"Not an Empty Vessel": Paths of Learning about Illness and Pain in the Autobiographical Work of Hilary Mantel

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Abstract

Experiences of illness and pain can affect all aspects of a person's life, from the daily organisation of work and social relations to the perception of past and future to the control they can exert over their body. People who are ill and in pain must therefore learn not only what their condition is, but also how to manage it socially and how to navigate environments of care.

These issues are examined through three autobiographical pieces by Hilary Mantel, a renowned British novelist who, in a book and several shorter works, described her lifelong suffering with endometriosis, migraine, and gout. The works illustrate the impact of the socio-cultural context, her autonomous search for knowledge, and the way in which the practice of writing supported her efforts toward self-reintegration. The analysis highlights themes related to health literacy, doctor-patient relations and different form of expressions that can support the witnessing and testimony of pain.

Keywords: *narrative medicine; illness narratives; health literacy; pain; Hilary Mantel; autobiography.*

1. Health literacy and illness narratives

When a person is visited by a chronic or prolonged illness, they also start on a learning journey. First, if a diagnosis has been reached, there is learning about the condition and the treatments, through health care practitioners or other sources. Second, there is learning about one's own relation with the condition: the way it manifests in one's body and mind, when to expect its effects, how to adjust to it. And third, there is learning about the medical world and how to interact with it: what is the medical perspective on the condition and the people affected, what appears relevant to report and when, what are the thresholds for requesting help.

The concept of 'health literacy' covers parts of this territory. In the last three decades, health literacy has expanded from the notion of a basic skill set required to understand and absorb medical information to a property

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of the system including the individual, the professionals and the relevant organisations (WHO, 2023), all of which is continuously evolving (Mancuso, 2008; see Parnell, 2014 for a review and comparison of definitions). The distributed nature of health literacy and its relationship with time are important points; however, definitions and policies can only go so far to meet the demands of individuals with complex conditions. For one thing, the socio-cultural responses to different illnesses and their carriers are in large part outside the control of healthcare institutions and policy-makers, especially around stigmatised conditions and demographic groups. Secondly, health literacy continues to be skewed on the patient's side; professionals enter the picture mostly as educators, whereas professionals' education about patients' experience is still lacking.

To aid medical professionals' understanding of the position of the patient, medicine (MacNaughton, 2001) has integrated 'lived experience' as one of the sources of knowledge for professionals in training and beyond. Patient's lived experience typically come in the form of narrative. Challenging the idea that patient's narrated experience can add at most some colourful illustration to solid, generally valid medical knowledge, phenomenological models of learning and expertise identify in narratives the elective vehicle for passing patients' learning to health care professionals (Toombs, 1987). Narrative medicine (Kleinman, 1988) has demonstrated the different ways in which a narrative approach can benefits medical practice (Charon *et al*. 2017). In doctor-patient interaction, eliciting narratives open new sights onto patients' lifeworld and improve outcomes from achieving a correct diagnosis to increasing the chances that the treatment is adhered to. By stepping into the everyday contexts of patients beyond the clinical parlour, possible co-determinants of symptom or barriers to treatment and healing can be identified. Prolonged treatments are encased in an overarching narrative that are co-written by patient and healthcare professional at each encounter and provide the dyad with shared history and future possibilities (Mattingly, 1998). As narratives are allowed within doctor-patient encounters, the clinician can be the witness of the integration between the patient's self and their changing body (Charon, 2011). Sharing stories with fellow sufferers also can have supportive and informational benefits. It can relieve the person from the self-blame and shame about their pains and grievances and create feelings of companionship, lifting the isolation that can be bestowed by illness even if someone has family and friends; sometimes it can also provide precious information about aspects of a conditions or experiences with treatments (Krause, 2003). As we will see later in the article, narrative scholars are also exploring the value of expressions of illness and pain that come in non-narrative forms.

In this article, I will be discussing issues of learning about illness and pain through a case study approach, using autobiographical pieces by Hilary Mantel (1952-2022). Mantel was a famed British writer of historical fiction, for which she was pluri-awarded and even received Damehood in 2014. She suffered since youth from a severe form of endometriosis, migraine, and gout, and wrote about her experiences in the second part of her life.

