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Illness, Injury, and the Phenomenology of Loss: A Dialogue

Jonathan Cole & Matthew Ratcliffe

Abstract. This paper explores similarities and differences between grief over the death of a person and other experiences of loss that are sometimes termed "grief", focusing on the impact of serious illness and bodily injury. It takes the form of a dialogue between a physician/neurophysiologist and a philosopher. Adopting a broad conception of grief, we suggest that experiences of lost or unrealised possibilities are central to all forms of grief. However, these unfold in different ways over prolonged periods. Experiences of grief are complex, diverse, difficult to articulate, and frequently under-acknowledged. This diversity, we note, complicates discussions of how to distinguish typical from pathological forms of grief. We raise the concern that thinking of grief through the lens of bereavement eclipses other circumstances in which people are required to comprehend and adapt to loss. With this lack of acknowledgement, the phenomenology of grief is characterized in ways that are overly tidy and people are deprived of important interpretive resources.

Introduction

The term "grief" is used in two principal ways. Sometimes, it refers specifically to an emotional response to bereavement. However, in everyday language, "grief" can also refer to how we experience and respond to losses of other kinds, such as the breakup of a relationship, loss of a career, loss of one's home, and the various effects of serious illness or injury.[1] It is not wholly clear what, if anything, all of these experiences consist of or share in common. In what follows, we address some of the relevant issues through a dialogue between a medical doctor and neurophysiologist (JC) and a philosopher (MR), focusing specifically on experiences of grief stemming from life-changing illness and injury.[2] For many years, JC has sought to understand—in depth— the ongoing experiences of those with life-changing conditions. This has involved working closely with people over long periods of time and exploring various different aspects of their lives. MR is a phenomenologist, whose work addresses the nature of interpersonal and emotional experience, especially in the contexts of psychiatric and somatic illness. By bringing together these areas of expertise, we seek to make explicit and illuminate several interconnected issues concerning what it is to experience

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[1] See also Richardson et al. (2020) and Varga and Gallagher (2020) for this broader conception of grief.

[2] For accounts of other forms of non-death loss, see the essays collected in Harris, ed. (2020). See also Harvey and Miller (1998), who propose a new field of interdisciplinary research concerned with experiences of loss in all their diversity.

grief (where "grief" is construed permissively, to include certain experiences of loss that are not attributable to bereavement). The themes of our discussion include which features—if any—are common to *all* experiences of grief, how we experience and adapt to loss in different situations, the interpersonal and social dimensions of grief, and how various factors disrupt the ability to comprehend and adjust to loss.[3]

Together, we arrive at the view that a tendency to think of grief in terms of bereavement (or, more specifically, a certain type of bereavement) may eclipse a variety of other experiences that are structurally similar and also described by people in terms of "grief" or "loss". The point also applies more specifically to recent efforts to distinguish pathological from typical forms of grief, which are often preoccupied exclusively with the effects of bereavement. Yet, as our discussion reveals, illness and injury, both acute and chronic, can equally be associated with forms of grief that require acknowledgement and—perhaps in some cases—treatment.

One might object that experiences of bereavement are qualitatively different from other forms of loss and that unqualified talk of "grief" therefore conflates two different subject matters. However, we identify a common theme. In all cases of grief, one experiences certain *possibilities* that were integral to one's *life structure* as extinguished or unrealized. Although the events that elicit an experience of loss may be short-lived and located in one's past, the sense of lost possibilities is temporally extended and also envelops one's present and future. Engagement with lost possibilities can unfold in very different ways over time and is sometimes inextricable from how one's bodily condition is experienced. The process further depends on how one experiences and relates to other people. Given this, the extent to which the nature, scope, and diversity of grief is understood and explicitly acknowledged by others will have important implications for how grief is experienced.

MR: In several books, including *Pride and a Daily Marathon*, *Still Lives*, and *About Face*, you address—in remarkable detail—the experiences of people with neurological conditions and how their lives change over time (Cole, 1991; 1999; 2004). As you know, I am currently involved in a project on the phenomenology of grief.[4] So, in light of your book projects, as

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[3] Our dialogue arose from conversations that followed a talk by JC on grief and life-changing conditions, at the University of York in February 2020. The dialogue was conducted in writing, via email. Footnotes and references were added later. Parts of the dialogue were elaborated and reorganized after the initial written exchange.

[4] The project, funded by the UK Arts and Humanities Research Council, is entitled "Grief: A Study of Human Emotional Experience". See: https://www.griefyork.com

well as your experiences as a clinician, I am curious hear your views concerning the sense of loss and how it unfolds over time. Do people in these situations experience what we might call “grief” and, if so, to what extent does this resemble the kinds of experiences associated with bereavement?

JC: Looking back over thirty years or so of working with people with neurological impairments of various sorts, I am now struck by how little “grieving” was raised by participants, or— to be honest—by me.

In my first book, *Pride*, Ian Waterman revealed how *depressed* he had been initially when incapacitated by his severe loss of touch and proprioception, and that he remembered his past experiences of climbing over rocks and running to school, but this was couched in terms of regret rather than grief. In *About Face*, I discussed with John Hull his experience of blindness in his forties. He mentioned grieving over the loss of the female face as an erotic object and told me of his profound depression on losing the remembered visual images of his loved ones with time.[5] Although he was clearly grieving in some way, this was not really mentioned and possibly not recognised as such. Again, in *About Face*, a man who had lost vision in his twenties told me that the fortunate ones had been blind from birth; they did not know what they had lost, whereas he was deeply affected by his sudden loss. Again, grieving seems to be implicit here, but not really explored. In listening to those who become tetraplegic, some found it difficult to move beyond their frustration, whereas others managed to explore their new possibilities of living from a wheelchair with openness. True, some regret actions that led to their injury—the wrong dive into a pool, or a careless gymnastics leap. But again, neither they nor I sought to understand this in terms of grief.

