



People Made of Glass

The Collapsing Temporalities of Chronic Conditions

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Title of article

People Made of Glass: The Collapsing Temporalities of Chronic Conditions

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Abstract

An increasing number of people worldwide are living with chronic conditions that have an aspect of bodily fragility as part of the condition or as an effect of treatment. In this article, I explore the temporal experience of bodily fragility and the particularities of consciousness states among people with the chronic condition osteogenesis imperfecta (OI) in Denmark. My aim is threefold. Firstly, my goal is to give an insight into life with OI, a rare and rarely studied condition. Secondly, I shed light on bodily fragility, a theme that lives in the shadows of other analytical foci in anthropology. Thirdly, I will contribute to the anthropological understanding of the connection between body, physical environment and consciousness. I argue that the lifeworlds of people with OI are haunted by mental and bodily memories and fearful future scenarios, which makes the past and the future collapse into the present.

Keywords: temporality, haunting, chronic conditions, bodily fragility, osteogenesis imperfecta

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Anna

“I think that my view on life is that I look, well, of course I try to live in the present moment, but I also look back, and I also look forward, and I also look a little bit to the sides, right, to constantly be prepared.” Anna.

I am having coffee with Anna, a single mother in her late thirties with three daughters, at her home one morning in May 2017. She and two of her daughters have the rare condition osteogenesis imperfecta (OI), also known as “brittle bone disease” in English and as “glasknogler” (bones of glass) in Danish; their lives are hence shaped by and experienced through bodies that are more fragile than most people’s bodies. Anna lives in an apartment building in the center of a suburban city in Denmark. It is quiet in the building and outside the windows, the small city is slowly waking up, which seems to contrast with Anna’s mood. She seems on edge. She keeps her mobile phone within reach, often looking at it nervously to check if someone is calling to tell her that one of her daughters has once again had a bone fracture. She never knows when she will be rushing to the hospital again, experiencing the all-consuming fear of not knowing what condition the child will be in when she arrives. Anna tells me how she has often received phone calls from a teacher at her children’s school telling her that one of her children with OI has been injured and hospitalized. The severity of injuries has varied from minor fractures that easily heal to a broken back that took months to heal and could potentially have resulted in permanent immobility. She also fears getting a serious fracture herself, she tells me, partly because of the pain but also because she does not know how she will be able to take care of her daughters if she is bound to her bed for months. Moreover, the emotional and practical hardships she has endured with every fracture have left her drained, she tells me. Even though she and her daughters will inevitably have bone fractures again, she tries to prevent them by keeping an eye out for features of the physical environment that can

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lead to fractures, such as cracks in pavements, which can make one stumble and fall. Yet, these features of the environment make the memories of past fractures and the fear of future fractures flare up, adding to Anna's restlessness and exhaustion.

Dagmar

“Structure—or lack of it—has been an ongoing theme in my life. From my earliest years, I have been used to the fact that there was no coherent structure in my skeleton. The bones could suddenly and without prior notice fall apart...that was just how it was, and I knew nothing else....My deepest experience of structure—all the way down to my cells—was that it didn't exist.” Dagmar.

Dagmar and I are sitting in her living room. The late afternoon sun casts flickering shadows along the floor and up the walls. We are eating the remains of the chocolates Dagmar was given by her loved ones during her latest hospitalization. Like Anna, Dagmar has OI. She never married or had children, and lives by herself in one of the bigger cities in Denmark. I ask her if she can describe an instance of a bone fracture. She leans back in her chair and thinks for a moment. “I cannot separate them from each other,” she says, “it is a bit blurry to me.” For a moment, she seems frustrated that she cannot answer my question, but then she smiles, grabs her crutches, and disappears into another room. She comes back shortly, carrying a little book. She started writing the book long ago, a project just for herself, to reflect on different aspects of her life. The above quote is an excerpt from the book, which she was kind enough to lend me. She reads aloud and interrupts herself to give further explanations:

“It lies deep within me that nothing coheres. Not my bones, nor the contexts or relations I am in. Everything can atomize so quickly....My most fundamental experience is that

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fragments fall apart in my body. Or rather, I fall apart, and then there are fragments.”

