opposition to blood kin relations, as the main support of his existence as a relational being. Moreover, he ran the extra mile to demonstrate his concern in cultivating friendships, also with me, throughout his life as an adult. Knowing that, betraying such friendship, he thought, was the worst I could do to him. He then communicated this to his friends by saying 'She [Ignacia] left me', as the friend who reached out to me explained at the funeral. Of course, the responsibility of this is only mine. A clearer definition of the roles and expectations that I could adhere to would have been extremely helpful, in hindsight. But that would have meant that participant observation in the construction of the world he desired was not an option. Going to church with him monthly, helping setting up the praying events for prosecuted Christians every two months, hanging out with his friends at McDonalds, bringing bread and cheese from the nearest supermarket to eat it at the hospital canteen every now and then, learning to use a rosary or learning to recite Our Father and Hail Mary in English based on his rushed jottings on a napkin, would not have been part of my fieldwork. Was all that so important anyway if I did not write about it at length in the thesis for which this fieldwork was carried out? To be honest, I basically could not do it – I was too close to it and emotionally damaged too (even if self-inflicted for the sake of the research). Instead, I chose to write about Ruth's process of ethical self-fashioning at the end of her life, an experience that, while it shared similarities with Simon's religious experience of finding solace in God, kept me within the remit of the treatment pathway.

If it were not for Simon's experience, this thesis would have not been about world-making. It would have still been about caregiving, but only considering the navigational skills of my research participants, following the original phrasing of my research question. Simon helped me to see that navigating treatment was not only about cancer, but also about going on with life despite cancer's presence. That caregiving is more than harm reduction practices. That coping with treatment is

more than just swallowing suffering and trying to remain intact. It was through Simon's eyes that I started looking at values in the first place. For him, values were what inspired health professionals' kind approach to patients in the hospital, making him feel as if he was in church. My approach to patients and relatives affected by cancer was infused with what I came (later) to understand as the concept of ethical imagination developed by Liisa Malkki. The encounters that made my fieldwork in the clinic as rich as it was proved to offer a kind of excess that I had to constantly negotiate in order to make sense and navigate the experience. Akin to the 'scalar impossibility' – equivalent to what I have referred to earlier as the 'incommensurate experience' – posed by the suffering that wars create and Finnish aid workers can but only grasp, fieldwork among people affected by cancer poses an existential excess that obliges the researcher to imagine. In *The Need to Help*, imagination is at the centre of processes of world-making for Finnish professional workers and volunteers involved in the international Red Cross. Workers' and volunteers' constructed (an idea) of the humanitarian subject as someone concrete who was in need and who was placed in a specific circumstance that called for action. Hence, imagination has reality effects. Drawing on anthropologist Amira Mittermaier (2011), Malkki argues that the imagination is constructed as a 'dialogical in-between space in which the invisible and the visible are intertwined' (Malkki, 2015, p. 18). This space manifested in my fieldwork as intuitions that I felt or sensed when interacting with participants, and it pointed to situations that were not in themselves available to me but nevertheless informed the situation. Knowledge is always partial. Crucially, this process of ethical imagination, which is clearly situated in the circumstance of each person, had a direct correlation in the forms of responsibility that the Red Cross workers made sense of and acted upon. Here, the resources informing the need to help cannot be disentangled from the needs of the workers themselves, making them vulnerable to the products of their own imagination.

