OPEN ACCESS

Chronicling the chronic: narrating the meaninglessness of chronic pain

Femke van Hout,[1] Aukje van Rooden ,[1] Jenny Slatman [2]

[1]Philosophy, University of Amsterdam, Amsterdam, Netherlands
[2]Department of Culture Studies, Tilburg University, Tilburg, Netherlands

Correspondence to
Femke van Hout, Philosophy, University of Amsterdam, Amsterdam, Noord-Holland, Netherlands; femkevanhout@hotmail.com

Accepted 5 April 2022
Published Online First 18 July 2022

ABSTRACT

This article proposes a way of narrating chronic pain: the telling of a *chronicle*. Recent work in the medical humanities has been critical of traditional approaches to illness narratives. In line with this criticism, we argue that the experience of chronic pain resists internally coherent, plot-driven—in other words, Aristotelian—narrative. Drawing on phenomenological studies, we state that chronic pain is an utterly meaningless experience due to its relentless continuation over time. It therefore defies any narrative search for a higher meaning or purpose as well as the search for a coherent and progressive 'plot'. However, we reject the idea that chronic pain could therefore only be captured in the form of a meaningless, unshareable and chaotic anti-narrative. Instead, we propose that chronic pain could be borne witness to through the speech act of *chronicling*—an ongoing telling about ongoing suffering. Building on work of contemporary philosophers Philippe Lacoue-Labarthe and Jean-Luc Nancy, we examine what the chronicle entails by touching on three themes: time, meaning, and the body. First, we argue that chronicling allows people to bear witness to chronic pain's purposeless continuation over time, thereby affirming the utter meaninglessness of the experience. Second, we argue that it is precisely in the affirmation of this meaninglessness that a *different kind of meaning* can be experienced: a meaning which cannot be detached from the sensory experience of telling and listening itself. Third, we examine how chronicling chronic pain could allow the muted and painful body to once again meaningfully express itself to others.

INTRODUCTION

Chronic pain is an urgent public health problem of our time, affecting about 20 per cent of the global adult population (Breivik et al. 2006; Fayaz et al. 2016; Goldberg and McGee 2011). Yet, despite this prevalence, chronic pain is still very poorly understood. One reason for this is that it defies the way in which we are used to conceptualise pain: ever since the writings of Hippocrates, Western medicine has attributed a specific legibility to pain as a symptom, a warning that there is something physically wrong. In this view, pain is something diagnosable and remediable. However, as a complex blend of somatic, interpersonal and affective elements, chronic pain mostly remains frustratingly mysterious, resisting a clear diagnosis as well as a proper cure.

Since chronic pain often involves an unclear aetiology, it challenges the codes of morality surrounding sickness and health (Jackson 2005, 139). Just like sufferers of other conditions with contested aetiology—such as chronic fatigue syndrome—people with chronic pain are often denied the 'sick role', that is, their problems are often not, recognised as real and therefore they have difficulty in obtaining good healthcare and social services (see Dumit 2006; Werner and Malterud 2003). Not uncommonly, they face psychologised interpretations—by friends, family and professionals alike—of their physical pain, which suggest that it is 'all in their head' (De Ruddere et al. 2012; De Ruddere and Graig 2016; Kappesser and de C Williams 2013; Wasson 2018). It is therefore not surprising that many people with chronic pain feel socially isolated. Indeed, patients with chronic pain tend to be separated from their social environment by walls of silence (David 1991).

Attempts to break this silence have, ever since the narrative turn in the social sciences (Kreiswirth 2000), often taken the form of a search for illness narratives. As is well described by various scholars, the dominant view towards illness narratives is that they allow patients to restructure time in a meaningful, coherent way according to a 'plot' (Slatman and van de Ven 2021; Wasson 2018; Woods 2011). In this way, people can once again make sense of their experiences (Kleinman 1988), counter the biomedical discourse and reclaim their own story and body (Frank 1995). However, since pain is a phenomenon that is hard to communicate (Scarry 1988), it is not easy to create pain narratives. Recent studies have shown that more flexible, intermodal and interactive types of narrating, as afforded by the internet and social media, might facilitate pain storytelling (Gonzalez-Polledo and Tarr 2016; Groenevelt 2021; Ressler et al. 2012).

We believe, however, that the difficulty in narrating chronic pain might involve more than a communication problem that could be solved while using a better tool. It is the *experience* of chronic pain itself that resists coherent, plot-driven narrative. In line with recent medical humanities studies that have criticised traditional approaches to narrativity (Slatman and van de Ven 2021; Wasson 2018; Woods 2011), this paper seeks to define an alternative way of narrating chronic pain. Relating Felman and Laub's theory on testimony to the work by contemporary French philosophers Philippe Lacoue-Labarthe and Jean-Luc Nancy, we will develop the notion of the chronic pain chronicle. To understand the reason why chronic pain resists coherent, plot-driven storytelling, we will start with a short exploration of the chronic pain experience, drawing on some phenomenological studies.

To cite: van Hout F, van Rooden A, Slatman J. *Med Humanit* 2023;**49**:1–8.

THE EXPERIENCE OF CHRONIC PAIN AND THE LIMITS OF PLOT-DRIVEN NARRATIVE

As is well observed by phenomenologists, pain is an experience which severely alienates patients from their own bodies. Rather than silently facilitating one's engagement with the world, the painful body becomes 'visible' to the sufferer as a strange thing, a physical hindrance to which one is inadvertently 'bound' or 'shackled' (Bullington 2009; Grüni 2004; Serrano de Haro 2012; Svenaeus 2015). These scholars also point out that pain can stretch beyond the limits of the body and saturate people's lifeworld, making their entire life feel alien and unhome-like. As Bullington (2009) and Svenaeus (2015) state, it is this alienation or distortion of the lifeworld which renders pain, and specifically chronic pain, so resilient to comprehensive language. They both refer to Elaine Scarry, who famously pointed out that pain can 'shatter' all meaningful language due to its world-destroying nature (Scarry 1988). In this view, chronic pain is a temporal extension of acute pain: the longer it lasts, the longer the person suffers from alienation and communication difficulties. We argue, however, that we need to understand the difference between acute and chronic pain not in a gradual sense, but in a categorical sense: chronic pain is given to us as a categorically different experience. This allows us to identify two reasons why chronic pain specifically resists coherent, plot-driven narrative.

