Topographies of "care pathways" and "healthscapes:"

Reconsidering the multiple journeys of people with a brain tumour

Authors

Henry Llewellyn,[a] Paul F Higgs,[b] Elizabeth L Sampson,[a] Louise Jones,[a] Lewis Thorne[c]

[a] Marie Curie Palliative Care Research Department, UCL Division of Psychiatry, University College London

[b] UCL Division of Psychiatry, University College London

[c] National Hospital for Neurology and Neurosurgery, University College London Hospitals NHS Foundation Trust

Corresponding author

Henry Llewellyn Marie Curie Palliative Care Research Department, UCL Division of Psychiatry Faculty of Brain Sciences 6th Floor, Wing B, Maple House, 149 Tottenham Court Road, London W1T 7NF. Email. h.llewellyn@ucl.ac.uk

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Abstract

People diagnosed with brain tumours enter new and unfamiliar worlds in which they must make complex and previously unimaginable decisions about care, treatment and how to live their lives. While decisions are increasingly based around care pathways, these are embedded in values that often fail to accord with those of patients. In this article, we examine the cases of people with a brain tumour and how they, their families and healthcare professionals navigate and intervene in the course of life-threatening disease. We use ethnographic data (2014-16) and modified social theory to highlight: (1) patients' interpretations of disease and care and how they might differ from dominant biomedical logics, (2) complexity and contingency in care decisions, (3) rapid and unanticipated change owing to disease and bodily change, and (4) how people find ways through a world that is continually in motion and which comes into being through the combined action of human and non-human agencies. Our modified "healthscapes" approach provides an analytic that emphasises the constant precariousness of life with a brain tumour. It helps to explain the times when patients' feel bumped off the pathway and moments when they themselves step away to make new spaces for choice.

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Introduction

People diagnosed with primary brain tumours are thrown into radically new and unfamiliar worlds where they must make complex and previously unimaginable decisions about care, treatment and how to live their lives. They do so with the abstract spectre of something growing inside their heads and the anticipation that it might soon affect their abilities to make sense of themselves and others, work through possibilities for intervening with disease, and disrupt their capacity to communicate. For some, these changes remain unrealised; for others, they come and go with flickering cognition or else become a permanent fixture of an ambiguous being-in-the-world. Either way, brain tumours are particularly difficult to manage given their unpredictability, recalcitrance to intervention, and their place in the delicate structures of the brain that frustrate routine surgical and oncological approaches to disease. Interventions—surgery, radiotherapy and chemotherapy—carry significant risks including further neurological deficit, catastrophic bleeds and secondary cancers. All brain tumours, whether malignant or non-malignant, are potentially deadly—less than half those diagnosed with malignant tumours will survive one year (Cancer Research UK 2016). In 2012, 256,000 people were newly affected worldwide with 10,981 new cases registered in the UK in 2014; more than half were malignant (Cancer Research UK 2016). Given this clinical picture, decision-making is extremely challenging.

In this article, we use in-depth ethnographic methods and modified social theory to examine the cases of people with primary brain tumours and how they and their families navigate life-threatening and neurologically damaging disease. We first critique the concept of care pathways, given their prominence in guiding medical intervention and setting the course for patients. We then modify the metaphor of "healthscape" (Clarke et al. 2010; Gold and Clapp 2011) as an analytic for navigation and the patient experience. Here, we offer "healthscapes" as the sum of the imagined possibilities for care and treatment in which patients find themselves, to which they contribute, and through which they must steer a course. We propose that while pathways remain the province of biomedicine and healthcare governance, underpinned by logics that might be unfamiliar or contrary to patients' expectations and values, healthscapes are inherently "of the patient." To capture the patient experience and the nature of brain tumours, we borrow from Henrik Vigh's work on social navigation (Vigh 2009), suggesting that the topography of healthscapes be considered as analogous to a seascape: fluid, capricious and fast-moving. This evokes a "motion within motion" (Vigh 2009) and implies how people "feel their way" through a world continually coming into being through the combined action of human and non-human agencies (Ingold 2000).

In short, we aim to: (1) give ethnographic texture to the experiences and decision-making of people with brain tumours, and (2) demonstrate the utility of an analytic which emphasises patients' interpretations, the unsettled and wavering terrains of disease and care, and the multiple contingencies that shape patients' experiences and capacities to act.

INSERT FIGURE 1

Care pathways

Modern medicine is increasingly based around care pathways (cf. patient pathways, clinical pathways, integrated care pathways, coordinated care pathways, protocols, algorithms) (Zander 1991; Ishikawa et al. 2013). Put simply, these are tools that map out chronologically key activities in a healthcare process (Allen 2009; Berg 1998) (see figure 1). Although not new to medicine, it was only in the 1960s and 1970s that pathways were formalized to address problems of variability in medical practice and concerns that physicians' choices were often arbitrary and poorly explained (Berg 1998). Through its branching structure, a physician could "at long last, specify the flow of logic in his reasoning" so that clinical reasoning "can begin to achieve the reproducibility and standardization required for science" (Feinstein 1974:6). Echoing Berg (1997, 1998), the early rhetorical foundations of pathways were therefore science, reproducibility and standardisation, and the figures subject to their implementation were physicians whose practices needed to be brought into "greater compliance with standards based on current biomedical research" (Kanouse et al. 1989:XV).