A lot has changed since the 1950s when she started dealing with her conditions and with the medical system, however her accounts illuminate aspects of these experiences in ways that are extremely relevant to these days. In recalling her struggles, Mantel not only offers insightful reflections on illness and pain, but also reveals how her vicissitudes with illness and cure were part of a story that included views on women and their place in society as well as medical approaches to pain at the time. Overall, this is the story of a health education gained at a very high price.

2. Hilary Mantel as a case study for chronic illness and pain

As Mantel notes, gout is a relatively straightforward diagnosis and the nature of pain it creates is generally known and accepted, whereas both endometriosis[1] and migraine[2] are complex conditions, with a large variation in symptomatology, and are difficult to diagnose. Endometriosis and migraine are also women's illnesses[3]. The two factors of the complexity of the conditions and their gendered nature interacted in shaping Mantel's own understanding of what was happening to her as well as her dealings with the health professionals.

Mantel's severe pains brought her, at 27 year old, on a surgical table where the endometriosis was first diagnosed, and her uterus and ovaries removed. Years later, as the pain came back, she had further surgery to remove scarred tissues. In the meantime, she was given high doses of hormones that made her, who had always been slender, put on a lot of weight that she was never able to shed again. Later the lack of natural hormones made her thyroid fail. Mantel's migraine, most likely caused by the hormonal imbalance, incapacitated her for days on end. As is

1 In endometriosis, cells that form the lining of the womb migrate to other parts of the body, which can be reproductive organs, like fallopian tubes, or other organs like intestines and bladder. The cells bleed without the blood being released outside the body, and scar tissue is also formed, creating adhesions between organs. Both the bleeding and the adhesions cause pain (World Health Organisation, 2023). Pain in the area is exacerbated in the menstrual period thus often confused with non pathological menstrual pain. Currently, the time for diagnosis of endometriosis is 7-10 year (Bullo &Weckesser, 2020).

2 The complexity of migraine lies in the extension of body areas affected, sometimes concentrating on the stomach and guts rather than the head, and in its unpredictable course. Migraine can in fact be affected by its own symptoms, for example when the exacerbation or reduction of a symptom during an episode can affect the trajectory of future attacks (Sacks, 1971). Migraine can also change during the course of a person's life, being influenced by many different parameters that vary with a person's age and circumstances.

3 Migraine affects both men and women but is "two to three times more prevalent in women than men, and women report a longer attack duration, increased risk of headache recurrence, greater disability, and a longer period of time required to recover" (Vetvik & MacGregor, 2017: 76).

typical of the condition, the manifestations changed over the years, alternating periods of successful management and of symptom worsening. As her writings reveal, close observation and learning were a matter of survival.

This work is mainly based on the 2003 book *Giving up the Ghost* (referred to here as GUG), and on two shorter pieces: an article piece written for the International Association for the Study of Pain, *How much pain is too much pain* (2013; HMP from now on) and the 2011 article *Meeting the Devil* (MTD), written for the London Review of Books in 2011, about the days after her first major surgery. Mantel's main literary works have been historical novels, but, after her memorial, she wrote more on matters of health and illness and became an important voice especially in support of women suffering[4].

My approach to Mantel's texts has been to select episodes and passages centring on the acquisition of expertise on her conditions while battling conjuring forces of social stereotyping and medical ideologies. The analysis and selection was led by the writings themselves; I had first examined HMP, a concise text mainly addressed to healthcare professionals to make them see the intersections between a person's life and their pain; that led to analysing the memoir GUG, which reconstructed those intersections as they panned out across her love life, her career and even the houses she chose; and finally, I focused on MTD, which brings to light the psychological impact of surgery's physical invasion and sudden loss of agency and control. My analysis is informed by two central tenets of narrative medicine, the situatedness and particularity of every person's illness story, and the way the act of narrating becomes a part of the person's journey (Kleinman, 1988; Hyden & Brockmeier 2008; Charon *et al*. 2017).