When we speak about coherent narrative, we refer to the prevalent Aristotelian notion of narrativity, which focuses on a plot unifying the narrated actions. As Aristotle states in his *Poetics*, *muthos* is a well-ordered story which has a beginning, a middle, and an end (Aristotle 1984, §7: 2321). For Aristotle, it is this power to construct plots that makes poetry so valuable. Poets are able to 'zoom out', as it were, and to provide a view from above of the world as a whole: they are standing on a higher place in the landscape, and are therefore able to see where the river beneath them, that is, the story, originated and where it is heading.

This specifically Western traditional story is still prevalent in our everyday culture as well as in notions of illness narratives (Baldwin 2016; Hyvärinen et al. 2010; Slatman and van de Ven 2021; Wasson 2018; Woods 2011). It is a commonly shared idea within narratology that the meaning of a story is informed by the end to which it moves (Brooks 1984; Kermode 1967; Ricoeur 1984; Ahmed 2010; Ricoeur 1994). In this view, persons orient themselves in life and find meaning in it by creating such a well-plotted story (Hyvärinen et al. 2010, 1–2). As a 'biographical disruption', illness, from this perspective, causes a loss of narrative coherence, and thus a loss of direction and meaning in life (Bury 1982). The telling of an illness narrative should then, as Hawkins suggests, "restore to reality its lost coherence and (…) discover, or create a meaning that can bind it together again" (Hawkins 1999, 2–3).

As Wasson (2018) observes, even though there are many ways in which one could narrate one's illness experiences, the urge to look for a meaningful 'plot' is a key way in which illness narratives achieve normative work (Wasson, 106). She observes that in Western cultural milieux, illness narratives which 'move' in a certain direction and which are internally coherent and self-consistent, are deemed more comprehensible and meaningful and thus have moral authority over other kind of illness narratives (Wasson, 106). However, the insistence on such linear, realistic, coherent and self-consistent narratives fails, as Baldwin (2016) states, "to do justice to the complexity, ambiguity, and messiness of lived experience" (p. 537). We argue that this is indeed the case for the experience of chronic pain: it cannot be captured in a plot-driven narrative, because it (1) knows no end and is therefore experienced as utterly *meaningless* and (2) it severely changes the sufferer's experience of *time*.

First, as chronic pain has no end, it defies any search for a higher meaning or purpose. We draw this idea from the anthropologist Buytendijk (1961), who argues that chronic pain fundamentally differs from acute pain because it is experienced as *meaningless*. Acute pain, he states, is given to us as something which will, over time, go away. It therefore fits within the commonly shared narrative about pain functioning as an alarm bell, warning us against something physically threatening: it is, in this sense, 'good for something'. However, the fact that chronic pain goes on and on and on results in it being experienced in a fundamentally different way: as something which will never cease. This means that in the very moment of suffering, the impossibility of the pain ceasing (or at least the possibility of it never ceasing) is already given. Buytendijk states that it is this relentless continuation over time which renders the experience of chronic pain utterly meaningless (p. 130). As the pain lasts and lasts and lasts, it becomes impossible to relate it in a satisfying way to a physical cause, and, what is more, to interpret it as having any 'moral benefit' for the sufferer. There is no lesson to be learnt, no 'truth' or overall meaning that transcends this suffering without end. The only 'truth' of chronic pain is that it is meaningless.

The second reason why chronic pain resists coherent, plot-driven narrative is that it defies the specific temporal orientation that this kind of storytelling requires, in which past, present and future stand in logical relation to one another. This is because chronic pain fundamentally changes the structure of the sufferer's lived temporality. Here, we follow Leder (2016), who states that the time experience of patients with chronic pain is characterised by two paradoxes. First, chronic pain is both 'now' and 'always': pain mercilessly draws you to the present moment, but simultaneously swallows up everything, making it almost impossible to recollect or imagine a pain-free past or future (p. 449). The second paradox refers to chronic pain being both 'never-changing' and 'ever-changing'. The pain is never-changing in the sense that it just goes on and on and on, "like a nightmarish version of Nietzsche's eternal recurrence" (p. 450). At the same time, the pain constantly changes: it might withdraw or return according to the time of day or one's activities, change from stinging to pinching pain, or become more or less intense. All these changes, however, never add up to any kind of progression: if a story moves to its closure, chronic pain moves without leading anywhere. In this sense, chronic pain is not only the pain of the body but also of time; as it lasts and lasts and lasts, temporality itself is severed.

It is because of this meaninglessness and these time paradoxes that people with chronic pain often have the feeling that they are not really allowed to exist. In our discourse, continuing pain without reason or purpose—that is, pain which continues to no end—just has no place. Chronic pain thus almost seems to take place 'outside' the parameters of our normal reality, 'outside' the world in which experiences make sense through causality, sequence, place and time. As an otherworldly phenomenon, chronic pain silences and isolates the suffering person through its incommunicability, inhibiting them to shape their identity by sharing their personal experience with others in their social environment or broader cultural community. As people in chronic pain cannot explain to others what they are going through, the very *reality* of their chronic pain experience—and, in a sense, who they are as a person—is at stake.