With hindsight, this lack of the articulation of loss in terms of grief may not reflect an absence of grief so much as a difficulty in being in the right space to talk about it. As a medical doctor, my focus may have been on the exploration and experience of neurological loss, and on subsequent external events and achievements. Asking what it is like to live without proprioception, or movement, or sight, or with a facial disfigurement preoccupied me and participants. I may have presumed a sense of loss at the start, and sometimes depression, but not couched this in terms of grief or the possibility of that grief continuing.

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[5] See also Hull (1990) for a detailed autobiographical account of the experience of blindness. See Sacks (2005) for further discussion of the different ways in which people experience and adapt to blindness.

Then again, it seems too blunt to ask whether a person might be grieving over the loss of their mobility or ability to pass without others commenting on their face, and the answer might be too painful. Perhaps in our culture, grief after bereavement is expected and can have a voice and a public space, but grieving over other losses, associated with illness, injury, and other circumstances, is neither expected nor recognised as much as it should be.

Grief may also have a depth and continuing rawness that makes it difficult to approach and articulate. In an account of his own profound grief following the death of how wife, the author Julian Barnes recalls how, in an earlier novel, he had sought to imagine the grief of a man widowed in his sixties:

> [People say] you'll come out if it… and you do come out of it, that's true. But you don't come out of it like a train coming out of a tunnel, bursting through the Downs into sunshine and that swift, rattling descent to the Channel; you come out of it as a gull comes out of an oil slick; you are tarred and feathered for life. (Barnes, 2013, pp. 114-115)

Earlier in his memoir, he writes that "only the old words would do: death, grief, sorrow, sadness, heartbreak. Nothing modern, evasive or medicalising. Grief is a human, not a medical, condition" (Barnes, 2014, p.71). One of the consequences of our own discussions is that I have begun to ask for the words, and recognise the human condition associated with the medical ones more. But I am also wary of generalising from a few narrative studies, however detailed they might be. *Still Lives* featured around a dozen people who had become tetraplegic as young men. Most were devastated by their losses of mobility, sensation, continence and sexual function, and by the profound alterations in employment, and life opportunities which resulted. However, there were some who almost immediately moved on after their spinal cord injury to explore their new way of living with an extraordinary openness.

> I never burst into tears because, from the early stages of living with the injury, I have seen the whole thing as a challenge. How do I overcome so and so? How do I deal with this? How do I come to terms with that? I never thought, "I can't do that".

How people experience loss differs hugely, and so one presumes the triggers for grief are idiosyncratic too.

MR: So, one of the problems we face in seeking to understand the nature of grief in response to illness and injury is that these experiences are often difficult to articulate or even to acknowledge. Although grief can become apparent upon reflection, it is often not made explicit as such. And what we fail to recognize in much of our everyday talk is not captured by current medical terminology either. As suggested by your quotations from Julian Barnes, grief is a "human condition" that somehow resists medicalization. The lack of shared understanding that you describe seems to approximate what Kenneth Doka (1999; 2022) has called "disenfranchised grief", a grief that is not acknowledged by a society or culture, not discussed or integrated into shared practice. This, Doka argues, can render one's loss harder to bear. If that is right, then wider acknowledgement that people often grieve in circumstances of illness and chronic injury may well have important implications for their ability to cope with loss.

One could adopt the alternative view that failure to recognize grief in certain circumstances is not really a problem. After all, the term "grief" is not univocal. For example, it would be unreasonable to request a unitary analysis of grief that accommodated experiences of bereavement, along with whatever is conveyed by the utterance "good grief!" or by talk of being "given grief" over something one did. However, when we talk of grief in contexts such as bereavement, illness, injury, relationship breakups, unemployment, and so forth, I do think that the relevant experiences have something important in common. (I should stress that this remains compatible with the acknowledgement that bereavement is distinctive in certain important ways, thus warranting an additional, narrower use of the term "grief". Although our responses to deaths and other losses may share certain features, it seems plausible that others are more typical of or even unique to the former.[6]) Furthermore, I agree with you that some of these experiences are under-acknowledged and poorly understood.

JC: If we think of "grief" in these broad terms, rather than as a more specific reaction to bereavement, what do all these experiences share? In your terms, is there a "phenomenological structure" common to experiences of bereavement and other forms of loss?

MR: Let me offer a brief sketch of what I take the relevant phenomenology to consist of. Perhaps this will help us to understand why some of these experiences are difficult to pin

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[6] As Throop (this issue) writes, a "defining aspect" of bereavement grief is that "another's embodied absence is experienced as a painful nullifying finality".

down and why medical approaches inevitably leave something out. With colleagues at the University of York, I recently conducted a qualitative survey of bereavement experiences (Ratcliffe, 2022). To our surprise, several respondents described grief over involuntary childlessness, rather than the death of a person. All were women, who had been directed to our study by the support group Gateway Women.[7] Some mentioned more specific circumstances, such as miscarriages, failed IVF, and harrowing relationship breakups. However, for the most of them, the principal source of grief was being unable to have children. We might wonder how someone could grieve over the loss of something they never had in the first place. It seems that the *object* of grief, what is experienced as lost, is not—first and foremost—something concrete, but, rather, certain valued *possibilities* that may once have been taken for granted. Consider the following testimonies:

> Because I haven't actually lost a person but lost the life I thought I would have, which was children, it feels all-consuming.
>
> It is the loss of a dreamed-of future, a life you have imagined since you were a child.
>
> I had to say goodbye to the child I desperately wanted but was never able to have, they died in my heart and will never leave.
>
> I am experiencing grief and loss around being unable to have children. I am grieving the future children I imagined and believed I would have but am unable to.