3. Learning pathways around illness and pain

3.1. *Sociocultural responses to the illness and its carrier*

> *Cultural contexts and expectations of illness story influence what can be heard in pain, what can be known about it, and who is respected as knowing. These are matters of epistemic justice.*
>
> Sara Wasson, 2023

In considering the influence of the sociocultural context on the response to her health issues, Mantel's displays her realisation that societal changes and cultural trends, as well as deep-seated prejudices, can shape someone's experience in unexpected and sometimes paradoxical ways:

4 For example, she became a patron of the Endometriosis SHE Trust, and was asked to write the foreword for a book about coping with endometriosis (Aziz & Eckersley, 2015).

> In those years, the late sixties, we were caught up in a cultural shift. A few years earlier, a schoolgirl like me would have been "off games" for a week every month. But the new idea was that, since menstruation wasn't an illness, you should carry on as if it wasn't happening. For most young women it's a good enough approach, but it was hard on me. I lost confidence even in my own pain; I thought I wasn't tough enough. My mother would not have let me see a doctor alone, and as she had never been troubled in that way, the whole matter seemed trivial to her. Regrettably, in my long career with this condition, women doctors were no more helpful to me than the men. Their attitude was, "I'm a woman, so I know; you're making a fuss about what we all have to endure." (HMP: 9-10)

As the quote shows, in society things change at different speed; the new Zeitgeist wanted to de-medicalize women's physiology, but Mantels' family mores did not change in relation to the young women's ability to take charge of her own health and go to the doctor on her own. More subtly, the new emphasis on women's strengths lessened empathy with, and acknowledgment of, conditions related to women's reproductive system even from other women, under the mistaken assumption that all women's experience those matters in the same way.

As Wasson (2023: 283) notes, societal views and cultural expectation impact "the legibility of pain", and shape sufferers' view of themselves together with the stories they feel entitled to tell. We just read how Mantel's doubts about herself, induced by lack of trust in her illness stories, added to the burden of her pain and effectively silenced her. In the epigraph, Wasson subsumes such processes under the notion of epistemic justice, i.e. the right of being seen as knowledgeable, and one's testimony credible (Fricker, 2007). Despite ownership of an illness and its symptoms, the sick status can reduce the credibility of a person, especially for given social categories (Kidd & Carel, 2017). Mantel's contacts with doctors in the next passage illustrates epistemic injustice in action. When she showed up to consultations, doctors saw the ambitious and scholarly young woman before even engaging with her symptoms. She consequently fell in the trap that has been common for women with a non conformist profile for centuries: she was referred to a psychiatrist and put on heavy dose of psychotropic drugs:

> A short time later I was vomiting a good deal. I had finished the course of anti-depressants, but felt no more cheerful, and my GP did what you do when someone says she is vomiting: send her to a psychiatrist. […] Dr G, the psychiatrist, was remote and bald. He had as much chance of understanding a girl like me as he had of rising from his desk and skimming from the window on silver pinions. He soon diagnosed my problem: stress, caused by overambition. This was a female complaint, one which people believed in, in those years, just as the Greeks believed that women were made ill by their wombs cutting loose and wandering about their bodies. (GUG: 159-60)

The passage sketches a scene of its time, but also illustrates the process of a prefabricated narrative closing in on – and closing off – the ill person, even when symptoms are not such an obvious match.

Eventually, after more than a decade of pain for which Mantel often fainted and was reduced to immobility for days, her endometriosis is diagnosed. The age of diagnosis aligns with the expectation that medicine held at the time, which, as she notes, was more a self-fulfilling prophecy than an epidemiological observation. In an interview to The Guardian (2004b) she explains:

> Myths about the condition had made their way into the textbooks. Endometriosis patients were «anxious perfectionists», white, middle-class career women in their 30s. The truth was, it was these well-educated women who were getting a correct diagnosis. Poor women and black women – characterised as promiscuous – were likely to be told they had inflammatory disease.
> We now know that endometriosis is an equal opportunities disease.

The history of Mantel's diagnosis is interesting beyond her personal misadventure and the historical vignette: the history of medicine is a replete of cases in which implicit sociocultural beliefs and prejudices, as well as straightforward moral judgments, stood in the way of correct diagnosis, like the idea that HIV only affected male homosexuals, or that cardiocirculatory problems are a men issues, or that autism is a developmental condition only, all beliefs that led to misdiagnosis in the categories that were a priori excluded. Such issues are hard to prevent, and not a problem of medicine alone: immediate comparisons are the police and the judicial system, in which "professional vision" (Goodwin, 2009) and judgments based on automatic and tacit knowledge (Dreyfus & Dreyfus, 1980) grooves criminal careers for marginalised groups. The reduction of epistemic injustice calls instead for "narrative humility" (DasGupta, 2008[5]): letting people's stories arise, in all their tentativeness and contradictions, and resisting the urge to impose familiar meaning onto their emergent sense-making.