It was not simply the medical profession that advocated for pathways in daily care. Governments and hospital managers used them to wrest the inner workings of healthcare and make it subject to their administration (Berg 1997; Starr 1982). In the UK, the shift away from individual discretion towards *de facto* rules that are capable of being audited (Pinder et al. 2005; Strathern 2000) accompanied the creation of 'joined-up services' (Ling 2002) and efforts to place patients at the centre of care (McCormack and McCance 2006; NICE 2012). In this reorganisation, disparate professional groups would cohere around a central matter of concern, avoiding the potential for professional conflict. It was assumed patients would be afforded new opportunities for equitable care and choice that hitherto had been the prerogative of physicians (Pinder et al. 2005; Stevenson et al. 2000).

Such discourses, however, obscure problems in how pathways have been embedded. Critics highlight how pathways assume an optimal path corresponding to every medical problem: the "widespread *illusion of a single answer*" (Berg 1997:1083, italics in original). This ignores the multiple overlapping modes of reasoning that characterise medical practice and the social lives of patients (Mol 2002; Pinder et al. 2005). Pathways end up being constituted by things—information, activities, people—that are easily codifiable (Berg, 1997). Patients become defined by impairment and bodies essentialised (Pinder et al. 2005); "soft" or experiential knowledge is side-lined in favour of the "scientific state of affairs" (Berg 1997:1085; Shaw et al. 2009); and care practices lacking an observable outcome become deprioritised or invisible (Allen 2015; Pinder et al. 2005). This reinforces tendencies to describe the management of patients' journeys as a sequence of rational decisions (Berg 1997) and gives the impression of closure and linearity as patients are moved towards an end goal (Pinder et al. 2005). There is therefore minor consideration of the contingent and improvised nature of care and in many cases an unduly optimistic and "can-do" attitude to management based around a technological imperative and medicine's mandate to extend lives (Kaufman 2005; 2015; 2016).

Insurers have also established themselves as key players in the reification of pathways and the disciplining of care (Berg, 1997; Kaufman, 2015). Sharon Kaufman convincingly argues that a chain of connections among science, politics, industry and insurance organises the production of evidence and drives US healthcare (Kaufman 2015; Kaufman 2016). In this "medical industrial complex," insurers make certain interventions, made *thinkable* in clinical trials, *doable* in routine practice by reimbursing for their use. This generates treatment standards that drive patients' expectations about what is "normal" and "needed." In 2016, the power of insurers to set pathways was revealed in the American Society for Clinical Oncology's recommendations for pathways (Zon et al. 2016). These cited problems in "patient access, quality of care, and transparency in the weighing of information on clinical outcomes, toxicities, and costs in final pathway development" and reported oncology practices having to adhere to multiple pathways for the same type and stage of cancer "because of the different requirements of the payers covering patients" (262).

Although less obvious in state-financed systems, such as the UK National Health Service (NHS), insurers still contribute to the shape of care, not least in the global congeries of care and medical research in which treatment imaginaries and technologies circulate; for patients with private health insurance (11% in the UK, reported by The King's Fund in 2014), the influence of insurers is clearly much greater. In the NHS, the particularities of pathways are locally configured. Yet they must adhere to standards set by the National Institute for Health and Care Excellence who marshal evidence about technologies and interventions, as well as the Department of Health and regulatory commissions who determine what is fundable across disease groups according to logics of cost effectiveness (Shaw et al. 2013).

Pathways work in medicine because they make disease navigable. But they do so according to parameters that unfold outside the lives of patients. Moreover, these are often unclear since pathways emerge from complicated histories and through the logics of multiple stakeholders. Far from neutral tools, pathways ascribe particular notions about risk and evidence, and impose sets of goals that circulate around ideas about longevity and quality of life, and what is tolerable regarding side effect and symptom. Importantly, these standards often differ from those of patients and families who enter new "arenas of constraint" (Inhorn 2003) and the condition of having "no choice but to choose" (Giddens 1994:75). Another way to think about how people navigate disease and care is through the metaphor of "healthscapes."

Healthscapes

"Healthscapes" approaches have variously been applied across social science literatures (e.g., Clarke, 2010; Clarke et al. 2010; Rainham et al. 2010) and recently gained currency in health systems management and marketing (e.g., Sahoo and Ghosh 2016). They have been used to articulate relationships between "place" or "space," "health," "health-seeking" and "care." However, constant reworking in new contexts and lack of cross-reference has caused significant conceptual ambiguity. Ambiguity lies in definitions given to the terms place, space, health, health-seeking and care, the scales to which they apply and whether the term *healthscape* denotes something singular and universal or plural and particular.