How, then, to affirm the reality of chronic pain? As is known, Frank (1995) presented a highly influential typology of illness narratives that distinguishes between the restitution narrative (a story in which the patient is unproblematically yet passively cured), the chaos narrative (an anti-narrative which lacks all coherence and meaning), and the quest narrative (an 'ideal' narrative, in which the patient finds higher meaning in their illness experience by accepting it as a 'vocation' or 'calling). According to this typology, the experience of chronic pain takes the form of a chaos story. As Frank points out, chaos stories mark the limit of what can be said. This type of story concerns a 'lack in speech' (p. 101); it is that "what never can be told" (p. 102). Whenever one is able to capture chaos in a story it is usually retrospective, when the chaos has passed again. When that happens the chaos story already changes into a more coherent quest or restitution story (p. 108–109). According to Frank, then, the chaos story thus represents that which can hardly be shared with others. Frank thus suggests that the experience of chaos is only shareable in a type of story—restitution or quest—that is plot-driven and that cannot take into account the plotless experience at hand. Frank's typology of narratives thus leads to the paradoxical conclusion that chaos can only be narrated while cancelling it. Even though we agree with Frank that the experience of chronic pain challenges coherent stories, we still believe that this experience can be shared without annulling its 'chaotic' nature, without taking the sting out of it. In this paper, we propose a way of narrating which exceeds Frank's typology, that is, a way of telling through which the meaningless experience of continual pain can once again be meaningfully shared with others. This is the telling of a *chronicle*—an ongoing telling about ongoing suffering—in which one tells about the events as they happen, one by one, time after time, in a matter of fact and detailed way, without reflecting on these events from above.

Inspired by Felman and Laub (1992), we argue that the telling of a chronicle could be seen as a way of *bearing witness* to a truth that is difficult or perhaps even impossible to communicate. In their book, they question how, after the Holocaust, we can still talk about and listen to the 'truth' of unspeakable events that "took place 'outside' the parameters of our normal reality", but that still have to be spoken about (Felman and Laub, 69). According to Felman and Laub, this can only happen through a process of witnessing, in which the teller and the listener take joint responsibility for affirming an unspeakable experience's reality. What is affirmed in the process of witnessing is that the experience is real and should be spoken about, but also that it can never be fully understood in terms of a coherent narrative. The listener responds to the sufferer, neither by rejecting their experience as meaningless nor by trying to fully understand them, but by staying: "I affirm the reality of your pain and I will be with you."

Based on an analysis of Philippe Lacoue-Labarthe's work *L'"Allégorie"* (The "Allegory"), a book consisting of more than 30 prose poems relating to a chronic form of existence written by Lacoue-Labarthe himself and an afterword by Jean-Luc Nancy (Lacoue-Labarthe 2006), we will develop the idea that the telling of a chronicle can affirm the meaninglessness of chronic pain because it bears witness to what renders it meaningless in the first place— its purposeless continuation over time. We will first explore how the work of these contemporary French thinkers relate the experience of the chronic as a non-progressive wandering condition to the speech act of chronicling the experience of this wandering, step by step, time and time again. Next, we will delve deeper into the work of Nancy to examine how the telling of the chronicle could once again allow for an experience of meaningfulness—although a different kind of meaning than the one found in, for instance, Frank's quest story. In the last section, we will explain why the chronicle can be understood as a form of reclaiming one's own body. Even though the world-destroying nature of chronic pain can never be undone, witnessing might at least allow for an affirmation of one's being a living body which can connect and share with others.

TIME: BEARING WITNESS TO ONE'S 'GOING ON'

To understand how Lacoue-Labarthe explores the spatiotemporal meanings of a chronic, non-progessive existence in *L'"Allégorie"*, let us first concentrate on his prose poem 'Chronique' (chronicle or chronic):

> The bleary water is immobile; the waterside leaning over it has just died: black grass and rocks. The heat is excessive. This is an oxbow lake, a lake cut off from the main stream (sleeping water): the water is so calm that its whole surface is covered with dust, making it look like a piece of land, albeit without the slightest inequality: there is only the quivering of the light that pierces through the leaves of the trees… (Lacoue-Labarthe 2006. Translation by van Rooden, quoted in van Rooden 2012.

Perhaps this landscape could be considered as peaceful and serene, were it not for Lacoue-Labarthe's multiple descriptions of utter physical discomfort. Rather than finding ourselves in a quiet, tranquil place where we can put ourselves to rest, we seem to be trapped in a feverish nightmare: 'the heat is excessive' and—further on in the poem—there is 'fever and sleep on the ground which is cold. We shiver' (p. 34).

What makes this nightmare all the more terrifying is that it seems impossible to escape from it; like chronic pain, it traps us in a paradoxical experience of both ever-changing and never-changing time. As van Rooden explained in her article 'The Grand Narrative Revisited', this landscape is not *motionless*—there are vibrations, quivers and movements—but it is *immobile*—it is not 'on its way' like a river is on its way, springing from a source and heading towards a final destination(van Rooden 2012). The poem's title, 'Chronique', captures this situation perfectly: chronic time evolves, although not in a progressive way, for better or worse: it is what it is. Lacoue-Labarthe shows us how there is something terribly discomforting and horrifying about this non-progressive passing of time. It just seems *unreal*: "Someone repeats in a horrified voice: It is not possible, it is not possible" (Lacoue-Labarthe 2006, 34).

Lacoue-Labarthe describes the chronic more or less explicitly in *L'"Allégorie"*'s other prose poems, although under different titles. In some of these poems, the spatial and temporal dimensions of chronic places and landscapes are combined with the other meaning of the word *chronique*: that of a story, or chronicle. The main question that Lacoue-Labarthe thus seems to raise in these texts is how to recount the story of something chronic, of something that does not develop in a progressive way.