Now, we could be said to "lose possibilities" all the time. But what renders this kind of loss distinctive is that the possibilities in question were utterly central to *who* these people were (which also included a sense of who or what they might become). The structures of their lives were oriented around the prospect of becoming a parent and thus became unsustainable: "I live with the grief for the children I never had and the identity I lost as a result"; "I am a completely different person". Granted, grief over childlessness may well be unrepresentative of grief in general, at least in some respects. Nevertheless, this example makes salient something that is common to experiences of bereavement grief and wider experiences of loss. In showing how one can grieve over something without the actual, historical subtraction of anything concrete, it makes explicit how experiences of grief are preoccupied with *lost*

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[7] See: https://gateway-women.com (last accessed 27th May 2022)

possibilities, involving projects, pastimes, abilities, commitments, and relationships that were central to who one was and who one might have become. The sense of loss need not be restricted to one's *own* possibilities, to what "I" have lost. It can also include the loss of someone else's possibilities, as well as the loss of possibilities that were once ours. For instance, some of those who described their grief over childlessness also referred to the lost possibilities of a child who never came into being.

I've offered this example for two main reasons. First of all, I want to suggest that much the same approach may be applicable to experiences of life-changing conditions. Second, I think this takes us some way to understanding why grief is a "human condition" that cannot be captured fully in medical terms. Appreciating a person's sense of loss involves recognising how a concrete change in circumstances relates to possibilities that were integral to their unique life structure: a biography, a network of relationships, and a sense of what the future holds or once held. So, understanding the impact of events upon that person involves a degree of particularity. For example, Paul Kalanithi, a brain surgeon who wrote an autobiographical account of his own terminal illness, reflects on how medical decisions involving a particular patient could not be made by appealing in general terms to conditions and prognoses. What one also needs to do is situate the impact of events in the context of that patient's distinctive life structure: "Before operating on a patient's brain, I realized, I must first understand his mind: his identity, his values, what makes it reasonable to let that life end" (2017, p.98).

Perhaps some of the differences that you have observed in people's responses to spinal injuries, such as the extent to which they are able to embrace and explore new ways of living, can be understood at least partly in this way. That would also help us to see why grief over certain forms of loss can be difficult to articulate and acknowledge. Grief is not just about the historical subtraction of something, which can be recognized easily and referred to by all. It also concerns how historical changes amount to losses of possibilities, which are not always so visible and sometimes evade description in more concrete terms. To be more specific, grief involves the loss of possibilities that were integral to a person's *life structure*, to a sense of who they are and what they might become (Ratcliffe, 2022). It can thus extend to everything of value in a person's life, much of which lies outside of specifically medical concerns.

Would it be fair to say that, in certain clinical situations, there is a tendency to think of symptoms in abstraction from the overall shape of a person's life? I would also like to hear your thoughts regarding how grief over illness and injury *is* addressed in clinical contexts, along with how it *ought to be* addressed. We seem to agree that the clinician cannot accommodate everything. Nevertheless, these experiences do need to be acknowledged, reliably identified, and investigated by clinicians. There is ongoing debate concerning how typical forms of grief ought to be distinguished from pathological grief, as exemplified by the recent inclusion of "prolonged grief disorder" in the 2022 text revision of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5).[8] However, this debate has been consistently bereavement-centric. Perhaps there is a wider-ranging distinction to be drawn between typical and pathological ways of experiencing loss?[9]

JC: Firstly, we might consider clinical medicine and its relation to grief. Take grief after bereavement. Initially, this could be regarded as a *normal* response and so non-medical. Later, as you suggest, prolonged grief (however defined) becomes of concern—potentially pathological, differentiated from depression, and in need of treatment. The specialties involved might be psychiatry and possibly primary care. Clinical medicine and surgery contain many widely differing specialties (from paediatrics to orthopaedics, for instance) and it may be impractical to expect them all to have the necessary skills and aptitude for this, laudable though that might be.

If we also allow scrutiny under the cold light of health economics, one needs to demonstrate than grief differs from—say—depression, in terms of its phenomenology and treatment outcomes, and that any proposed changes to current medical practice are likely to be effective. Whilst many within medicine, and arguably more within the paramedical professions, are sensitive to the experiences of patients with various conditions, it must be admitted that there are others who see the profession as providing treatments in a more reductive way. Many very good doctors might agree with Julian Barnes that grief is a human and not a medical condition, though I would say it can be both.

Something I would like to discuss further is *how* chronic medical conditions might lead to grief. I mentioned the example of spinal cord injury. This can involve an abrupt, massive change in one's embodiment, with huge consequences for independence and the possibilities available. Though it may have additional effects later in life (for instance, arthritis affecting shoulders used to transfer and mobilise over the years), it is usually a

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[8] See Prigerson et al. (2021) for a helpful survey of historical and current developments concerning conceptions of pathological grief and, more specifically, the category "prolonged grief disorder".