We draw upon Appadurai's notion of "scape" (1990) and its re-articulation first by Adele Clarke (Clarke 2010; Clarke et al 2010) and then by Gold and Clapp (2011). Both reworkings confer meanings of place and space beyond the physical, and a plurality of approaches to health, health-seeking and care. Clarke's appeal is in her attempt to capture health and medicine alongside notions of family, religion, economy, polity and media in "kinds of assemblages … infrastructures of assumptions as well as people, things, places, images" (2010:105). In this way, health and medicine are deeply embedded in multiple systems of meaning rather than bounded and separate. Her attempt is to historicise approaches to care through the healthscapes of "medicine," "medicalisation," and "biomedicalisation" and hence reveal its temporality and ethics. Her healthscapes approach therefore grasps patterned changes occurring across varied sites where health and medicine are performed: "who is involved, sciences and technologies in use, media coverage, political and economic elements, and changing and ideological framings of health, illness, healthcare and medicine" (2010:105).

Gold and Clapp (2011) have instead applied a healthscapes approach to understanding medical pluralism and failing integrationist programmes that attempt to reconcile the import of biomedical discourse and practice with ideas around disease and healing endemic to indigenous rural communities. They compared institutional systems with individual health-seeking patterns and as such suggested useful conceptual specificity and bifurcation between "healthscape" (*singular*) and "healthscapes" (*plural*). Overall they understood "healthscape" to be the "biophysical, social, and psychological space in which everyday 'health-seeking' plays out, within the interstices of the various medical systems" (p.96). Yet within this, *healthscape* (*singular*) denoted a particular landscape and its social, biophysical, and institutional resources related to health, while *healthscapes* (*plural*) called forth "the multiplicity of visions, each based on a unique experience but shared and overlapping within social networks" (2011:97).

This distinction between the shared institutional and systemic *healthscape* and the unique and multiple *healthscapes* helps clarify the loci of visions. Here, we are mostly concerned with the concept of *healthscapes* (*plural*) for its focus on individuals within broader social networks and the multiplicity of meanings and possibilities within imaginations. This calls greater attention to Appadurai's positioning of individuals as "the last locus in a layering of perspectives, given those individual agents eventually navigate landscapes in part by what these landscapes offer" (1990:296). Here, Appadurai emphasises that "scapes" are not objectively given and uniform but rather "deeply perspectival constructs, inflected very much by the historical, linguistic and political situatedness of different sorts of actors" (1990:296). Accordingly, individuals are "able to contest and even subvert the 'imagined worlds' of the official mind" (1990:297).

Unlike pathways, which are rooted in modern medicine and its regulatory apparatuses, the healthscapes we describe here are inherently "of the patient" and utterly unique in scale and the features they include. They are the sum of imagined possibilities for care and treatment that patients construct and through which they must find a way. They are open and unfolding, contingent on patients' own interpretations of disease and the body, risk, uncertainty, evidence, and the goals of care given in consultations with healthcare professionals and held in the broader social imaginaries of care. Next, we turn to assumptions about time and stability in pathways and healthscapes, highlighting "landscape" as the topographical image of that which is navigated. We first consider diagnosis.

"Fixing the terrain"

Diagnosis is a fundamental classificatory tool in medicine—at once an act of naming and mobilising an impetus to act. It is therefore a vehicle of authoritative medical reference (Smith-Morris 2016). Following our navigational focus, we might consider the diagnostic moment as one that "fixes the terrain." By this, we mean to emphasise the ways in which modern medicine fixes uncertainty and instability in relatively static landscapes as well as the implication to intervene in, or "fix," the course of disease. There is therefore an imposition of demand given in diagnosis, as it is a process already entangled in attempts to intervene (Jain 2013). It is this process of diagnosing which makes disease navigable by constituting a fixed terrain—or landscape—over which pathways can be routed.

Healthscapes also work a terrain analogous to landscape. This is in part held in the suffix of "scape" in the way it correlates with "landscape" in Appadurai's initial formulation. In this, Appadurai delineated a "global cultural economy" in which global flows operate through the movements of people (ethnoscapes), technology (technoscapes), money (finanscapes), images (mediascapes), and ideas (ideoscapes). While he understood these to be fluid and unpredictable, the immediacy and pace of change is immeasurably slower than that contingent on disease. In addition, while healthscapes highlight plural and shifting disease concepts and care resources, they do not give adequate place to the action of disease itself. In essence, they have been theorised in the abstraction of disease, where disease is always interpellated in acts of care and the will to intervene. The challenge in conceptualising navigation means therefore to account for the speed, acceleration and suddenness of change wrought by disease.