A coherent narrative miserably fails to do justice to the 'truth' of chronic pain as a relentlessly continuing yet constantly disruptive experience, deprived of any adventurous development, unravelling plot or even beginning or end. What Lacoue-Labarthe shows us in his poetry is that a chronic world is *flat*: it does not contain any 'higher places', where we can take a rest and reflect on the things from above in order to create an ordered whole (van Rooden 2012). This flatness is especially present in Lacoue-Labarthe's prose poem 'Allusion à une commencement' (Allusion to a beginning) (Lacoue-Labarthe 2006, 66–70). In this poem, Lacoue-Labarthe recounts a heedless wandering through

'the wide flatlands'. He and his companions are hoping to find a resting place before 'the big frost', only to discover after a while that they have made no progress at all: "We had to admit that we were lost […] Everything around us was without boundaries; it became evident that there was no endpoint, nor any means of a possible return to the beginning" (p. 66–70).

Chronic suffering as a heedless wandering without a resting place—this is how the French writer Alphonse Daudet repeatedly describes continual pain caused by neurosyphilis in his fragmented collection of notes in *In the Land of Pain* (Daudet 2018). He writes: "It would be so good just to be able to stop, but no, day and night the spider goes on spinning; a few hours respite can be gained only through doses of chloral. Macbeth murdered sleep years and years ago" (p. 22–23). And, later: "You have to die so many times before you die" (p. 41). How, then, to recount the story of this directionless wandering? Or, as Lacoue-Labarthe puts it in 'Allusion à une commencement' (Allusion to a beginning): "If they interrogate me, what fable, what improbable story could I tell?" (Lacoue-Labarthe 2006, 70).

In her autobiographical essay, Fridman (2018) writes that language is unable to hold the utter uncertainty of her continual pain caused by endometriosis. She does not know how to put into words that her condition does not have any progression or next steps, that her pain constantly changes but at the same time just is what it is. She therefore withholds all language about her condition from others, 'awaiting a narrative that is clear' (Fridman 2018, §2).

> Without an elevator pitch of a story, there is never enough time to fully explain. There is never a right moment to tell someone about your illness: not over beers or breakfast by the BART, not at the march, not at work, not during sex. It's too *peculiar*.
> This leaves me very little time. Then, when to tell? What to tell? What do I owe people, to tell? (§4)

Chronic pain is 'too peculiar'—Fridman makes this statement multiple times in her essay. "*Peculiar,* with its implication of privacy from *pecularias* of private property: my condition as my private property, and any sharing of it *peculiar*, too—odd" (§3). Her experience is too peculiar to share because its existence cannot be affirmed by doctors and because it is not translatable into a story that other people can relate to. Therefore, she tells herself: "Hold onto it, keep it. Keep it to yourself" (§3).

Fridman contrasts her own refusal to tell to the perpetual sharing by her chronically ill friend Kelin, who "will tell anyone, anywhere" (§4). In *Testimony*, Laub states that people indeed often fall into extremes when the imperative to tell about their experiences "is inhabited by the impossibility of telling": they either do not stop telling at all or get stuck in a total "silence about the truth." But, as he states, "the 'not telling' of the story serves as a perpetuation of its tyranny" (Felman and Laub 1992, 79). The longer the experience remains untold, the more distorted the sufferer's conception of it becomes. Indeed, Fridman's perpetual silence severely isolates her from others and even results in her doubting the existence of her continual, unexplainable pain: "what if I, too, 'have' nothing?" (Fridman 2018, §3).

But even if we accept that it is impossible to fashion the experience of chronic pain in the form of a plot-driven story that other people can understand, we cannot deny that Fridman *did* write a text about it. We cannot deny that Lacoue-Labarthe and Daudet, even if they were unable to provide a clear account or story, at least managed to tell about their ongoing wandering condition. We suggest that it is exactly in the telling about this 'ongoing' or 'going on' that the spatiotemporal meaning and the storytelling meaning of the chronic find their culmination point: what chronic pain demands is neither a coherent, plot-driven narrative nor an anti-narrative, but this other kind of narrative, the chronicle. What remains is the possibility to bear witness to one's own endless wandering, to the endless wandering itself.

For Fridman, it is exactly the realisation that she can at least bear witness to her own 'continuation' over time that allows her to start speaking about her pain again.

> "I still want you to tell me what's going on with your body," my friend Cailey says, "even if you don't know." […]
> "But why," I ask her, "when there's nothing certain to say?"
> "Because it's what's going on with you." She smiles. My continuation, then ("going on") is what I am supposed to communicate, even if I have no words to explain the experience itself (Fridman 2018, §6).

Fridman then cites the poem 'NOTE', written by a friend of hers (we have been unable to detect the writer). In this poem, it is stated that continual pain—the 'it' that comes and goes—is still worthy of being spoken about, even if it resists any comprehensive language.

> It should be noted.
> (When)
> When it hurts,
> "it" can be a specific location. *My chest hurts*.
> It can be a specific activity. *Breathing hurts*.
> But even in cases that are *acute/local,*
> "it" remains chronic/generalized
> […]
> The very same "it" that comes and goes without saying, that was before and still is worth mentioning.

Paradoxically, both in Fridman's essay and in 'NOTE', what makes chronic pain meaningless and unspeakable—the fact that it goes on and on without reason or purpose—is also exactly what makes it 'worth mentioning': it is still important to share, 'because it's what's going on with you', because it is and remains such an important part of your life.

As Felman states in *Testimony*, it is exactly this breaking of all discourse—in this case: the breaking of a certain discourse about pain, in which continuing pain without reason or purpose just has no place—that at the same time demands a breaking of the silence. Testimony, she writes, has the "contradictory double task of the breaking of silence and the simultaneous shattering of any given discourse, of the breaking—or the bursting open—of all frames" (Felman and Laub 1992, 224). Chronicling the chronic—an ongoing telling about ongoing suffering—could be a way of bearing witness to the bursting open of the existing frameworks about pain. This is what, in the end, takes the experience of chronic pain 'beyond' the mere peculiar: in chronicling the chronic, you are taking "responsibility—in speech—for history or for the truth of an occurrence, for something which, by definition, goes beyond the personal, in having general (nonpersonal) validity and consequences" (p. 204).