[9] For example, Shear et al. (2011) and Papa et al. (2014) report that symptoms that meet diagnostic criteria proposed for "complicated grief" and "prolonged grief disorder" can also be associated with non-death losses.

singular event—people never forget the day of their injury. This event affects everything they do from then on in a continuing and intrusive way. Consider, more specifically, the experience of pain. The nineteenth century writer, Alphonse Daudet, developed severe syphilitic pain and wrote an extraordinary memoir capturing his experience of it:

> “What are you doing at the moment?”
> “I am in pain.”
> Pain is always new to the sufferer, but loses its originality for those around him. Everyone will get used to it except me. (Daudet, 2002, p.3, p.19)

Admittedly, pain presents itself with an intensity greater than many other conditions, but one can imagine someone with lung disease answering the questions of what they are doing as “being short of breath”, just as a person with tetraplegia might answer, “balancing in a wheelchair precariously, with background pain”, or someone with Parkinson’s replying “shaking uncontrollably”, or “being rigid”. The ways in which chronic illness presents itself to a person’s consciousness may make it even more *intrusive*, at least in certain ways and at certain times, than the effects of bereavement. This is not to imply that it should therefore be thought of in terms of grief, rather than frustration or resignation combined with more immediately *bodily* experiences. Even so, with persistent experiences of difficulty, effort, discomfort, and pain, there is potential for feelings of *loss* concerning one’s habitually behaving body.

In the phenomenological literature, there is an oft made distinction between the body as a subject and object of experience. Ordinarily, it has been suggested, the body disappears into the background and operates as an organ or subject of perception, shaping how we experience our surroundings. However, under certain conditions, the body or parts of it become unpleasantly conspicuous, obstructing one’s experience of and engagement with the surrounding environment (e.g., Leder, 1990; Fuchs, 2005). I have never been quite convinced by this distinction. When I walk, sit, and climb stairs, let alone run or cycle for pleasure, I have a bodily awareness of doing so, something that also applies when I feel how comfortable (as opposed to conspicuously uncomfortable) my shoes are. Bodily awareness, then, is complex; we also have relations with our bodies and their actions that are pleasurable and sometimes aesthetic in nature. Over the last decade or so, while this has been increasingly recognised in relation to practices such as dance and yoga, what has not been considered is that, for those who live with chronic impairment of the body, the aesthetic dimension may be reduced or abolished. This, in itself, is a possible cause of grief. In *Still Lives*, I quoted a man twenty years after spinal cord injury:

> Two years ago I bought a tracker, (a tricycle moved with arm cranks), and I must admit that I have had more pleasure out of it than from anything else since I have ever been disabled. I am cycling, going from one place to another under my own control. I am amazed at how much pleasure it is giving me. I did it simply to get a bit of exercise. I disappear off on my own and because I am working and exercising it almost feels as though I am not disabled. (Cole, 2004, p. 32).

In a complementary way, John Hockenberry, who lived with paraplegia, describes his progress down a Chicago Street one day:

> It had been a long day. I was tired and I stopped worrying about speed and pedestrians: a dreamy dissolve… the walking people became moving posts in a slalom course… the territory between the bodies became an ether, a river of space into which I could glide… Gravity pushed the chair ahead, and with the smoothness of curves on a lathe, I carved a trajectory around the pedestrians. The space between pedestrians became my space, and the whole scene unfolded as a postulate: Can this be done? Wheel jazz.
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> When the fear of collision vanished, I ceased to look like a piano rolling down a hill. The chair and legs joined for all to see in an unsolicited statement of grace. (Hockenberry, 1995, p. 213).

In contrast to this, an experience of loss can involve being unable to experience and relate to our bodies in such ways. Without a sufficiently nuanced grasp of the relevant bodily phenomenology, there is the worry that such experiences will pass unacknowledged. It is also important to distinguish aspects of grief that are principally concerned with the body from others that involve loss of access to *something else* due to bodily changes. Hence, also implicit in these accounts is the realisation that losses change not only how we experience our bodies, but also how we experience and relate to our surroundings.

If an *awareness* of lost functioning can be integral to the immediate experience of one's bodily condition, and if we are right that grief reflects a sense of loss, then grief may be a far more pervasive experience in those who are ill than is generally recognised. One might even argue that we need a new expression for the combination of presently or continuously experienced symptoms of disease or illness or disability, and its corollary, inverse or negative—a continuous awareness of what has been lost. Then, perhaps, we can better understand the young man who had gone blind in his twenties saying that the fortunate ones were blind from birth, for they did not know what they had lost.

Another important consideration is that few medical conditions remain static. One of the triumphs of modern medicine, which Jonathan Miller dated to the development of modern drugs after World War II, has been to improve and cure a host of previously untreatable conditions; asthma, pneumonia and other infections, heart disease, and many cancers are now curable, or at least liveable with (Miller, 2000). We sometimes forget how yesterday's medical miracle becomes tomorrow's routine treatment. What remain, though, are the chronic conditions, many of which are degenerative and neurological, and either untreatable, like motor neurone disease, or able to be delayed rather than reversed, like Parkinson's and some dementias. Then, the person experiencing the disease has to come to terms not only with the diagnosis and what it imposes, but with new and progressive symptoms of decline, together with a realisation that progression will occur. Not only do they have to contend with increasing disability, but also with the anticipation of further decline and loss.

MR: I see your point about medical specialities – those who treat bone fractures, for instance, may not be those best trained to recognize and respond to grief. But perhaps there are indeed some important issues here for current clinical practice. In the case of bereavement grief and depression, there seems to be a consensus that the difference in presentation and treatment *is* clinically significant. That said, it is debatable how the assessment ought to proceed. It could be taken to involve determining whether some experience is proportionate or appropriate to its cause or object—while typical grief is understandable in that way, depression is not. However, others maintain that depression is *phenomenologically* distinct from typical grief; what is needed is greater sensitivity to such differences (e.g., Pies, 2008; Zisook and Shear, 2009).[10] Elsewhere, I have argued that this is right, and that grief tends to involve a dynamism, openness to possibilities, and capacity for interpersonal connection that are lacking in clinically significant forms of depression (Ratcliffe, 2019; 2022). If we accept that depression is similarly distinct from various other experiences of loss, this needs to be kept in

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[10] There remains disagreement over whether, when, and how bereavement grief is to be distinguished from depression. See Zachar, First, and Kendler (2017) for an informative retrospective discussion with key participants in the debate that preceded publication of DSM-5 (American Psychiatric Association, 2013)

mind when diagnosing and treating the depression associated with life-changing conditions.[11] Similar points apply to distinctions between typical grief and prolonged grief disorder, which—one might worry—are currently too bereavement-centric. We not only need to know whether someone with a life-changing condition is grieving, rather than suffering from depression, but also whether and how their grief has become problematic.