We therefore wish to foreground disease itself and the corporeality of patients' bodies; that is to say, the "relatively unmediated materiality of the body" (Gilleard and Higgs 2015:17). We look towards recent critiques of anthropocentrism and the divides between culture-nature, life-matter, subject-object that have been articulated in movements towards a "new materialism." These have variously sought to endow nonhuman materialities with a "positive productive power of their own" (Bennett 2010:2) and to position them as "actants" (Haraway 1997; Latour 2005) capable of shaping the movements of others. This allows disease some kind of agency of its own that forces interpretation and the need to intervene or indeed something that itself prevents intervention—its *positive productive power*.

With this, it is not just ideas, images, assumptions, places, institutions, diagnoses, practices and technologies, that is to say the *resources and their broader frameworks*, that fill healthscapes and which patients have to navigate, but *disease itself*. Here, disease becomes more visible in the healthscape rather than something entirely reducible to the contexts in which we place it. This differs from pathways that imply the subjugation of disease to intervention and which have tended to obscure the actions of disease on intervention. We argue that this has ignored the recursive nature of relationships between intervention and disease. Including disease in this way makes room for its sudden turns, its inherent uncertainty, its recalcitrance, and the multiple contingencies inevitable in the body's response to treatment—factors which so often constrain the ability to intervene. Given their capacities to impose themselves in such rapid and dramatic ways, this inclusion is especially important for brain tumours and other diseases for which we lack surety and control.

In moving forward a conceptual vocabulary that acknowledges the irregular temporal patterns of disease, we consider Henrik Vigh's (2009) critique of the "spatial turn" in anthropology. Vigh works through similar assumptions of "landscape" implicit in how navigation has been applied to people's negotiations and movements through social environments, especially those subject to rapid, hard-to-imagine change. His intervention is to evoke the seafaring reference in navigation and to shift images from landscape to seascape, thereby introducing a third dimension. He draws attention to a "motion within motion" in acts of moving through an environment that is wavering and unsettled. This, he suggests, moves studies of the social beyond a focus either on the way social formations change over time or the ways individual agents move within social formations; the focus is rather at "the intersection—or rather interactivity—of the two" (Vigh 2009:420). Such an image is useful for our current project by highlighting the particular kinds of fluidity encountered in patients' navigations of disease and care. It also points towards the artificial split given in the heuristic of making navigable in projects to "fix the terrain" and subsequent navigation. Rather, as Tim Ingold suggests, people "'feel their way' through a world that is itself in motion, continually coming into being through the combined action of human and non-human agencies" (Ingold 2000:155).

While healthscapes help to reflect the unmapped particularities of patients, they do not capture the "motion within motion" characteristic of navigations through care and disease. This is because the image conjured remains that of the solidified surfaces of landscape. Grounding the healthscape metaphor in the image of seascape allows a different meditation on time and the interplay between rapidly changing healthscapes and the movements of individuals—it foregrounds the intersections between disease and intervention. Following a description of fieldwork, we turn to the meandering journeys of people with brain tumours and use the moves made above to highlight the capricious nature of disease, constraints, and contingent, improvised care.

Fieldwork

Data are based on eighteen months of ethnographic research (2014-16) in a UK hospital specialising in the care and treatment of people with conditions requiring neurological or neurosurgical intervention. The aim of this research was to understand how clinical decision-making is distributed across multidisciplinary clinical teams and how patients and families are placed within this configuration. London-Harrow Research Ethics Committee approved the study (14/LO/1277). Participants gave informed consent; names mentioned are pseudonyms.

Throughout the research, [author name] followed the journeys of sixteen people[1] with a primary brain tumour through various points of care. These people were sampled purposefully by diagnosis, gender and age. In addition to numerous informal conversations recorded in fieldnotes, [author name] repeatedly interviewed patients,yielding fifty audiorecorded open-ended semi-strucured interviews about daily life with a brain tumour, ideas about care and treatment, and decision-making. Interviews typically lasted between one and three hours and were conducted in private spaces in participants' homes, cafés, clinic rooms or hospital waiting areas. [Author name] also attended patients' clinical appointments as they met with surgeons, oncologists, neurologists, nurses and others to get clinical tests, discuss results and treatment options, clinical trials, and receive various forms of standard and experimental treatments. [Author name] conducted participant-observation in multidisciplinary team meetings, hospital wards, chemotherapy and radiotherapy treatment suites, waiting areas, operating theatres, hospital laboratories, radiology departments, public meetings and conferences about oncology research and practice. Observations were recorded in fieldnotes. Participants' hospital records were read and relevant information extracted.

Here, we focus primarily on interviews, which were transcribed and indexed using open codes, allowing us to develop themes and patterns across participants. We used observational data to help assemble descriptive narrative accounts for each participant. This preserved the content of individual journeys and gave insight into how early events and decisions impacted those made later. During analysis, we paid attention to personal meanings and values attached to disease, health, treatment and care and how these featured in decision-making. We developed and modified the analytic presented above iteratively alongside data collection and analysis across cases using memos to keep track of emerging themes and broader analytic ideas.