What we suggest is that the (non-personal or general) truth of chronic pain—it's meaninglessness which is caused by its purposeless continuation over time—can only be affirmed when one bears witness to this purposeless, chronic passing of time itself. We believe that this can be done through the speech act of chronicling: bearing witness to events in their passing, one by one, without interpreting them. It is a way to bear witness to experiences which do not allow for an overview but imprison one in a flat world. Unlike the Aristotelian poet, who creates

an ordered whole 'from above', one narrates, like the Aristotelian *chroniqueur*, every detail without distinguishing that which is important from that which is trivial. In this sense, chronicling is non-interpretative: one thing follows another without the author changing or interpreting them or fitting them in a coherent plot. In that way, that what makes chronic pain meaningless—its purposeless 'going on'—is borne witness to in the very act of telling itself, again and again, detail by detail.

Narrating in the form of such details might, as Felman observes in *Testimony*, be the only way in which one can at least *say something* when telling a coherent story has become impossible. In that sense, the title of the poem 'NOTE' could be read in two ways: as if it were an order ('it should be noted'; it is our responsibility to break the silence), but also as if it were just a little note—a little detail. A collection of such details is given by Daudet in *In the Land of Pain*—he provides us with small, sometimes unfinished notes, fragments of feelings, impressions and observations. Asking or searching for little details instead of general truths might break the 'sacralization of silence' that surrounds the experience (Felman and Laub 1992, 219), leading us from the depths of an experience defined by its unspeakability to 'a retrieval of the possibility of speaking and a return of the voice' (p. xix). This has interesting implications for therapeutic practices: instead of helping the patient to (re)create a life story with an overarching meaning, it might be better to start from the little details, to ask them to tell or write, like Daudet did, about little feelings, impressions, observations (this could for instance be done by keeping a notebook or a diary). It is a way of telling that does not turn away from, but speaks *through* the meaninglessness of chronic pain by continuously, and without purpose, bearing witness to its purposeless continuation. And, paradoxically, this speaking *through* chronic pain's meaninglessness might once again allow for an experience of meaning.

MEANING: JEAN-LUC NANCY'S 'SENSE'

To examine how the telling of the chronicle can be experienced as meaningful, we will use Jean-Luc Nancy's idea of meaning—'sense', as he calls it—as a starting point. The question of the possibility of sense is central to Nancy's many different philosophical analyses—whether they address issues of ontology, religion, politics, art or literature (Nancy 1997; Nancy 2008; Nancy 2000). Nancy contrasts sense to another kind of meaning, 'signification'. Following Nancy, we will argue that we can understand the telling of a chronicle as a turning away from signification towards sense.

Signification, Nancy states, is "what is said"; it is what can be reported, told or accounted prior to or after a certain experience (Nancy 2000, 27). It is meaning which can be detached *from* the actual sensory experience; what can be said *about* the experience. To illustrate, we could say that the meaning that is found in Frank's quest story can be characterised as signification. Over time, the hero of the quest story discovers that their illness journey has a certain purpose or meaning that transcends the illness-experience itself: for example, "I have learned how important it is to listen to my own body", or "Life is vulnerable and should be cherished." For Frank, this lesson or purpose can (or must) then be shared with other people, who can relate to it and understand it. 'Sense', in contrast, is Nancy's term for a kind of meaning which *cannot* be detached from the (sensory) experience itself. It is what makes sense despite, or in, the failed attempt to find meaning.

The recurrent question in Nancy's work is how life can still be meaningful when all unities of syntax and meaning have broken down. He states that, after 'the death of God', we can no longer presuppose an individual sense-making subject that provides our meaningless existence with an overarching, transcendent meaning (Nancy 2000, xi-xii). Rather, Nancy states that the idea of an individual subject is in fact an abstraction from the naked fact that existence always involves the being of multiple subjects, multiple bodies and bodies other than mine; existence thus always already involves coexistence. Moreover, Nancy argues that these bodies discover that meaning does not *transcend* coexistence, but that coexistence *is* meaning (Nancy 2000, 1).

Sense *cannot* be detached from embodied sensory experience and expression itself: for Nancy, experience does not *have* meaning, it *is* meaning. Nancy here plays with all the different meanings of the word sense—'sense' means both meaning and experience, but also the five senses, feeling, intuition, and direction—stating that sense is what happens when 'we'—bodies—experience, feel, touch, see and address each other. Indeed, Nancy often suggests that sense could perhaps best be characterised as a sensual relation, a living voice, a sound, a tone, or a piece of music (Nancy in Lacoue-Labarthe (2006)). This illustrates why one cannot transform sense into a 'lesson' or 'purpose' that can be reported to and understood by others; trying to do so would do away with the very meaningfulness of the experience.

In 'Un commencement' (A Beginning), the afterword of *L'"Allégorie"*, Nancy states that this is exactly how we should read Lacoue-Labarthe's prose poetry on the chronic: as a sensory experience, a living voice calling us, addressing us and thus sharing (a world) with us (Nancy in Lacoue-Labarthe (2006)). Indeed, in many of Lacoue-Labarthe's poems, there is a voice that utters, murmurs, cries and sings. Nancy states that this voice allows the chronic to express itself in its directionless, non-progressive flatness. This means, he states, that it does not provide an allegory of what is happening. In Greek, the words *allo* and *agoreuin* mean to speak (*agoreuin*) by something other (*allos*), which means that an allegorical text provides a representation of the world in an indirect way, by means of another vocabulary, at another level. Rather, according to Nancy Lacoue-Labarthe offers us an 'allegory' between inverted commas, or rather a *tautogory*. This means that his poetry is not saying something other than it says, but exactly what it says: just like chronic pain, it just is what it is.