3.2 *Self-guided health literacy*

Mantel narrates how, a few years before her surgery but already with many years of untreated pain behind her, she found a sympathetic doctor, who had taken her pain seriously and prescribed pain killers. She was grateful and relieved, however even this doctor was not willing to investigate the causes of her symptoms; time passed, the painkillers were losing their effect and the prescription kept increasing. Mantel, who knew how to use a library, decided to then take things in her own hands:

5 I wish to thank Benjamin Levett for alerting me to this concept.

> A few months earlier – […] – I had thought, once again: enough's enough. My doctor […] seemed disinclined to investigate, though happy to prescribe me stronger and stronger pain relief. Whatever he gave me (and however much alcohol I knocked back to accompany it) the pain grew over the top. So one day I went up to the capital, to the university library, and combed through the medical books. I found a textbook of surgery, with a female figure, her organs clearly depicted, and black lines-like the long pins with which they used to stick witches-striking through her hips and ribcage, carrying a name for each organ. For each organ, there was a pain, and of each pain, I had a sample. (GUG: 191)

In those days, it was not as common as in the internet era to look up your symptoms on publicly available platforms; independent learning meant a journey to a different city, and a considerable time spent in the library. Mantel did not even have a name to look up, but arrived nonetheless at a diagnosis. The medical textbook, as she explains, becomes the mirror of her pains, and begins to introduce meaning to her plight. As we will see later, however, independent learning may become a source of stress on its own.

When Mantel finally had surgery, hospital life came with its own learning pathway. At the end of the 1970s in the big London hospital the staff is not always sympathetic ("inclined to treat the patient as malingerers", GUG: 193), and explanations were seldom added to instructions. A meticulous observer and fast learner, Mantel realises that some medical procedures belonged more to the tradition of the trade than to firm medical knowledge:

> Before I began the journey, I was to drink as much water as I could possibly bear to drink, to distend my bladder, which was a good thing for a reason nobody explained. In a way, you didn't want to ask. What if they didn't know? There was a trade-off in ignorance going on. They told me nothing, and I didn't ask questions in case I was shocked by finding how much they didn't know. I waited, sitting on my bed, pensively swigging from a hospital tumbler. (GUG: 196)

A history of neglect and approximation in the way Mantel's illness was dealt with left her with a basic mistrust in the medical profession, and led her to adopt strategies to avoid being faced with unsatisfactory accounts. The quote above points to an area of the conversation between doctors and patients that is difficult to study, namely the questions the patient withholds. Patient's self-restraint has been reported in both primary and specialist visits (Judson *et al.*, 2013). Patients learn unwritten preferences of doctor patient dialogue in the same way in which pupils learn school (Mehan, 1979), namely by predicting their behaviours and adapting to those (Galatolo & Fasulo, 2022). Learning what *not to say* is a key part of this.

In the period after surgery, when her pains had returned, Mantel stopped looking for help after a few attempts. She had learnt how doctors reacted to her new large body and her bringing up stress, which further silenced her and kept her away from necessary care:

> I was aware that my condition was exacerbated by stress, and I knew that if I confessed to this, stress would be blamed for everything, and my career success (the only thing I could cling to) would come to look like an aspect of my pathology. Besides, every visit to every doctor would begin with a lecture about my weight. Since I was often unable to eat, and as I'd gained weight in the first place as a consequence of the drug treatment for endometriosis, I found this unbearable – less bearable than the pain, in truth. (HMP: 10)

Visits were experienced as further attacks on her ability to cope, threatening to undermine the only solid domain left in her life, which was her writing and her success with it. This is the kind of negative learning that can compromise patients' relation with health care and ultimately their health outcomes.