Even if that is correct, what you have said raises some additional and important phenomenological challenges. We could think of an experience of grief that is directed at one's changed bodily experience as *distinct from* the bodily experience in question—one's bodily experience is the object of one's grief. But you suggest that the bodily experience can *itself* incorporate a sense of loss: the sense of having lost certain aesthetic or pleasurable ways of experiencing one's body is inseparable from the immediate bodily experience. So, where the object of a grief experience itself incorporates an experience of loss, the boundary between the two becomes unclear.[12] I wonder whether something like this might also apply to certain experiences of pain: is the first-person experience of the "pain" of loss always clearly distinguishable from the pain of one's bodily condition? Consider the case of bereavement grief. Several accounts that I obtained (via the qualitative survey mentioned earlier) emphasize that grief is associated with pains that are unambiguously bodily in nature: "Sometimes the physical pain becomes unbearable"; "I've had tension in my neck and feel like a lead weight is sitting in my chest". Participants distinguished these from the pain *of* grief, the way in which the loss is itself painful: "There will never be anything else in my life that is as painful as losing my son". Even so, the pain of loss remains very much a bodily experience: "The pain of grief chokes my throat, and my heart does hurt with the pain of loss"; "Even the mental pain was somehow located—in the head and chest".

Hence, it may be difficult to distinguish pains that are somehow attributable to grief, along with the pain *of* grief, from more immediate experiences of one's bodily condition. Suppose someone does not conceptualise their pain as the *pain of loss* and that it is not recognized as such by others either, due to a lack of shared interpretive resources. I am not sure whether the relevant experience would then be distinguishable from other types and sources of pain, at least to naïve reflection. One might therefore misattribute it to something else, such as a current bodily experience.

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[11] Consistent with this, Periyakoil et al. (2012, p.1350) suggest that distinguishing between grief and depression in seriously ill patients is vitally important, as the treatments differ". See also Jacobsen at al. (2010) for a discussion of the differences between depression and grief in advanced cancer patients.

[12] See also Periyakoil et al. (2012) for the observation that experience of a bodily condition can be difficult to tease apart from bodily experiences that are attributable to either depression or grief.

JC: Grief "hurts" and could also be said to "ache" and "gnaw". The loss of mobility in spinal cord injury, or in Parkinson's, not only reveals the intellectual frustration of reduced function and lost independence. It also reflects the affective relationship we have with our bodies and their role in social functioning. Within the grief associated with impairment may lie a reflection of our affective embodied presence, just as socially induced disability reveals the importance of intersubjectivity. Grief across its various manifestations, causes and experiences shares a sense of loss, and reveals how important, precious, or loved the lost or grieved-over person, faculty, or function was. As Barnes writes (2013, p.113) writes, "if the pain is not exactly relished, it no longer seems futile. Pain shows you have not forgotten; pain is proof of love".

However, this is not to suggest that we cannot usually distinguish the pain of grief from pain stemming from other causes. Admittedly, it can be really difficult to capture the experience of the varieties of what it called "pain" in words. Even within medically accepted painful conditions, an experienced clinician listens to how those words are spoken, as well as the postures and gestures of the patient; words alone are insufficient. This has led to the use of visual analogue scales and emojis, although both have their limitations. There are also models of both acute and chronic pain, which are recognised as being associated with certain medical conditions. These are often, though not always, effective diagnostic "tells" (at least in our culture; the ways in which pains present can be very different in other cultures). Of course, there are some presentations where this is not the case, but a clinician learns to home in on the more medically salient aspects of a case (sometimes aided by additional information such as test results). That is not to say that grief does not become embodied as pain, but this presentation can reveal some clues about itself as well. I do not claim medicine is perfect in this regard, but I would have been rightly castigated as an intern (or house officer) if I had mistaken appendicitis or a myocardial infarction for grief.

MR: Agreed, but does there not remain a problem in the case of grief *over* one's bodily condition? If clinicians are not trained to look for grief in certain contexts, they—and their patients as well—may be prone to misinterpret or misattribute aspects of that experience.[13] Perhaps this will turn out to be an epistemic challenge—that of teasing apart aspects of experience that are in fact distinct but sometimes difficult to tell apart. But, even if that is so

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[13] See Radden (this special issue) for a more detailed discussion of pain and grief.

for pain, I am not sure that it applies to your reflections on the aesthetic and pleasurable dimensions of bodily experience, where the sense of lacking something important seems inseparable from one's immediate experience of bodily states and capabilities.

Another phenomenological problem that your observations point to concerns the distinction between the body as subject and object. A pervasive theme in first-person accounts of grief is that of feeling cut off from the rest of the social world for a period of time. Here are two representative survey responses: "The world carried on turning, I was a mere part of the audience not a participant, I felt"; "It feels as if you are in a glass bowl, with everything going on normally around you, but you're not participating". But an incapacitated, conspicuous, uncomfortable, or painful body might equally leave one feeling detached from a shared social world in which one was once immersed. Again, it is difficult to tease apart the bodily phenomenology from that of grief or loss.