Malkki advocates for the relevance of those processes of world-maintenance that inform both undervalued forms of aid and care work in which her interlocutors are engaged. Writing against the belittling of humanitarian forms of help that are mundane, such as the one performed by Finnish isolated ladies who knit blankets and teddy bears (Aid Bunnies and Trauma Bears) for children materially and psychologically affected by the war in other parts of the world, Malkki argues for the reality effects that those forms of imagination have over the world. Frequently thought of as politically naive, the domestic arts and crafts are seen as 'the mere' in the service of international aid, which mirrors the trivialisation of humanitarianism against 'real politics'. However, humanitarian aid, in its own domesticity, has the potential to connect people to each other, offering transformative resources for all

those who engage in the encounter. Malkki suggests that this process has a parallel in the undertaking of ethnography when conceived as a situated sensibility. Fieldwork is then an intersubjective social practice through which the ethnographer recognises the contrast between her own position of privilege and the structural position of the concrete other with whom she engages. ‘It is out of being someone, somewhere in particular, that one ends up making greater ethical and imaginative connections’ (Malkki, 2015, p. 52). It is the concreteness of the circumstance that requires improvisation, to make decisions and act *in real time*, with no script at hand but the training and embodied experience one brings from without the field. In this endeavour, Malkki suggests that ethics and affect are entangled. The balance between distance and proximity is at the nerve of the process of emotional management in fieldwork, where imagination again fills the space. As a Red Cross psychologist interviewed by Malkki says: ‘We don’t just react to what really happened, but also to a mental image of what could have happened.’ There is an impasse or impossibility where there is no right balance, where ethics have to be improvised and created anew. It is through this form of improvisation that anthropological knowledge is created.

9.3 A lived pathway

Unlike most of the countries around the globe, the British NHS offers a possibility of experience other than indebtedness and death to people affected by cancer. Since most of my research participants would have not been able to afford treatment if its economic cost was free at the point of care, this thesis has proposed to consider the NHS as the material engine of cancer care. Institutionally, it creates a healthcare environment that affords a different possibility of experience to those who are entitled to receive treatment. Despite funding pressures, professional understaffing and the lack of integration (in themselves institutional dimensions that cry out for improvement), the NHS offers a sequence of treatment options to people affected by cancer, which are organised around a set of clinical interventions. After the confirmation of diagnosis of colorectal cancer and the staging of the disease, patients can decide to undergo surgery (if the tumour is resectable), radiotherapy (if the tumour sits in the rectum and needs to be downsized), and systemic treatment (including chemotherapy) with curative or palliative intent. This thesis has sought to unpack what those clinical trajectories look like from the point of view of patients and caregivers, and understand how they navigate the effects that it has on their bodies, relationships and understandings of the self.

Colorectal cancer interrupted the everyday lives of my research participants, and yet they strived to persevere to keep on living. ‘Life must go on’ is an account of the

practices they articulated to get on with treatment, creating a different possibility of experience and the values that inspired them to do so. I have suggested that enjoyable relationality, the affection one feels for others, could be understood as the main ethical value that gave meaning to patients' efforts to adhere to treatment. As an extension of the anthropological literature framing the relevance of hope for a cure as the key affect informing cancer trajectories, in this thesis, I have suggested that seeking treatment to stave off death is a simplification of the perspective of people affected by cancer when adhering to treatments. Indeed, my research participants sought to achieve remission to get on with their lives, a goal that may have been informed by a cancer narrative that tends to praise those who achieve a cure, yet they did not do it for the sake of it. They embraced treatment for the sake of the commitments and affections they felt for others. The challenge was then faced when the realisation of this value that was organising my research participants' caregiving efforts came into tension with other values, or with the economic and affective resources that they have at their disposal. It has been through this line of analysis that I have stressed the fragility of world-making efforts.

This thesis has thus combined a focus on the wilfulness that motivates my research participants to adhere to cancer treatment – thereby putting up with the pain, fatigue and temporal social impairment that occur as side effects or consequences of treatments – and the material and structural conditions that enabled them to move on and live with cancer. As such, economic deprivation was an important prism that was implicit throughout the thesis. In Chapter 3, I sought to provide a political and historical context in which the cancer clinic was working and my research participants sought treatment. I argued for the relevance of the welfare state, NHS included, to buffer the catastrophic impact of cancer treatments in the house economies of several families who not only could not have afforded treatment, but also depended on the supplementary income and housing, among other benefits that welfare policies granted them. However, historical budget constraints and political dynamics at the national level have been threatening to jeopardise such life-giving institutional arrangements, making it more likely that support will be denied to those people who are most vulnerable, with fewer informal networks in the country. I showed how Brexit, coupled with the rationing of the welfare state, were shaping the idioms of entitlement and deservingness through which people affected by cancer relate to the state and made sense of such relationship.