Following Nancy, we suggest that, in the telling of the chronicle, meaning, or 'sense', is not found in 'what is said', in what can be reported to and understood by others, but in the very process of witnessing—of saying and listening—itself. This meaning is not found *prior to* or *after* the utterance, but *in* the utterance itself, *in* the ways in which the witnessing voice plays with language, sounds, melody, clashing echoes, rhythm, tone, timbre and silence. This will allow for reading and listening practices which do not search for any overarching meaning but instead tune in to the meaning expressed *in* the chronicle, that is, *in* the text, *in* the utterance.

To take Daudet's *In the Land of Pain* as an example, when we consider it a chronicle, this collection of notes does not just amount to total chaos, a failure to tell a coherent narrative. Rather, it is an expression of the impossibility of speaking about chronic pain by means of an overarching level. What seems to be happening in this text is that the meaning of chronic pain expresses itself in its flatness, in the form of little notes or fragments that are written down day by day, week by week, continuously bearing witness to its non-progressive 'going on'. Daudet's notes also make tangible—sometimes by their silence, their absence over long periods of time—how the experience of chronic pain is never a 'stable' state of being-in-the-world, but something which evolves, changes, disrupts your life by

inhibiting your abilities to write or communicate. Pain thus expresses itself in language but also interrupts language.

Similarly, we argue that reading Fridman's essay as a chronicle can fundamentally change one's perception of this text: it is then no longer a failed story, but a text written by someone who expressed herself *through* her own pain. Sometimes, words fall short to do this. Fridman writes that what is left in those moments is

> continuing, flow—a sense of sound or words that are more indications of ongoing experience and aliveness than they are determined language. […]
> *Oh-woah-woah-woah*, I went, followed by the *hee* on the sharp intake of breath, the language that means nothing but is the only kind for that time (Fridman 2018, §6–7).

What we have in these texts is language that operates at the limits of meaning, at the limits of what can be said and determined (Nancy 2007, 7). As Felman points out in *Testimony*, in this way these texts put into question and unsettle the very limits of reality (Felman and Laub 1992, 205). They paradoxically articulate a loss of voice—addressing us by *saying* that there is *nothing to be said*, reported, or understood. As Fridman states at the very end of her essay

> The pain does not 'say' in language. But what we can expect of pain language is more about remaining, about indicating to another that we are still alive. It signals that we haven't yet gone under enough to stop *saying* for good (Fridman 2018, §9).

In the end, what remains in the absence of anything that can be 'said' is saying and sharing meaning with other human beings.

This has important implications for therapeutic practices: instead of looking for ways in which the patient's experiences can be turned into a meaningful narrative, or for more flexible or intermodal tools for doing so, therapists could offer a safe space where patients once again learn that they can *meaningfully express* their own continuation to another human being. Even if this expression cannot take the form of comprehensive language (in some cases it might be more helpful to look, as some body-oriented therapists do, for other forms of expression: sounds, sighs, body movements), it might help them to realise that, despite the fundamental meaningless of their pain, they can still share and experience meaning.

BODY: THE REPOSSESSION OF THE LIVING VOICE

As telling a chronicle allows the person to once again express themselves to someone else, this can be understood as the *body* freeing itself from its prison of muteness. As stated above, chronic pain is often said to shackle you to your own body, imprisoning you in it (Serrano de Haro 2012; Svenaeus 2015). But apart from leaving the body helplessly surrendered to its own suffering, chronic pain also 'robs' the body of all possibilities to meaningfully express what it is going through. Acute physical pain to an extent already has the capacity to do so. However, whereas acute pain is given to us as something which will, at some point, go away, chronic pain becomes fundamentally meaningless through its purposeless continuation over time, leaving the body entirely lost for words. As a result the person can feel reduced to nothing but their purposelessly hurting body, a body imprisoned by its own muteness.

There is a very understandable urge to turn away from, or to escape this meaninglessly aching body. This urge is, we think, not just present in the way in which individuals try to deny or turn away from their pain. It is also there in biomedical models of chronic pain, which often draw the paradoxical conclusion that chronic pain is not a physical, but a purely psychological phenomenon. It is also present in traditional narrative approaches which state that we can only bear witness to illness experiences when we tell a coherent story with an overarching purpose, as this does not leave space for the actual meaninglessness of the body's pain. Although these ways of thinking are very understandable and often sympathetic, they form an ontological denial of what the chronically suffering body is actually going through, silencing it even more.

Instead of giving in to this urge to turn away from the body, telling a chronicle could be a way of going *through* the living body, allowing it to express itself in its flat, meaningless suffering. Indeed, Felman and Laub state that witnessing can be understood as a 'repossession of the living voice' (Felman and Laub 1992, xix). Perhaps the term 'repossessing' seems odd here, as it seems to suggest that, by giving testimony, the witness is once again in full control of what they are saying. But rather than as a mastery or possession of the *experience*, the 'repossession of the living voice' could be understood as the body once again regaining the *possibility of speaking* by bearing witness to its own endless wandering. Even though the experience of chronic pain can never be fully *mine* in the sense that I can fully understand it, it is still *my voice* that can tell about this 'going on' of mine, *my hand* that can write about it, *my body* that can, again and again, day by day, moment by moment, bear witness to it.

This bearing witness always requires the presence of a listener. In this case, listening is not an act of grasping or recognising what is going on (as is the case with Franks' narrative types, resulting in the suggestion that what cannot be recognised as a narrative must amount to total chaos), but a tuning into something you cannot understand. It is a kind of listening which allows the experience to exist in all its alien ungraspability, like listening to a piece of music or a singing voice—a sensory experience. In that sense, the 'repossessing' or 'return' of the living voice always requires the presence of 'a living ear'; the presence of another body—be it a loved one or a therapist—who affirms the reality of the experience without trying to understand or grasp it, and who is, for the duration of this testimony, totally present with and for you.