The importance of learning comes through under a different light in Mantel's experience with her other life companion, migraine. The astounding variety of migraine manifestations, especially in the "aura" prodromal phase, makes it difficult for sufferers to explain. Manifestations can even be similar to hallucinations. Mantel speculates: "starving saints in Lent, hypoglycaemic and jittery, saw visions to meet their expectations" (GUG: 2). In migraine, self-management is crucial but in order to achieve it, the person needs both self-observation and expert guidance. The first guide Mantel finds is Oliver Sacks. Sacks' approach to medical practice involved a strong interest in individual patients, and keeping track of historical developments in medical understanding, which produced the extraordinary narratives he is famous for. *Migraine* (1971), his first and more scholarly book, is rich in descriptions from historical medical books and from his clinical notes, and opens up for Mantel the first real understanding of her symptoms:

> Until I read Oliver Sacks's book *Migraine*, I did not realize how diverse and individual the manifestations of the aura could be. For a patient, knowledge is power, and I felt reassured by the book. (HMP: 11)

After realising the breadth of manifestations of the aura, Mantel starts to recognise her prodromal symptoms, which included sleepiness and speech disturbance:

> Late in the afternoon, a migrainous sleep steals up on me. It plants on my forehead a clammy ogre's kiss. 'Don't worry', I say, as the ogre sucks me into sleep. 'If the phone wakes, it will ring us'. I knew the migraine was coming yesterday, when I stood in a Norfolk fishmonger choosing a treat

> for the cats. 'No', I said, 'cod's too expensive just now to feed to fish. Even fish like ours'. (GUG: 4).

After several years of acceptable management, Mantel has a period of more intense attacks, and she seeks professional help. This time the story is one of good doctoring:

> A few years ago, when the pattern of pain had become more insistent and less easily managed, I was referred to a neurologist. My hour with him stays with me as a shining example of good practice. His history-taking was so structured, so searching, so thorough, that I felt that, for the first time, my pain was being listened to. The consultation was, in itself, therapeutic. At the end of it he offered me three options. I chose to try the simplest, and it worked. So I have about 75 percent success in aborting an attack, and what's left, I feel I can live with. (HMP: 11)

The passage can be read as a concise manual for effective healthcare. The positive impact of the episode can be heard in her words, as she describes the warm space created in the interaction, the way her pain was honoured, and the tailored strategies she was offered to choose amongst. Mantel's history is first and foremost one of being disenfranchised, her voice written over in view of the greater good, the territories of her body and mind occupied and alienated from her. In all her autobiographical writings, this aspect of her experience emerges as a cause of suffering at least as powerful as the physical pain. The episode of the neurological visit offers an example of positive autonomy favoured by a professional who explores the illness with the patient in the first place: like Charon (2009: 124) says, healthcare can "reveal bodily concerns and situations to the patient himself or herself", supporting the patient's self-knowledge with the professional "as mediator or interpreter". However, pursuing knowledge autonomously because of mistrust or trauma can lead to feelings of isolation and confusion, heightening the attraction of dubious informal medical communities, or simply staying away from care services, like Mantel did for years after her pain had returned.

4. Self-estrangement and redress

4.1. *Self estrangement*

Toombs (1987) speaks of the "body as other-than-me" that the sick person finds themselves tied to. The body-become-other is also what the physicians treat and deal with, marking further distance from the person and the self they used to know. At the beginning of her journey toward narrative medicine, Charon marvelled at the reflection that her role was to "explain back to the self of the patient what I had learned from his or her

body" (2009: 121). This process is also captured by Mantel, as she deals with the aftermath of the invasive surgery:

> And I too think of my body as consisting of some substance that I can split apart from myself, and hand over to the professionals, while I take an informed interest in what they do to it. (MTD: 255)

This separation contributes to the feeling of abandoning the land of certainty about oneself and having to come to terms with the new positions and identities the illness enforces on you: "Each day I was taking, though I didn't know it, a small step toward the unlit terrain of sickness, a featureless landscape of humiliation and loss" (GUG: 167).

The choice of words here is poignant; the elements of unknown that come with enduring sickness are described through a spatial metaphor of a place where there are no distinct landmarks, finding one's way is hard, and "humiliation and loss" are part of the landscape itself.