There is also the question of where and how we draw the line here. Until our dialogue, I had thought of grief and loss in the following terms: there is a fact of the matter over whether we have or have not suffered a loss, depending on the impact something has upon the structure of our life. There is also our experience of loss, which we may or may not decide to call "grief" (depending on whether or not we restrict the scope of grief to bereavement losses). However, where loss is concerned, it now seems clear that we need to further distinguish the fact of loss from the bodily experience of loss, where some bodily experiences of loss are inextricable from grief, some are objects of grief, and others do not relate to grief at all. Furthermore, illness and injury could, in principle, involve an experience of grief without an intermediary *bodily experience* of loss. So you have made me think that we need to be more careful when referring to "experiences of loss". In the context of illness and injury, as well as elsewhere, there are clearly many experiences of absence, loss, negation, and the like that we would not want to term "grief", some of which are plausible ingredients of or precursors to grief and others not. So, there can be several different relationships between a sense that certain life possibilities are irrevocably gone and bodily experiences that are described more loosely in terms of "loss".

JC: I wonder whether some of this reflects our different disciplines and fields of study. I focus on altered bodily states and how these are experienced and assimilated by the person, with subsequent attention to how that affects their interactions with others and hence perceptions of their own selves. My primary focus is bottom up, "How does a bodily impairment affect a person?" Your concern might be said to start higher up, "What commonalities are there with bereavement grief?” These can, in my view, be complementary approaches. It could be that, precisely because my concern is with bodily impairment, I have not focussed so much on grief, which sat beyond my medical horizon. In contrast, you have begun there and worked backwards. I have often teased phenomenologists that they ought to “get their hands dirty”, by which I mean become engaged with people’s experience more.

MR: That might well be right, and I agree that the two perspectives can be complementary. For one thing, the combination of phenomenological reflection and “hands on” insights serves to emphasize the complexity and diversity of loss experiences. To this, I would like to add that our reflections also raise issues about grief’s temporal trajectory. Taking an unexpected and sudden bereavement as our exemplar, we might think of grief as a temporally extended engagement with the implications of something that has *already happened*. However, pain and discomfort are often experienced over a lengthy period. Furthermore, those with chronic progressive conditions do not merely comprehend and adapt to something that has already happened—there is continuing change in one’s condition, often involving considerable uncertainty and the anticipation of further losses. Thus, it is unclear how a distinction between typical and pathologically prolonged grief might be applied here.

JC: Yes, one’s grief may well be prolonged when its cause is a temporally extended process, as with the experience of Parkinson’s, where there is often continuing uncertainty over what kind of future one faces. This would surely interfere with attempts to integrate or adjust to loss over time. A prolonged grief of this nature differs both phenomenologically and aetiologically from a prolonged grief that is traceable to a single historical cause, though how these two differ remains to be explored. In fact, I wonder whether it is possible to make any confident normative judgments about the appropriateness of one or another form of grief, once we consider the full diversity of human lives and the different kinds of losses that we face. One also needs to keep in mind how a human life unfolds over years and decades, which can change the significance of a bodily condition, such that it is associated with the loss or privation of possibilities at certain life-stages, sometimes eliciting grief only at a later time. Without wishing to overgeneralise, young children tend to accept things as they are, having neither experienced nor been aware of other possibilities. Sadness, even grief, may depend upon a growing awareness of other ways of living. Christy Brown, who lived with severe cerebral palsy, wrote of his awakening to difference when he was around ten years old:

> Then one day my go-car broke. I was lost. Everything changed. I could no longer go out with my brothers. The bottom fell out of my world… I was 10, a boy who couldn't walk, speak, feed or dress himself. Only now did I realise how helpless I was. I could not reason out why I was different, I could only feel it… Up till then I had never thought about myself. There was occasionally a vague feeling, but I soon forget it and had gone on playing with my brothers, unconscious of myself. Now it was different. I saw everything, not through the eyes of a little boy eager for fun, but through those of a cripple who has just discovered his affliction. (Brown, 1990, p36-48).

There is the impression that Brown grieved over his lost innocence—that it was better not to know, a very Chekhovian concept. We might also consider the experience of facial disfigurement. For a blessedly short period, children are unaware and accepting, but then by age eight or so difference becomes perceived, both by the person with the difference and his/her peers. We sometimes presume adults are more resilient, but vulnerability may endure or re-surface, renewing itself by changing with the years. In young adulthood, someone with a disfigurement may find themselves marooned as friends become independent, marry, and become parents. Later, the prospect of old age and decline, alone, can lead not only to depression but to renewed awareness of loss and so the potential for grief.

Sometimes one does not experience one's own loss, or visible difference, *per se*. Rather, one becomes aware of it in a certain way through the behaviour of individuals and also wider-ranging aspects of one's social and cultural environment. Some facial disfigurements affect facial functioning (e.g., a cleft lip and palate), but others do not (e.g., a facial scar or blemish). Nevertheless, those with differences of the latter kind may have blighted lives because of others' reactions. Sometimes the personal is less relevant than the interpersonal, social, or cultural. James Partridge, who lived with the consequences of facial burns, once remarked to me how refreshing it was to walk down a street in India because people did not look twice at him.

Here is another issue to think about when reflecting on lost possibilities: we also need to take into account the perspectives of family members, including carers. For instance, there have been studies involving the partners of those with motor neurone disease, (Aoun et al., 2020). In addition, one may experience one's own losses as *losses for others*. For someone with Parkinson's, there may be a slow reduction in the ease of movement and its initiation, but then this becomes centre stage when a grandchild asks why you cannot help them play. A further complication is the "anticipatory grief" that may arise, for oneself and for others, as one experiences a succession of losses and also looks ahead, e.g. when living with dementia, (Holley and Mast, 2009).[14] Hence, it can be unclear when grief starts but also when and how and in whom, and then whether and how it fades or becomes something less pervasive and more tolerable.