What follows are findings related to how people with a brain tumour navigated healthcare settings and engaged in care and treatment decisions over time. Through two extended case studies we highlight encounters with constraint and the corresponding ways in which patients move outside the standard model of care to create choices that support their own ideas about disease, care and what it means to live well. Using case studies allows us to characterise in detailed ways the complexity of patients' lives and contingencies in care. We chose these particular cases because they are both typical and especially illustrative of how patients and families challenge the logics of medicine and create spaces for choice outside standard care. Together, they show the breadth of constraint encountered by study participants, including hospital routine and bureaucracy, experimental design and the sudden changes wrought by disease and treatment. Moreover, they reflect the deep ambiguities, hesitancies and actions of participants alongside powerful drives to intervene, which characterised experiences across a variety of backgrounds and diagnoses.

The case of John

Now in his early fifties, John had lived alone with a non-malignant brain tumour for almost eight years. While working as a hospital IT manager, he had been admitted for emergency surgery after sickness, headaches and dizziness, and a “fuzzy smudge” on his MRI scan. He was diagnosed with a haemangioblastoma, a rare tumour that develops from blood vessels. Fours years later, he underwent a second operation following regrowth. A bleed during this second operation confined him to a hospital bed for five weeks and it took him more than another year to “feel himself.” Shortly after, and just before first study interview, John was told that his tumour had grown again and soon he would need treatment.

In separate consultations, his surgeon and oncologist had recommended “Gamma Knife.” Developed by surgeons in Stockholm in the 1960s and introduced to the UK in the early 1980s, Gamma Knife is said by its marketers to replace the surgeon’s knife with multiple beams of radiation targeted to a specific area. "Gamma knife. No incision. No hospital stay. Documented outcomes" (ELEKTA 2016) ran the header of one website John studied, which framed his preference for Gamma Knife over alternatives. However, not long after being recommended the treatment, John was told he was ineligible under a recent NHS commission ruling that Gamma Knife would only be funded for certain tumours. In another consultation, John's oncologist, who maintained it was as if the commission had mistakenly left haemangioblastoma off the list, explained the alternatives of further surgery or conventional radiotherapy.

"I can't face surgery again," John said afterwards, "That would be the third time. The doctors have got this thing, it's a fancy term called sequelae, it's like 'sequel' with an 'A' at the end. It just means the consequences of surgery, […] there's always a risk and if you're going to continue to do it, you're just increasing your risk." He imagined his future filled with operations, each one riskier than the other and failing to deal with the growth of the tumour.

Following appeals to the commission, a bid to be considered one of the hundred additional cases treated annually outside the list of tumours eligible for Gamma Knife and failed plans to garner support from his local member of parliament, John awaited a redraft of the rules which he described as being on the cusp of publication. Meanwhile, he looked for Gamma Knife treatments abroad and asked his oncologist about Proton Beam therapy. Another radiation therapy assumed more targeted, Proton Beam received significant media attention in 2014 following the controversial case of Ashya King, a five-year-old boy with a malignant brain tumour who had been at the centre of a high court judgement in England. Ashya's parents had arrested in Spain after removing him from a NHS hospital and once prosecutors had decided there was a serious threat to Ashya's life "unless he was under the care of medical professionals" (CPS 2014). Aysha's parents had been arranging for him to go to Prague to have Proton Beam Therapy which was denied to him in the UK on grounds that there was "likely to be no difference in survival between standard radiotherapy and proton radiotherapy and overall no proven significant benefit" (University Hospital Southampton NHS Foundation Trust 2014).

Like many others diagnosed with a brain tumour, John had read about the case. And like Ashya's parents he challenged conventional radiotherapy on grounds that it carried major risks of secondary cancers and brain damage. He drew diagrams on paper scraps and talked them through to show how Gamma Knife and Proton Beam mitigated these risks by exploiting a different physics. Explaining Proton Beam, he said: "this one is extremely precise so the radiation doesn't go where it shouldn't go. This particular physical effect, the Bragg effect, means the radiation doesn't go beyond the tumour."

He went on, explaining how he had learned about this: "I read the [scientific] papers. I look at the abstracts. You've just got to know what you can know. You have to be prepared to understand that you're not an expert, so you've always got to have the mental attitude that you're going to listen. But equally what I've found is you have to be prepared to ask questions […] for example, when I was with [my oncologist] it's being prepared to ask, 'what's the diminishing rate of radiation outside the target?' Well we didn't drill into that too much. So I went and had a look afterwards and I could see that the radiation doesn't diminish very much [in conventional radiotherapy]—it sort of flies out—so whatever direction it's going in it continues to go. And that's through the rest of your brain."

Finding centres abroad where Gamma Knife or Proton Beam were available for fee-paying overseas patients became a daily project. Unlike private centres in the UK, these were within financial reach. He evaluated treatment costs and costs of travel; the processes of booking the treatments and how to send digital scan images and other clinical reports to the centres. He judged the legitimacy of centres by how "official" they looked online and by the tenor of the conversations he had with administrators on the phone and in emails with clinicians. Having worked in the NHS he thought himself to have an edge over others in being able to navigate complex bureaucracies and the obfuscations of commissioning bodies.