Chapter 4 took on the task of analysing the relationship between my research participants and both the NHS and the cancer clinic in particular. Even though cancer care enjoyed relative wealth when compared to the national budget allocated for the treatment of other clinical conditions of high prevalence in the country,

I showed that the distribution of those resources is geographically uneven. As a result of a political economy of health that creates incentives for competition, rather than collaboration, between healthcare providers, and a complex re-arrangement of responsibilities at community-based and specialist health providers, treatment outcomes are distributed along the deprivation gradient in the country. Higher overall cancer survival and quality of life after colorectal cancer treatments are disproportionately concentrated on the patients who have the advantage of living in better-off geographical areas across the country. This is what is referred to as the ‘post-code lottery’, a form of inequality that the NHS has historically (but not always successfully) tried to tackle in everything it does, from treatment pathways to clinical partnerships, including cancer care guidelines and support services. Still, economic deprivation emerged as an important factor shaping people’s experiences of treatment. Under the recent Care Act modification in the UK, patients affected by cancer who work with a contract are entitled to request reasonable and flexible working arrangements, and also request sick leave during their time of treatment and recovery after surgery. That is in theory; however, I learnt from my participants’ experiences that, in practice, 0-hour contracts don’t offer sick leave but ask you to stop providing services (as happened to Simon, who lost his job after the cancer diagnosis) and paid sick leaves for some patients are time limited (as happened to Leia, who started using her holidays). From Elizabeth and Ruth, I learnt that the reduction of income created by the absence from work makes household economies heavily dependent on the company’s insurance to make up for the remaining amount of money that the employee stops paying.

The clinic, in the eyes of my research participants, stood out because of its professionalism, resourcefulness and innovation. I asked: how does it feel to receive treatment in a reputable hospital when everyday lives are marked by some form of economic deprivation? I teased out some of the practices through which my research participants navigated access to the cancer clinic to obtain a treatment after diagnosis. One of the aims of the chapter was to describe ethnographically the fluidity of positions that London residents navigate in their everyday lives, where advantages and disadvantages were not necessarily structurally predetermined, even though deprivation at the point of origin mattered to a great extent. In fact, throughout the thesis, deprivation has appeared as affecting people’s cancer outcomes and quality of life negatively. More research is necessary to understand what happened to those cancer patients outside the cancer clinic, when seeking (or not) healthcare in their local neighbourhoods and when going (or not) to general practices, to find out what was burdening them. Policy research in cancer care has shown the higher burden of disease in this patient population (DH, 2014; Glaser et al., 2015; NHSE, 2016).

If we want to further improve survival in the UK, people living in deprived areas – harder to reach by researchers most of the time – must become an important focus of qualitative research in the country.

Among the standard interventions available to treat cancer, surgery stands for the technique with highest curative potential. However, bowel surgery for eligible colorectal cancer patients created important issues of bowel motility and faecal incontinence for my research participants, who had to learn how to get acquainted with their modified bodies over time. A fundamental type of body modification occurred when a stoma was temporarily or permanently created. In Chapter 5, I unpacked the socio-material practices that make up the body with stoma in order to complement academic perspectives than understand the challenge of faecal incontinence from the point of view of its effects on the individual's self-image and integration into social dynamics. Drawing on three ethnographic cases (Jay, Elizabeth and Simon), I offered a description of the practices through which the stoma is managed. Highlighting some material aspects, I attempted to shed light on the preconditions of bowel control for people with stomas, people who must achieve control every day. By doing that, I complicated the concept of 'adjustment' widely used by clinical practitioners to assess the extent to which a person undergoing stoma formation is able to cope with the demands and consequences of the surgery. In dialogue with the literature on psychosocial oncology, I argued that adjustment, a normative concept that defines how well a person is able to modulate the emotional impact of the stoma in terms of her/his definition of the self and her/his social world, could be better understood when taking into account the material affordances that make both life and stoma care liveable during and beyond treatment. By unpacking the myriad care practices that patients and caregivers engaged with to navigate changing metabolic processes and leaky stoma bags, I argued that the everyday is not a given for my research participants. Even when stomas are reversed, bowel urgency may still be a challenge. Instead of focusing on patients' perceptions of lack of control (what is widely understood as self-efficacy) or their disregard for the recommendations they received from clinical professionals (understood as non-compliance), my ethnography in this chapter indicated that well-fitting stoma bags over healthy skin solve most of the struggle if basic infrastructure is provided.