Threats to the continuity of the sense of self also come with the body changes that an illness brings about. In the case of Mantel, her change in size led to the discovery that other people projected a new personality and temperament onto her, and her own perception of herself was shaken:

> When you get fat, you get a new personality. You can't help it. Complete strangers ascribe it to you. When I was thin and quick on my feet, a girl with a head of blonde hair, I went for weeks without a kind word. But why would I need one? When I grew fat, I was assumed to be placid. I was the same strung-out fired-up person I'd always been, but to the outward eye I had acquired serenity. A whole range of maternal virtues were ascribed to me. I was (and am) unsure about how I am related to my old self, or to myself from year to year. (GUG: 230)

Summarising the recollection of the changes and health deterioration that were precipitated by her conditions and their treatments, she notes:

> Nowadays, more than twenty years on from my trip to St. George's Hospital [when she had her first operation, ND] everything about me – my physiology, my psychology feels constantly under assault: I am a shabby old building in an area of heavy shelling, which the inhabitants have vacated years ago. (GUG: 222)

Illnesses and invasive treatments exerted existential damage; they took away the basis of her self as she knew it, and induced a sense of incumbent danger for a body that has become weak and unpredictable. There is an imagery of void, of emptiness where once the elements that made her feel alive were, as the metaphor of the vacated buildings suggests.

From such reflections came Mantel's appeal – to healthcare professionals and her audience in general – to see the history of person and illness as

conjoined, especially if the illness comes with pain. Pain can temporarily occupy the entire space of one's self, in a body which feels emptied of anything else (like "a body cavity"):

> Pain cannot easily be divided from the emotions surrounding it. Apprehension sharpens it, hopelessness intensifies it, loneliness protracts it by making hours seem like days. The worst pain is unexplained pain. Gout is explicable and it's visible; the hot and throbbing joint illustrates the inner pathology. It's not frightening, like a pain in the body cavity. It's a pain you have, not a pain you are. (HMP: 9)

Apprehension and hopelessness, Mantel explains, can transfuse into qualities of the painful sensations themselves, and this is why the attitude of healthcare professionals can make so much difference. Mantel speaks passionately about the need for health services to "help patients remain physically and economically active and catch them before they fall into a pattern of chronic suffering – before pain erodes their personality and intellect." (HMP: 12). These words have a ring of emergency to them: people's lives are at stake as we speak, pain eroding away their vital core. Her appeal in the HMP piece is to be mindful of a person's history with their condition, how they live with it, and what will stay with the person even if the problem is solved:

> But a person in pain is not an empty vessel, filled temporarily with a sensory experience that can be emptied out like water and leave no trace. Pain changes us. It takes more than a pill to reverse or manage that change. (HMP: 11)

The description flashes out the distance patients can feel from health professionals when they limit their view to the narrow issue; the patient needs to find their bearing again, orienting themselves in the indistinct zone their illness has pushed them into, so they need someone willing to see them whole and guide them through (Toombs, 1987).

4.2. *Writing as self integration*

While the psychological and physical experiences Mantel describes are destabilising and disruptive, she suggests that there is redemption in the power of words, whereby the experiences become approachable, part of a world that can be shared again.

Until her fifties, Mantel had not written autobiographical pieces, and was a little suspicious of the genre; at that age though, she felt the urge to do so. The title of the book *Giving up the Ghost* plays with the idiomatic meaning of the phrase in English, i.e. "to stop trying to do something because you know that you will not succeed", but also "to die" (Cambridge English Dictionary). Toward the end of the book, Mantel discusses the

lack of children and grandchildren in her life: they never happened, but their shadows were inhabiting her present in very concrete, if not totally conscious ways:

> For a year or two in the new house, our possessions expanded to fill the rooms. The cupboards were packed with linen and towels. We bought everything by the dozen. […] There must have been a moment of realisation, though I don't remember it clearly: a moment when I looked at the contents of the cupboards and said: but who is all this for? Who am I expecting? I knew, if I thought about it, that I was expecting the unborn. (GUG: 238-9)

The reflexive work implicated in writing (Demetrio, 1995) emerges as the ultimate pathway for learning, one in which the unthought and the untold can be laboriously traced until they are born as words, or as the inchoate space between them:

> I am writing in order to take charge of the story of my childhood and my childlessness; and in order to locate myself, if not with a body, then in the narrow space between one letter and the next, between the lines where the ghosts of meanings are. (GUG: 222)

This passage dialogues with a current debate in narrative medicine and pain studies about how to frame the healing power of narrative, or indeed the pertinence of the narrative category for testimonies about illness and pain. On the one hand, engaging with her story at length makes Mantel feel like she is taking charge of her past; on the other hand, as concerns her living body the restitution cannot but be incomplete. She hints at the work of writing in itself as the physical surrogate of feeling in charge of her physical presence. In the movement towards the next word, she says, embodied meaning can fleetingly appear, but a full-fledged story can be challenging to fathom.

Touching again on this problem in the shorter piece MTD, which recollects the torturous period after her first surgery, Mantel notes:

> Just before my discharge I scribbled: 'When I go home I could write up my hospital diary. Or, you know, I could not. I could defiantly leave it unprocessed, and that way the marks of experience might fade'. The truth is that, needing more surgery, I am not sure what kind of story I am in. Perhaps a shaggy dog story[6], or a mangled joke with the punchline delivered first. The poet Jo Shapcott used a nice phrase recently about confessional writing: 'chasing your own ambulance'[7], she called it. I am guilty of that. (MTD: 266)

6 "A long story that is intended to be amusing and that has an intentionally silly or meaningless ending" (Cambridge English Dictionary, 2025).

7 The phrase appears in an interview for the *Guardian* (Crown, 2010).

The lines capture the dilemma of the young Mantel just before the potential turning point of hospital release, when she is caught between the urge to write and the wish to forget. Beside the fear of renewing her pain, she missed the sense of directionality that a narrative should have. She is filled instead with uncertainty about the shape her life will take, and feels somehow behind it, writing her story into being rather than recounting it.

Something else to note about these very dense lines is that Mantel writes in the present tense, even though the events date back several decades; she had explained the switch earlier in the same piece, noting how "pain is a present-tense business" (p. 252). Time gets out of joint under intense distress, and the biography's timeline loops back onto itself (Madsen, 2021).

In illness narrative theorization, the healing power of narration is often synthetised as emplotting chaotic experiences into an ordered series of event, a sense of resolution being lent on a person's troubles by this retrospective attribution of meaning (e.g. Frank, 1995). Wasson (2018) contests the underlying idea that the active principle of healing in patient's narratives is to re-establish time directionality. Though groundbreaking at the time, this account leaves out many experiences that do not fit the model (van Hout *et al*., 2022). This could be because a firm point of view from which to look back cannot be reached, like in chronic conditions, but also because a person may feel caught in a perpetual middle, rather than able to embroider a pattern of beginning, middle and end. A strong version of narrativity, warns Wasson (2018), may even bring back the power imbalance between healthcare professionals and patient, adding a normative dimension to the exchange via the expectation that the patient has sorted their story out. She argues that the experiences could be best attended to as made of *moments* and *episodes* rather than complete narratives with internal organisation (Wasson, 2018). Reflecting on genres of writing, van Haut et al. (2023) argue that the *chronicle* is often a more fitting choice for people living with pain.

Mantel's work exemplifies how an author can deal with the same autobiographical material in different ways, across different genres, but in all her writings, including the more consistent effort of the book, she never forces her biography into an accomplished narrative arc. She rather indicates a humbler temporality inscribed in the writing process, one which may not have a strong directional flow, but that recalls the more intimate and cyclic rhythm of the body at work:

> I am fascinated by the line between writing and physical survival. In the days after the procedure I was sometimes so exhausted by movement that I would wait patiently for someone to come in and give me a paper cup of pills that was almost, not quite, out of my reach. But somehow, I would always contrive to get my pen in my hand, however far it had rolled; my mood was even, despite uprushes of shame, and the only thing that would really have upset me was running out of paper. The black ink, looping across

> the page, flowing easily and more like water than like blood, reassured me that I was alive and could act in the world. (MTD: 266)

The physical reality of reading and writing was what came to Mantel's rescue in her weakest moments, with the power to restore herself to herself, and mend the relation with time that the physical assaults to her body had warped.