“You’ve got to follow the machine,” he said, “it’s essentially about provision and costs. So you find out that it’s possible. At first, finding a machine and then seeing whether they’re offering private treatment. And then you say to yourself ok, that’s fine, that’s an example, and then it’s about if there is any form of certification.”

After several months, he narrowed the sites down to Malaga and Prague, where Ashya King eventually received treatment following a new ruling that allowed his parents to seek treatment abroad. However, difficulties arranging treatment via different customs and administrations and the discomfort of being in an unfamiliar place and under a new team kept John from committing to treatment abroad. Instead, he reconsidered a third operation. Yet still, he feared this and, after over a year of failed appeals and indecision, John continued without treatment. He placed himself within the hope of a redraft of the rules by the commission, which he continued to follow closely.

The case of Matthew

Matthew had been living with a glioblastoma—a cancerous and highly aggressive tumour—a little over two years before first interview. He had been diagnosed in an Accident and Emergency department having crashed his bike commuting to his city job. He had no prior symptoms and, now in his late fifties, had already outlived the median 15-month survival for patients with a glioblastoma. He had undergone surgery, radiotherapy and chemotherapy as standard, and would be monitored in the routine “watch and wait.” Like others, chemotherapy was exacting a toll on his body. He was exhausted and his white blood cells had fallen dangerously low, making it unsafe to continue treatment. Each week Matthew returned for blood tests, hopeful that he could continue treatment, only to be told his bloods were too low. Matthew became alarmed and upset. He feared having to stop treatment altogether. It was almost a month before his bloods were restored enough for chemotherapy but at a lower dose. He finished the six-month course. But this experience pushed him to consider a tumour left alone. Surely it would grow, he thought. Fearful of this, Matthew and his wife, Nicky, wanted to continue attacking it. Like so many others, they placed their hopes in clinical trials and the promise of medical innovation. Eyes bright, Nicky explained:

"More and more what was coming up as 'the future' was immunotherapy. Everywhere we turned that's what people were saying. And funnily enough I'd even asked [Matthew's surgeon] on that meeting before [his] surgery (two years ago). I'd said to him, what's the future? What should we be looking at? And he said 'immunotherapy.'"

Immunotherapies are treatments that exploit the body's immune system and drew significant gains in oncology from recent advances in molecular genetics. Expensive and without adequate trial data, they are not standard in the NHS for brain tumours and hence not included on care pathways. However, they are available to those who can pay privately and a promising immunotherapy was under trial in the hospital where Matthew was being treated. At this juncture Matthew and Nicky encountered a series of constraints.

Matthew: "We saw the consultants running the trials and they just said 'we can't do it because your tumour isn't frozen' […] well what's all this about tumours being frozen? We didn't know. We didn't even know. Nobody said anything about that to us."
Nicky: "[Matthew's tumour] was just done in the standard petroleum wax which means it's pretty useless."

When a tumour is removed from a patient it is set in wax. This is standard practice in pathology departments across the world. The wax makes tissue a workable material in the laboratory and allows it to be stored for years. However, some immunotherapies use tumour tissue to make personalised vaccinations and the wax changes it in a way that renders it unusable.

Nicky: “I knew we were on the right path but of course we were finding that paths were being blocked because of the tumour material required.”
Matthew: “And that in a way set how we’re now used to it. We’re used to options being closed to us—especially trials—because of something we’ve done in the past without realizing the implications. And that’s very frustrating.”

After more searching for treatments and more dead-end appointments, Matthew and Nicky self-funded a different immunotherapy in a private hospital in Germany. Unlike the one being trialled, this did not require tumour tissue for the vaccine’s preparation. Each month for almost a year Matthew travelled overnight to Germany by plane, train and taxi until routine MRI scans in the UK suggested his tumour had grown again and he became too exhausted for the monthly visits. He then found another UK-based trial for recurrent glioblastoma, which again had promising early results. This was for Avastin, a now controversial drug that affects blood flow to tumours. But as Matthew explained:

“I’ve been a Judas and had immunotherapy. My immunotherapy in Germany, apparently it excluded me from the trial. Now we get more cynical and questioning of these consultants’ decision-making and I actually suspect he made that up, or at least he could have easily bent the rules and let us in the trial […] and that’s just been our experiences all along with the trials. First of all it was this, ‘well the tumour isn’t frozen.’ And we’ve looked at other trials over the months and first thing we do is look down the exclusion list and I’ll be excluded by something always.”

Matthew never made it onto a trial; in fact less than 3% of patients do enter clinical trials (NCRI 2016), a figure much below other cancers (The Brain Tumour Charity 2015). Instead, he and Nicky raised enough money through crowdfunding to pay for six-months of Avastin and a chemotherapy called Lomustine both of which he received privately in the UK. He also made further trips to Germany for immunotherapy boosters and took an “unconventional” perillyl alcohol inhalation developed for cancers in Brazil and trialled in California. This they bought directly from a laboratory in Italy. Although he had private healthcare insurance, it funded neither treatment given they were not standard and considered of unproven benefit. Their journey is not uncommon.