MR: I agree that it is important to consider the interpersonal, social, and cultural dimensions of grief over illness and injury. Someone who is ill may grieve for others, such as family members who will also be deprived of life possibilities. Similarly, others grieve over the losses that one suffers and will suffer due to progressive illness. There are also shared losses: *we* will never do this again and never achieve that. In addition, it is important to emphasize wider social norms and attitudes, which may serve to exacerbate or even generate a sense of loss, sometimes due to prejudicial discrimination. Another point to keep in mind is that—in the case of bereavement at least—established practices, rituals, norms, and narratives play roles in shaping and regulating the course of grief over time (Ratcliffe, 2022). In the absence of a shared interpretive context, grief and its trajectory may well be experienced very differently. For instance, in a book that documented changing attitudes to bereavement at the time of writing, Geoffrey Gorer (1965) suggested that grief in Britain was becoming "unpatterned" due to the diversification and loss of shared practices. If something like this is right, then we might expect other experiences of grief, which are not so widely acknowledged or embedded in culture, to involve a comparable lack of structure and direction.

Stepping back for a moment, it seems we at least remain confident that life-changing conditions can be associated with forms of experience that resemble bereavement grief, at least in certain important respects. In the contexts of illness and injury, the experience and comprehension of what you referred to as a *loss of function* can manifest itself as what I have called an experience of *lost possibilities*. Sometimes, but not always, this sense of loss takes the more specific form that we are calling "grief". But experiences of lost possibilities can have various different causes, many of which change over time and thus present one with a moving target. And the process whereby one experiences, comprehends, and engages with them over time varies considerably too. Even so, loss of possibilities that were integral to,

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[14] See, for example, Sweeting and Gilhooly (1990) for a historical and critical review of changing conceptions of anticipatory grief. More recently, Varga and Gallagher (2020) have offered an interesting account of what they call "anticipatory vicarious grief": anticipatory grief concerning what others will lose with one's own death.

and sometimes central to, the structure of one's life remains a consistent theme. Sometimes, this sense of loss is especially pronounced—there are moments when one is *struck by* it. I mentioned Paul Kalanithi earlier, himself a medical doctor. Here is how he describes his own experience of being diagnosed with terminal cancer:

> A young nurse, one I hadn't met, poked her head in.
> "The doctor will be in soon."
> And with that, the future I had imagined, the one just about to be realized, the culmination of decades of striving, evaporated. (2017, p.16)

With the diagnosis comes a sense of losing a previously taken-for-granted future, no longer being able to actualize a host of possibilities that one's life had—up to that point—been structured around. Yet one does not grasp all of this in a single moment. Reorienting oneself, accommodating the fact that one's whole life has changed, takes time. There is a temporally extended process of "sinking in", complicated by the fact that one's situation keeps changing, sometimes in unanticipated ways. Later in his account, Kalanithi writes:

> My life had been building potential, potential that would now go unrealized. I had planned to do so much, and I had come so close. I was physically debilitated, my imagined future and my personal identity collapsed, and I faced the same existential quandaries as my patients faced. (2017, p.120)

Experiences of bereavement similarly involve a comprehension of loss that "sinks in" over time. However, we have noted that, in the case of a chronic progressive condition, this is complicated by change and uncertainty. Furthermore, the sense of loss may be equivocal—perhaps this is not inevitable; perhaps the prognosis will change. So, instead of grieving over what has happened, one vacillates for a time between resignation and hope, where one's hopes may or may not be realistic. This relates to what Pauline Boss (1999) has termed "ambiguous loss"—a form of grief that is rendered even more challenging by epistemic uncertainty (as when one does not know for sure that someone has died) or difficulties involved in understanding the situation (as when a person one loves has been radically changed and it is unclear whether or not that person is still "there"). Hence, temporally extended experiences of lost possibilities vary in many ways and are entwined with various other aspects of experience. So, where does all this lead us?

Perhaps our discussion points to the conclusion that the nature, complexity, and diversity of grief have been obfuscated by over-reliance on a certain exemplar: a bereavement where a person whom one loves dies suddenly and unexpectedly, after which one grieves for a period of time. The problem with thinking about grief more generally in these terms, is that matters are seldom so clearly delineated. The circumstances of bereavement are themselves diverse. For instance, you mentioned anticipatory grief earlier, something we experience in recognizing that a person we love will soon die. And this needs to be further disambiguated: preceding someone's death, one may anticipate a loss that *will be* experienced while at the same time having a *current* sense of loss, associated with all those shared possibilities that have already been extinguished. Likewise with illness and injury, the sense of loss can concern something ongoing, rather than just the implications of what has already happened. Furthermore, the object(s) of one's experience of loss can be difficult to identify and distinguish. What one has lost may relate to one's bodily condition in numerous different ways, with varying degrees of proximity. So, rather than trying to tidy things up (as philosophers are often inclined to do), I instead propose that we turn things on their head and maintain that the shortcoming has been to think of grief and loss in too tidy a way, thus failing to acknowledge the breadth, diversity and, indeed, ubiquity of loss during the course of a human life. Does that sound plausible?