According to Laub, when someone listens to you in this way, this allows for the 'return of the inner witness' (Felman and Laub 1992, 88). This means that, by being listened to, the teller can start *listening to themselves*. By chronicling—in a non-progessive way, without a goal or purpose—they discover that the world-destroying and language-destroying nature of their chronic pain can be affirmed *by* using language, *in* this shared world. The experience is thus, as Laub states, re-externalised: the teller learns that, even though this terrible, meaningless experience might stay with them forever, they can at least take this meaninglessness up in their life in such a way that they are no longer constantly overwhelmed by the horror of it (p. 68). They realise that, as a human being which is part of a shared world, they are more than just this pain. And even though the pain might stay with them forever, torment them forever, it is now accompanied by the realisation that they no longer have to bear it all by themselves.

CONCLUSION

By proposing an alternative to the coherent, plot-driven narrative, this article's aim was to offer a way of narrating the meaninglessness of chronic pain. As such, this paper ties in with the current discussion in medical humanities about how to do justice

to illness experiences that cannot be captured in a coherent story. Our conception of the chronicle specifically shares features with episodic reading or writing, an idea which was famously introduced by Galen Strawson in his paper 'Against Narrativity' (Strawson 2004). Both the chronicle and episodic reading/writing offer an alternative, non-narrative way of engaging with *time* when the interrelation between past, present and future as a coherent whole is ruptured. Indeed, as Wasson (2018) states, instead of reading for a certain direction or progression, episodic reading means "looking for a place to pause—to cease looking for the arc of the individual longitudinal journey and instead to consider how a particular scene constructs an emergent present" (p. 3). Thus, instead of just concluding that a particular narrative on chronic pain is incoherent and unhinged, episodic reading allows one to actively engage with *specific moments* of suffering within this narrative: it reads into the lived present, recognising its complexity, affective weight and meaning in its own right. As Wasson puts it: "to read episodically is to recognise that the meaning of a scene may not stem only from its sequel" (Wasson 2018, 6).

Both the chronicle and episodic reading thus turn away from a conception of meaning which purely stems from the coherence of the overarching plot. Instead, it finds meaning in the text itself, in textual fragments, details, episodes and moments outside the narrative framework. However, whereas episodic reading looks for a place to pause, centralising the *present moment*, the act of chronicling specifically offers a way of bearing witness to the pain's 'going on', its relentless *continuation over time*. Chronicling is an act of bearing witness to the paradoxical nature of chronic time: time which evolves but does not add up to any kind of progression, which changes but at the same time just is what it is. It does so, not by focusing on the present moment, but by bearing witness to one's 'going on'; recounting this continual suffering, this relentless wandering, step by step, time and time again. Thus, if chronic pain is a pain of time, the chronicle is a way of acknowledging that pain, of allowing it to exist and to express itself.

In this text, we have mostly analysed written autofictions. However, we want to emphasise that any medium that affords the presence of a reader or listener as well as ways to capture the 'ongoing' could be used to chronicle chronic pain. We specifically think that social media such as blogs, Instagram, Facebook and YouTube could be suitable for this. This is because by design, these media allow people to bear witness to their own continuation: to post something day by day, bit by bit, while not having to provide a coherent plot which leads to a definite endpoint or to share an overarching 'lesson' or 'meaning'. These media could thus enable people to keep a fragmented collection of notes about their day-to-day experiences of pain, just like Daudet did in his diary. But in contrast to a handwritten diary, these media are immediately 'social', that is, meant to be witnessed and responded to by others. In our future research, we aim to further investigate how offline and online chronicling can support people who suffer from chronic conditions.

Contributors This paper is the result of joint authorship. FvH was responsible for the development of the main argument in this paper. AvR and JS provided for the embedding of this position within contemporary discussions on illness narratives. FvH acts as the guarantor responsible for the overall content of this work.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study.

ORCID iDs
Aukje van Rooden http://orcid.org/0000-0001-6482-535X
Jenny Slatman http://orcid.org/0000-0002-1451-9378