Nevertheless, the long-term effects of bowel surgery and chemo-radiation were sometimes insufficiently understood among my research participants, affecting the ways in which they could prepare for treatment and resume their lives outside the clinic. Two female patients in their 30s who underwent chemo-radiation to shrink rectal tumours commented separately on their painful and deteriorating sexual lives. They told me, separately, that even though the skin around the groin had healed, their

vaginas had stretched considerably. Having observed chemo-radiotherapy clinics and talked with CNS A, I asked them if they kept using the dilator that is recommended. They did not. One of them told me that ‘the biggest one is not penis size so I do not see the point of using it’. After a year, I asked both of them how they were doing. One told me that, at the beginning, sex was very painful and she could not bear it. She realised that she had to just ‘put up with the pain’. ‘Sexual pleasure is a capacity that I have lost after treatment,’ she lamented. Sexual complications are known to be one of the lowest rated outcomes reported by rectal patients after cancer treatments. Given how important it was for my participants to honour the affection they felt for the people they loved, chemo-radiation appeared to them as an effective but handicapping clinical technology.

The lived experience of cancer treatments has multiple tenses. To the present of the medical condition and the future projection of its prognosis, one could add the perfect futurity of regret, that which could have happened if one would have done things differently. Changing the temporal track from stoma management and looking at anticipatory dynamics that colour how the future could be seen in hindsight, in Chapter 6, I looked at the care for the post-cancerous body in the context of people who underwent surgery with curative intent, but were accepted to receive adjuvant chemotherapy as ‘an insurance, not a guarantee’ to prevent cancer recurrence, the main cause of death of that patient population. The key question that I addressed in this chapter was: how do my research participants draw the line between efficacy and quality of life for the purposes of preventing regret? I teased out the values that healthcare professionals, patients and caregivers produce and negotiate when chemo-prevention is pursued. Engaging with anthropological literature on medical risk and cancer survivorship, I explored a domain in which the medicalisation of risk takes place, producing epistemic values vis-à-vis ethical values. In particular, I looked at chemoprevention that was used as an ‘insurance policy’, unpacking the lived dimension of this hopeful last treatment by looking at the hurdles patients go through when caring for a toxic yet post-cancerous body. However, unlike social science literature that focuses on the moralisation of risk management as a sort of biomedical imperative posed to patients by the scientific-commercial cancer industry, I chose to foreground the motivations that my research participants expressed when adhering to chemotherapy, and the ways in which the clinical team appraised clinical situations combining evidence and situational judgement. I suggested that the ethical values that patients and their support networks strive for might rest upon anticipation. They subjected themselves to drug regimes that could minimise the unfavourable probabilities of cancer recurrence in order to prove to themselves, and to the people that they love, that (at the very least) they were doing something about the risk.