JC: In support of that point, let me offer some further reflections on this diversity. Michael Oliver, active in the disability movements of the 1970s, once told me that initially they would all meet and try to determine whether blindness was worse than deafness or paralysis, but that they soon gave up on such a futile task. It is similarly fruitless to compare grief between its various triggers, say, loss of a loved one or of one's own bodily capacities. Robert Murphy, who was made tetraplegic by a spinal tumour late in life and was not well adapted to his new condition, wrote that the four most far-reaching changes involved in consciousness of one's impairment are as follows: (1) lowered self-esteem; (2) invasion and occupation of thought by physical deficits; (3) anger; (4) acquisition of a new, undesirable identity (Murphy, 1987). The last of these relates most closely to the loss and transformation of one's life structure and possibilities, and this you rightly focus on. But, within a medical perspective, I would also highlight Murphy's second far-reaching change, in his altered, pervasively present, physical state of being. These, of course, are not independent. Murphy wrote:

> Our lives are built upon a constant struggle between the need to reach out to others and a contrary urge to fall back into ourselves. Amongst the disabled the inward pull becomes compelling, often irresistible... (Murphy, 1987, p.93)

As we have stressed, though, generalizations across people with the same medical condition are not possible either. One man I interviewed, thirty years after he became tetraplegic, told me:

> Over the last few years, managing entirely by myself, I'm comfortable with who I am. There are all sorts of things in life that I miss but they tend to be minor. I don't miss being able to walk; I miss the little things, feeling the springiness of grass under your feet, I miss being able to make music. Piano was the most expressive way of getting my emotions out.

I asked him if, given the chance, he would return to full movement and sensation. He thought for a moment:

> Why might I not want to? Well, I think 30 years down the line I am used to being who I am. I would actually have to go through a grieving process for losing me as I am now. It might come across as negating all the love and friendship as a result of being spinally injured. Because I am as happy as I am I don't really feel the need to want to change.

One might put such attitudes down to people's differing degrees of "resilience", something that may depend on a range of intrapersonal mechanisms, as well as one's interpersonal and social situation (e.g., Bonanno, 2009). But remember also that there are some people who never felt anger or frustration at their fate. Rather than being simply "resilient", they appear to be inherently more flexible. Where this relates to the loss of a loved one, it would not be accurate to say that those with enviable flexibility love less. Rather, they have an extraordinary ability in being able to move on and live in the moment and to look forward with relish rather than dread. Although I would like to say more about this, my impression is that the nature of this flexibility, its dimensions of variation, and its relationship to the ways in which we love and grieve all remain poorly understood, and I would rather not over-speculate.

MR: Even so, that last point about flexibility may prove to be an important one. As you say, it is not simply that some are more resilient than others (where resilience could be construed primarily as an internal psychological trait or, alternatively, something that depends on one's wider interpersonal and social situation). Even if resilience often does involve flexibility, that is not all there is to it. Furthermore, flexibility involves something more general—the extent to which one is able or willing to set aside possibilities that were central to one's life and embrace others, whether due to inevitability or choice. We could think of this in terms that approximate what Korsgaard (1996) calls "practical identity"—we identify with various categories, such as "teacher", "mother", "medical practitioner", and "Christian", which together constitute a sense of our distinctiveness, *who* we are. To these categories can be added various projects, commitments, habits, pastimes, and capacities, which together determine what matters to us and how. We might say that the malleability of practical identity varies markedly and that one's response to loss depends partly on this.

We could also relate greater malleability to living in the present, in contrast to encountering a rigidly structured long-term future, dictated by a largely fixed historical organization of projects, roles, and so forth. As you say, flexibility need not involve loving less. For instance, one could continue to care deeply for a person, while at the same time reorganizing the practical structure of one's life in ways that accommodate the death. Grief is not simply a matter of how much we care, but of the many different ways in which we care. That there is such flexibility raises some interesting and difficult normative issues. For instance, it is unclear whether or why a given degree of flexibility ought to be regarded as medically, morally, rationally, or practically *appropriate*. Furthermore, it may be that different *kinds* of flexibility are desirable or undesirable in certain situations or in general. These points, along with others we have made, apply not only to bereavement grief, but to the full range of losses that people experience.

JC: I might finish with two observations. We agree that grief contains elements of loss, in such a way that it can occur not only after, or in anticipation of, bereavement, but also with some medical conditions, especially those which are chronic. It is something that can be experienced both by the person with the condition and by carers and loved ones. This has also been recognized by support organisations for certain chronic and progressive conditions and is something that could be more embedded within medicine.[15]

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[15] There are websites offering support for those grieving over medical conditions. For example, in the case of grief relating to spinal cord injury, see: https://www.spinalcord.com/blog/getting-through-the-phases-of-grieving-after-a-spinal-cord-injury (last accessed 20th February 2022).

However, your focus has been more on the social dimensions of loss, whereas, from a medical perspective, I am brought back again and again to the body. When one starts there, one comes to see that resilience and flexibility of response may differ widely between people with the same condition, though it may depend on both personal and social factors too. Your interest in grief has led me to consider how it may occur in some medical conditions, and how its forms may differ from that seen after bereavement. On the basis of our discussion, it seems clear that both perspectives, medical and phenomenologically informed, are needed to understand people's experiences in such situations. Furthermore, they require integration, given that experiences of one's body and one's grief are not separable phenomenological "components", but inextricable aspects of forms of experience that are intricate, dynamic, and diverse. Acknowledging this may enable us to tease apart some of the subtle differences between experiences of illness, depression, typical grief, and prolonged grief, as well as respond to them more effectively.

MR: That seems like a good point to end on—I agree with you about the need for integration and greater acknowledgement. More generally, we seem to agree that it is sometimes fruitful to conceive of grief in a broad way (in light of important phenomenological similarities between bereavement and non-bereavement losses) and also that more work is needed to clarify and distinguish the various kinds of experiences that might be described in terms of "loss".

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