BIBLIOGRAPHY

Ahmed, S. 2010. *The Promise of Happiness*. Durham: Duke University Press.
Aristotle. 1984. "Poetics." In *The Complete Works*. Vol. 2. Princeton: Princeton University Press.
Baldwin, C. 2016. "Ethics and the Tyranny of Narrative." In *The Routledge International Handbook on Narrative and Life History*, edited by Ivor Goodson, Ari Antikainen, Pat Sikes, and Molly Adrews, 536–49. London: Routledge.
Breivik, H., B. Collett, V. Ventafridda, R. Cohen, and D. Gallacher. 2006. "Survey of Chronic Pain in Europe: Prevalence, Impact on Daily Life, and Treatment." *European Journal of Pain (London, England)* 10 (4): 287–333.
Brooks, P. 1984. *Reading for the Plot*. Clarendon: Oxford.
Bullington, J. 2009. "Embodiment and Chronic Pain: Implications for Rehabilitation Practice." *Health Care Analysis* 17 (2): 100–109.
Bury, M. 1982. "Chronic Illness as Biographical Disruption." *Sociology of Health & Illness* 4 (2): 167–82.
Buytendijk, F. J. J. 1961. *Pain*. Translated by Eda O'Shiel. London: Hutchingson & Co.
Daudet, A. 2018. *In the Land of Pain*. Translated by Julian Barnes. London: Vintage.
David, M. 1991. *The Culture of Pain*. Berkeley: University of California Press.
De Ruddere, L., and K. D. Graig. 2016. "Understanding Stigma and Chronic Pain: A State-of-the-Art Review." *Pain* 157 (8): 1607–10.
De Ruddere, L., L. Goubert, T. Vervoort, K. M. Prkachin, and G. Crombez. 2012. "We Discount the Pain of Others When Pain Has No Medical Explanation." *The Journal of Pain* 13 (12): S1526-5900(12)00804-8: 1198–1205.
Dumit, J. 2006. "Illnesses You Have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses." *Social Science & Medicine* 62 (3): 577–90.
Fayaz, A., P. Croft, R. M. Langford, L. J. Donaldson, and G. T. Jones. 2016. "Prevalence of Chronic Pain in the UK: A Systematic Review and Meta-Analysis of Population Studies." *BMJ Open* 6 (6): e010364: 1–12.
Felman, S., and D. Laub. 1992. *Testimony: Crises of Witnessing in Literature, Psychoanalysis and History*. London: Routledge.
Frank, A. W. 1995. *The Wounded Storyteller: Body, Illness and Ethics*. 2nd ed. Chicago: The University of Chicago Press.
Fridman, L. 2018. "On Saying: Finding the Language to Describe Chronic Pain." *The Millions*. https://themillions.com/2018/08/on-saying-finding-the-language-to-describe-chronic-pain.html.
Goldberg, D. S., and S. J. McGee. 2011. "Pain as a Global Public Health Priority." *BMC Public Health* 11: 770.
Gonzalez-Polledo, E., and J. Tarr. 2016. "The Thing about Pain: The Remaking of Illness Narratives in Chronic Pain Expressions on Social Media." *New Media & Society* 18 (8): 1455–72.
Groenevelt, I. 2021. "It's Not All Nice and Fun": Narrating Contested Illness on YouTube and Instagram." *Health. An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*.
Grüni, C. 2004. *Zerstörte Erfahrung: Eine Phänomenologie Des Schmerzes*. Würzburg: Königshausen & Neumann.
Hawkins, A. H. 1999. *Reconstructing Illness*. 2nd ed. West Lafayette: Purdue University Press.
Hyvärinen, M., L.-C. Hydén, M. Saarenheimo, and M. Tamboukou. 2010. *Beyond Narrative Coherence*. Amsterdam: John Benjamins.
Jackson, J. E. 2005. "Stigma, Liminality, and Chronic Pain: Mind-Body Borderlands." *American Ethnologist* 32 (3): 332–53.
Kappesser, J., and A. C. de C Williams. 2013. "Clinical Judgement Heuristics: Methods and Models." *European Journal of Pain (London, England)* 17 (10): 1423–24.
Kermode, F. 1967. *The Sense of an Ending*. Oxford: Oxford University Press.
Kleinman, A. 1988. *The Illness Narratives*. Oxford: Oxford University Press.
Kreiswirth, M. 2000. "Merely Telling Stories? Narrative and Knowledge in the Human Sciences." *Poetics Today* 21 (2): 293–318.
Lacoue-Labarthe, P. 2006. *L'"Allégorie": Suivi d'un Commencement Par Jean-Luc Nancy*. Paris: Galilée.
Leder, D. 2016. "The Experiential Paradoxes of Pain." *The Journal of Medicine and Philosophy* 41 (5): 444–60.

Nancy, J.-L. 1997. "*The Sense of the World.*" Translated by Jeffrey S. Librett. Minneapolis: University of Minnesota Press.
Nancy, J.-L. 2000. *Being Singular Plural*. Translated by Robert D. Richardson and Anne E. O'Byrne. California: Stanford University Press.
Nancy, J.-L. 2007. *Listening*. Translated by Charlotte Mandel. New York: Fordham University Press.
Nancy, J.-L. 2008. *Corpus*. Translated by Richard A. Rand. New York: Fordham University Press.
Ressler, P. K., Y. S. Bradshaw, L. Gualtieri, and Kenneth Kwan Ho Chui. 2012. "Communicating the Experience of Chronic Pain and Illness through Blogging." *Journal of Medical Internet Research* 14 (5): e143.
Ricoeur, P. 1984. *Time and Narrative*. Translated by Kathleen McLaughlin and David Pellauer. Vol. 1. Chicago, IL and London, UK: The University of Chicago Press.
Ricoeur, P. 1994. *Oneself as Another*. Translated by Kathleen Blamey. Chicago, IL and London, UK: The University of Chicago Press.
Scarry, E. 1988. *The Body in Pain: The Making and Unmaking of the World*. Oxford: Oxford University Press.
Serrano de Haro, A., Agustín. 2012. "New and Old Approaches to the Phenomenology of Pain." *Studia Phaenomenologica* 12: 227–37.
Slatman, J., and van de Ven I. 2021. "Gut Feelings: Depression as an Embodied and Affective Phenomenon in Houellebecq's *Serotonin*." *Medical Humanities* 47 (3): 257–65.
Strawson, G. 2004. "Against Narrativity." *Ratio* 17 (4): 428–52.
Svenaeus, F. 2015. "The Phenomenology of Chronic Pain: Embodiment and Alienation." *Continental Philosophy Review* 48 (2): 107–22.
van Rooden, A. 2012. "The Grand Narrative Revisited: Contemporary Flemish Novelists Take Up The Challenge to Create Plots of the Flat World." *Arcadia* 47 (1): 134–52.
Wasson, S. 2018. "Before Narrative: Episodic Reading and Representations of Chronic Pain." *Medical Humanities* 44 (2): 106–12.
Werner, A., and K. Malterud. 2003. "It Is Hard Work Behaving as a Credible Patient: Encounters between Women with Chronic Pain and Their Doctors." *Social Science & Medicine (1982)* 57 (8): 1409–19.
Woods, A. 2011. "The Limits of Narrative: Provocations for the Medical Humanities." *Medical Humanities* 37 (2): 73–78.