On top of diarrhoea and fatigue, an important (albeit unstated) side effect experienced by all my interlocutors receiving chemotherapy and which is not considered a kind of toxicity by the consultants but a ‘normal experience of treatment’ is that patients deal with the emotional side effects of looking after an achy, tired and leaky body at least until treatment finishes (after that, bodies are expected to slowly start to ‘bounce back’ together with people’s moods). I argued that being able to see the other end of the lengthy treatment involves doing a vast amount of emotional work *to get on* and *to keep the spirits up* despite the vicissitudes of cancer and the uncertainty of the effectiveness of treatment. Chapter 7 was a bridge chapter in this sense. It provided a perspective of what it takes to adhere to cancer treatments affectively speaking. By looking at emotion work, it suggested a closure of the treatment pathway with curative intent and it opened the discussion to incorporate the essential feature of colorectal cancer types that cannot be cured: the proximity of death. I asked: how does it feel to commit to the suffering other? Highlighting the affective experience of both health professionals and patients’ close relatives, the chapter presented the argument that silence may be understood as a practice of world-making. Following the concept of emotion work as an interactional dynamic through which a specific atmosphere of containment or harmony is articulated to care for the relationship with the suffering other, I argued that silence is an active practice that enables informal caregivers to dwell in a moral experience that is suffused with frustration. Frustration was an affective atmosphere that I first found in the clinic and on the ward, and lately felt its weight at patients’ homes even after treatment had finished. I showed that, unlike healthcare professionals who have learnt to deal with this atmosphere by ‘switching off’ after work, informal caregivers must negotiate a complex tension around the repression of their own frustration and tiredness, and the expression of compassion for the benefit of the patient. Moreover, unlike healthcare professionals, friends and relatives were not protagonists of the story, which blurred any clear delimitation of safe spaces in which they could openly talk about their emotions without experiencing guilt. Therefore, I suggested that the practice of silence that structured emotion work for caregivers not only reproduced a normative distribution of voice, but also pointed towards how the affective labour that mostly women carry out is undermined. Committing to the suffering other meant that carers could not move on with their lives as usual as they had to be with the patient or accompany them to medical appointments. This caused isolation for some of them, especially since some patients were reluctant to spread the news of their diagnosis among the people around them. Therefore, the effect that looking after someone with cancer has on their mental health was also silenced. Clearly, the fact that male lay caregivers tend to not express the emotional burden of cancer in

the same way that women do does not directly imply that they do not feel it. There is more research to do to understand what are the safe spaces or modes through which they debrief.

In Chapter 8, this thesis approached patients' experiences when sitting at the edge of the biomedical imaginary. I explored the performative role of clinical narratives to understand the emergence of ethical subjectivities of people affected with advanced bowel cancer when they are approaching death. Caught in the tension between doing and not doing as two forms of clinical activity that gave shape to Ruth's experience of puzzlement and distrust with the clinical team, I analysed Ruth's clinical narrative to make sense of such perceived tension that balanced practices guided by a technological imperative and by symptom control. As seen in Ruth's narrative, her adherence to treatment for over a year was premised upon the fact that she trusted the knowledge, intentions and abilities of the clinical team, until the point that she got those 'two revelations', referring to the impression that the clinical team was doing educated guesswork because, basically, there was a tension between 'not doing anything' and then 'rushing to act when feeling desperate'. From the outside, we could argue that Ruth's revelations were accurate descriptions of the dynamics of palliative care, which are based on symptom control, offering relief 'as and when' something threatens patients' comfort, and stopping futile treatments. These dynamics were articulated by senior palliative nurses who gave strong sedative doses upon Ruth's request and constantly checked on her, and registrars who called on surgical measures to avoid further damage to the kidneys. Yet, professional palliative care carried out by experienced palliative nurses and other clinical professionals was seen by Ruth as 'not doing', leading to her waning of trust. In that context, Ruth could at least do something: to build trust with God, the one who always had her back. Throughout that narrative, I described the ways in which Ruth negotiated normative expectations and individual desires in the hospital ward. Analytically, I looked at Ruth's practices that made up her life while dying, focusing on her cultivation of trust and hope as essential markers of an emerging ethical subjectivity that gave her spiritual comfort despite the pain. I described how she invested her efforts in bringing about a different possibility of experience through the concurrent cultivation of a religious relationship with God while simultaneously embracing the biomedical imaginary until it stopped producing any improvement. Following Ruth's lead, I argued that when biomedicine reaches its limits, one's hope for a life worth living becomes referred and cultivated so significant others can flourish. In this chapter, it is even more important to underscore that the argument I develop is by no means generalisable to understand how other cancer patients approach death. Further research could indeed unpack what resources non-religiously committed