Matthew died almost three years after being diagnosed and pursuing treatment to the last. Before he died, he spoke of how his experiences of constraint had provoked unimaginable dilemmas and hard-to-swallow paradoxes for him and Nicky. Days before a scan, and not long before Matthew died, they had willed his tumour to grow enough for a second operation to harvest more tissue for the personalised immunotherapy vaccination, such was their hope in its early results. His tumour had grown. But it had grown skein-like through the tangles of his brain and was no longer operable.

Navigating routines, bureaucracies, and the caprices of disease

These cases, together with the others we followed, demonstrate how patients challenge medical hegemony and the regulatory constraints configured in standard care. Participants continually encountered constraints that were structured around what constituted effective, evidence-based and fundable treatment. In John's case, he was ineligible for the treatment clinically recommended to him because the commission governing the use of Gamma Knife did not sanction its use on tumours like his. But he knew that in other countries this tumour is treated by Gamma Knife "because it's a good candidate for treatment." He challenged further surgery because his prior surgical experience had already marked for him its cumulative risk and ineffectiveness, and he challenged conventional radiotherapy on grounds that it risked causing cancer and damaging his brain. His experiences illustrate ambiguities even within the fundaments of standard care: what it is, who decides and who pays. It reveals separations between patients' ideas about risk and those of the system, as well as the deep fissures between national bureaucracies and clinical recommendations. He lived this as an ambiguous waiting around, all the while guessing at how his tumour would grow and the critical question of when to intervene.

Through their encounters with clinical trials, Mathew and his wife Nicky learned to be wary of making decisions in the present that might foreclose future possibilities of care. These encounters also made them cynical of trial design and its conception of the naïve body free of the medical histories that deviate from a narrowly defined norm. After pushing aside standard and experimental treatments, they paid greater attention to patient anecdotes and survivor narratives, which they read in newspapers, social media and the many online forums. This focus towards a way of knowing based on experience over evidence led them to pursue "unconventional" treatments. They also learned that choice is confounded by the intrusion of disease and the body's tolerance to treatment—intrusions that can quickly change the course of things to come.

Together these experiences illustrate how choices are constrained by hospital routines and national bureaucracies, the caprice of disease and the corporeal body. What patients, families, and healthcare professionals navigate is complex and changeable; not the closed, solidified surfaces implied by pathways or the slow-moving landscapes of healthscapes. Rather than simply following a path laid out in front them, everyone "muddles through" (Kaufman 2005): doctors "tinker" (Mol 2008; Mol and Berg 1994) and patients and their families search for ways around to create spaces for choice beyond standard models of care. They create spaces in experimental treatments or private care, in other countries or forms of care termed "unconventional."

These spaces are inevitably delimited by the resources—economic and otherwise—available to patients. However, links between education, gender, social class or other structural factors and tendencies to reject or defer to doctors and standards of care were not straightforward in our study. Nor did these factors necessarily determine a patient's likelihood to dismiss or pursue care alternatives. John and Matthew—white, educated males with well-paid jobs—both had means to pursue private treatments up to a point. Yet beyond this, they were ushered down certain routes or made attempts to generate further reserves. For Matthew, the significant costs of treatment meant crowdfunding—unusual among participants in the present study but an increasingly common way to fund medical treatments for those lacking financial means (Snyder et al 2016); John looked to manage the financial demands of alternative care by drawing up detailed cost comparisons of treatment and was prepared to travel abroad for treatment at significantly lower costs. Importantly, our analysis revealed how understandings developed over the longue durée of illness and how unpredictable disease combined with the treatment imperative to motivate the improvisations of those with life-threatening disease. This imperative is firmly rooted in the social imaginaries of care; treatments like immunotherapies circulate widely through forums and the media, and are topics of conversation in hospital waiting rooms.

Notably, almost two thirds of participants received some form of private, non-conventional or experimental treatments in addition to standard care, chose to forego standard treatment in part or total, or were forced to stop because of medical complications. Very few followed standard care pathways without seriously questioning the risks, side effects, efficacy or evidence of treatment, either privately or publically in clinical consultations. In the spaces they create, patients attempt to enact agencies based on their own ideas about what is tolerable as symptom of disease or treatment side effect and what is acceptable as a goal of care. During this, standard care, which might hitherto be the only possibility, becomes but one among many and further disembedded as the dominant form of care and treatment.

These experiences also illustrate patients' indecisions and their interminable waits for things to change: for their tumours to grow, for their bloods to come up, for commissions to make different rules. Finally, they show how decisions are always embedded in actions made upstream and often with the anticipation of future choice. While patients want to keep their options open, they learn this is often not possible. The terrain, which they must traverse, is in constant motion.