5. Discussion and conclusions

This paper aimed to explore the multiple pathways of learning that a person living with illness and pain can find themselves on. Mantel's reflections at the same time provided several entry points to central questions in narrative medicine: How do the socio-cultural views inform individual experience? Is there a place for autonomy in a situation almost defined by the person's dependence from others? In what ways is a person's sense of self affected, and can writing restore (parts of) it?

I have first considered responses to Mantel's illness and pain that were obvious mediated by her sociocultural environment. A historian by trade, Mantel points out the prejudices and untested beliefs that caused side tracking and misjudgements in her care. Inahara (2021) discussing Frida Kahlo's as well as her own history of pain, uses Merleau-Ponty (1993: 125-126) expression "instituted meanings" to refer to the classifications that precede a person's individual action, creating the frame within which their pain will be seen. For women especially, such frames are heavy, and distorting of the picture: in Mantel's case, too ambitious, too nervous, too thin, then too fat. She laments how neither the female nor the male gaze were laid on her kindly, in both the lay and medical communities. Alarmingly, she learnt that admitting to the psychological effects that illness and pain were exerting on her could lead to further misinterpretation and irrelevant treatments, leading to the building up of mistrust, fear and contempt of medicine. Recent critical approaches to medicine as a gendered science are gaining ground in medicine and health research, looking at gender as a determinant of health and advocating for a realignment of research practice in this sense (Ray *et al*., 2024).

Based on Mantel's recollections I have discussed autonomous learning, and its double edge. On the one hand, through independent research she could found answers, normalise her symptoms and discover commonalities with other people's stories; on the other, it caused scepticism, and even fear to learn too much. In relation to migraine, she describes instead the transformative effects of doctor-patient interaction when learning occurs on both sides: an interested, thorough investigation can already function as treatment; allowing informed autonomous choices between available solutions facilitates the patient's acceptance of the condition.

I have then explored the sense of estrangement that Mantel describes from both her body and her sense of self, both submitted to the control of others. The experience of disorientation and loss of continuity were multiplied by uncertainty and fear. In her analysis of stories of people with brittle bone disease, Madsen (2021) argues that the fear for what the future holds, in connection with the experience of pain, can create a "haunting" effect of psychological invasion. Toombs (1987) points out that emotions are an area at high risk of misunderstanding between doctors and patients: the efforts of doctors to downplay causes for concern can leave even less space for emotions to be aired by patients, who feel that their apprehension will be regarded as irrational. In general, healthcare professionals can contribute to the sense of self displacement by focusing on the sick body in isolation from the life of the patient. Mantel takes it upon herself to instruct her audience about reintegrating the patient and her pain, seeing them in their historical intertwining and mutual relation.

The ways in which illness and pain can be voiced by the sick person were considered in the final part of the article. While Mantel uses the lengthier format and the slower pace of the autobiographical book to unravel latent meanings in her life, both in the book and in the fulminant prose of the shorter pieces she presents pain and chronic conditions as resistant to a neat storyline. We saw how her present co-existed with the terrified post-operatory days as well as with the might-have-been of her never born children. Time is not linear in any life, but the continuous bending of time and changes of pace that illness imposes are inescapable to the sick person's consciousness. Cultural studies on pain address this issue by considering different forms of representation, but also widening the view to encompass the context within which sickness and care unfold. Wasson (2018) offers the term "temporality of thwarted connection" to keep together the experience of the individual engaged in sense-making in relations with others and the lines of force of culture and politics that cut through them. Within psychology, Brockmeier and Medved (2023) highlight how understanding cultural and social determinants of health in peoples' life-words require a way of listening and a type of cultural analysis that may escape even experience-focused research approaches. Through Mantel's reflections on what writing felt to her we caught a glimpse of how working through words supported a rehoming of the self, the slow, and never definitive, rebuilding of the foundations that were so deeply shaken throughout her history with pain.

In conclusion, the autobiographical work of Mantel, an author often described as ice-cold and unflinching in her descriptions of human misery and shortcomings, offered a stark illustration of the learning that comes through illness and pain, of how knowledge can be the product of fruitful collaboration or of lonely and fearful self-teaching, and of how writing about it all was sometimes the only medicine at hand.

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