people hang on to so as to find comfort at the end of their lives and how this ‘non-referential hope’ (if there is any) takes shape in their circumstances.

9.4 Precariousness and the future

The single idea that inspired this thesis is that values organise our caregiving practices when looking after oneself/others affected by cancer in the everyday. However, I have repeated that such projects are essentially fragile. The NHS strives for equality, but it is underfunded and the safety net that the welfare arrangement offered risks severe deterioration. The cancer clinic strives for excellence, within a landscape of unequal outcomes in cancer care, but time pressures and heavy workloads sometimes prevent over-stretched health professionals from providing excellent care. Bowel surgery offers the possibility of total resection, but creates bowel incontinence. Achieving bowel control gives autonomy to patients to resume their everyday lives and fulfil social obligations, but without infrastructure, ‘adjustment’ is a real challenge. Adhering to chemotherapy offers the possibility of continuing to enjoy life with others, but toxicity may impair the body and the efficacy of treatment is only an insurance. Creating an atmosphere of harmony enables caregivers to contain the frustration that cancer and its treatments produce, but reduces possibilities of self-expression for some of the overwhelmed caregivers. Hope for recovery animates patients and caregivers to adhere to lengthy and debilitating treatments, but biomedical care in cancer still has its limits, and some people still die from the disease. Here it is possible to notice that even though world-making seeks to be a collaborative effort, there exist important challenges in making their reality effects even possible, last over time, or become accessible to all participants involved. Clearly, the reality of cancer is hard despite wilful attempts to make it better.

Throughout this thesis, I have developed the concept of caregiving as a world-making project to tease out the potential of the practices that patients and caregivers carry out to get on with treatment. These practices, I have said, are usually beyond the scope of current reports on patient experiences and patient-reported outcomes. I have insisted that caregiving can be understood as world-making because those practices, organised by values, have reality effects that shape the experience of treatment for my research participants. However, I have been cautious to pose the question of the duration of such effects. In a way, I have attempted to avoid getting into the debate over post-cancer growth, or what anthropologist Kirsten Bell calls ‘cancer as a teachable moment’ (Bell, 2012; see also Livingston, 2012). A cancer diagnosis does not make anybody a better person, and all my research participants would be ready to demonstrate that. However, the existential force of cancer invited

them to improvise, sometimes with a high degree of desperation, new practices and try to apprehend new knowledge to look after themselves and their loved ones. This does not necessarily change who they are. My research participants would deal with the cancer treatment using the social, emotional and economic resources they already had. Cancer is not an exception – my participants were clear in stating that it has to be absorbed in the everyday. Sceptical about the ways in which their futures would play out, they wanted to get on with treatment, for life must go on. Yet, cancer is uncertain, and sometimes uncontrollable. Bodies leak, frustration seeps into others, cancer relapses and spreads.

In its frailty, temporality and ambivalence, this thesis has shown that caregiving allows people affected by cancer to create liveable worlds in which they can find comfort, at least momentarily. Further ethnographic research is required to unpack the myriad practices, forms of stratification and possibilities that the increasing promise of immunotherapy treatments may bring for people affected by cancer, increasing cancer patients' survival and quality of life. Is this concept of world-making analytically useful to understand the making of experiences of care for other life-threatening conditions, or institutional contexts? Comparative ethnographic research in this area could help us to further elucidate the anthropological value of unpacking 'possibility' across different contexts, which will continue examining the unfinished nature of the co-constitution of subjects and their worlds.

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