Conclusion

We sought to conceptualise how people diagnosed with primary brain tumours navigate decisions about care and treatment. Throughout the article we have questioned what exactly it is that patients, families and healthcare professionals navigate. We explored the topographies implied in "care pathways" and "healthscapes." We suggest that pathways route patients through a system according to national and local bureaucracies and sets of embodied practices, which result from complex histories and multiple stakeholders. In doing so, they shape patients' lives by particular and often hidden valuations about risk, evidence, tolerability of side effects and symptoms, and fundamentally the goals of care. They also assume bounded and linear paths that imply a "can do" sensibility to management that is frequently characterised by aggressive treatments. These assumptions and valuations often differ to those of patients. The concept of healthscapes addresses this gap by acknowledging patients' values and interpretations. These healthscapes are the sum of the imagined possibilities of care and treatment that patients construct and through which they must find a way. However, we argue that like pathways, healthscapes reproduce a geographical fallacy of static or slow moving landscapes incommensurate to fast moving and unpredictable disease. Accordingly, we suggest that the positive productive power of disease itself and the corporeal condition of patients be accounted for in ideas about what it is that is navigated. Here, we borrowed from Henrik Vigh (2009) the image of "seascape" to evoke the particular kinds of fluidity encountered in patients' navigations of disease and care. This suggests a "motion within motion" and implies how people "feel their way" through a world that continually comes into being through the combined action of human and non-human agencies (Ingold 2000). Such an elaboration of healthscapes allows insight into the complexities of patients' lives and experiences of disease, care and navigation and better explains times when they are bumped off pathways or themselves decide to step away; it is therefore a useful analytic to study the actions of patients whose lives are constantly precarious.

Footnotes

[1] Diagnoses included glioblastoma multiforme, WHO grade IV (N=10; 5 female, 5 male); anaplastic astrocytoma, WHO grade III (N=3; 1 female, 2 male), oligodendroglioma, WHO

grade II (N=1 female); astrocytoma, WHO grade II (N=1 female); and haemangioblastoma, WHO grade 1 (N=1 male). Mean age 50 years (range 32-70).

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Figures

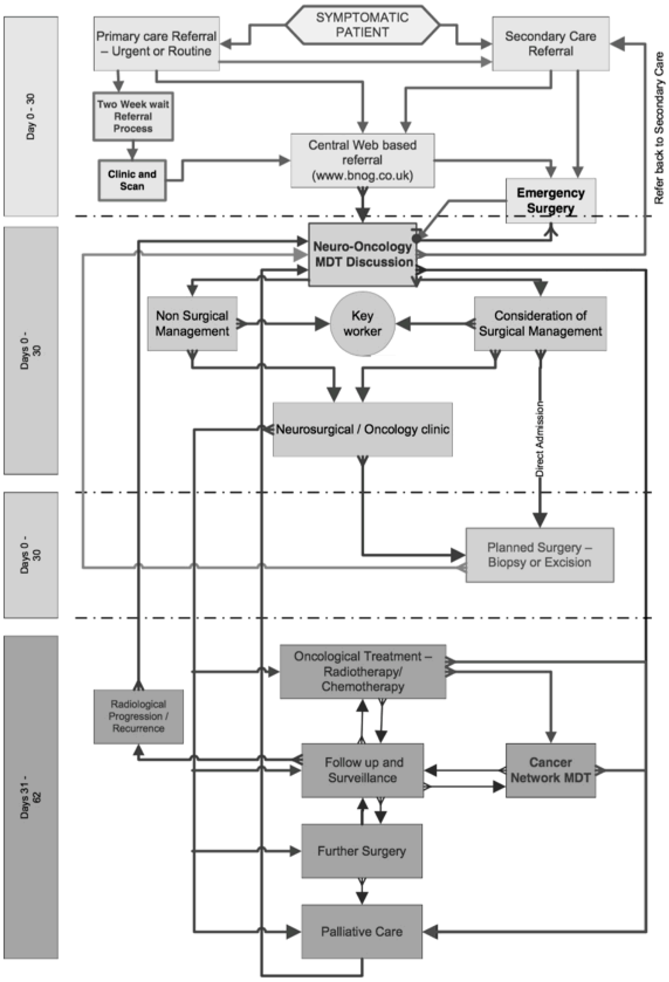

FIGURE 1. A patient pathway for high-grade brain tumours

This schematic shows the branching structure and timing characteristic of care pathways. The pathway begins with a symptomatic patient, admitted either through primary or secondary care, and routes them through various diagnostic processes and decision points towards intervention. For high-grade brain tumours, like glioblastoma, intervention typically means surgery; concomitant chemotherapy and radiotherapy over six weeks; and adjuvant chemotherapy over six months. Following this, patients are followed-up with scans and clinical appointments. Since 2005, this pathway has represented the standard treatment for glioblastoma in the UK and has been adopted by most economically developed countries. *Source: North Bristol NHS Trust*