Dagmar.

Dagmar cannot remember the fractures individually or tell them apart from one another, a phenomenon I continuously encountered during fieldwork. Until this moment, I had been interested in the temporal experience of living with OI in terms of the relation between events of bone fractures. Dagmar talks explicitly about fragments, and after the interview with her, I started noticing the theme of fragments—fragments of pain, of memories, of bodily sensations—in my empirical material more generally, yet in more subtle ways. I started to get a growing sense that the temporal experience of OI is “blurry” rather than bound to isolated events. It turned out that fragments of the past and fragments of the future exist alongside each other in the present. Time blurs and temporalities collapse as bones fracture and bodies “fall apart.”

Introduction

In this article, I explore the interconnections of consciousness, the physical environment, and temporal experiences of bodily fragility among Anna, Dagmar, and other people with OI.

OI is an incurable, congenital chronic condition that can stem from a hereditary genetic variation or a spontaneous gene mutation occurring at the time of conception (OIF 2015). It is characterized by low bone mass density and strength so that the bones break easily (ibid.), and it is estimated that 120-240 people in Denmark have OI (Sjældne Diagnoser 2016). In Denmark, OI is treated with bisphosphonate injections and calcium and vitamin D supplements to strengthen the bones, surgery in acute cases of fractures or as corrective procedure, and physiotherapy and aquatic therapy to ease the pain¹ (sundhed.dk 2017; Sjældne Diagnoser

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2016). All treatment is free as it is paid for via taxes. The majority of people with OI are able to work, yet as the physical consequences of the condition vary greatly, their ability to work varies accordingly.² The majority are able to manage by themselves, while some, for example, receive state-financed help with cleaning. Moreover, many adults with OI have spouses and children.³

This article is based on four months of fieldwork in the fall of 2017 and a short pilot study with three participants in the spring of 2017 among people with OI in Denmark. Men and women aged 13 to 76 from all over the country participated.⁴ I had 12 main interlocutors with OI, as well as their relatives and friends with and without OI. I interviewed them for the most part in their homes, and conducted participant observation of the everyday lives of five of them. The interviews were recorded and designed as person-centered (Hollan 2005) and semi-structured (Bernard 2011), with a focus on the individuals' experience of bone fractures over time, social relations, and the view of the physical environment. The analysis in this article builds mainly on the interviews; however, participant observation contributed rapport as well as insight into the rhythms of everyday life. These rhythms differ greatly, yet in most cases, I came to understand that people with OI are able to live like most people do in Denmark, i.e., have jobs, play sports, have a social life, etc., yet they often have to take breaks or do things slowly and/or extra carefully.

Chronic conditions, bodily fragility, and consciousness

According to the WHO (2017; 2014; 2005), an increasing number of people worldwide are living with chronic conditions. Many chronic conditions have an element of bodily fragility as part of the condition or as a side effect of treatment.⁵ My aim is that insights from this article can both shed light on OI, a rare and rarely studied condition, and be of use in future studies of

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consciousness-related aspects of chronic conditions that have an aspect of bodily fragility. It is now the consensus in anthropology that chronic conditions are not static but should rather be understood as dynamic due to the changes in the conditions and in treatment (Manderson and Smith-Morris 2010). In this article, I show that a focus on consciousness-related aspects of chronic conditions can add another layer to this. Through ethnographic examples, I show that when bodily fragility is a central element of a chronic condition, consciousness can be affected by psychophysical experiences of temporal collapse: the past and the future come to influence the present in specific ways. This can happen without parallels to physical changes in the condition or treatment. It is rather a result of shifts in consciousness: in this case, shifts in the intensity of memories and images of the future related to bone fractures. This experience, I argue, happens in the context of the temporal and social complexity of the lifeworlds of these people, and is especially brought about and shaped by emotion and sensorial experience. Hence, this article shows how chronic conditions and experiences of bodily fragility are also dynamic when it comes to their consciousness-related aspects.

Besides being a rare chronic condition, OI is a rare topic in anthropological literature. One anthropologist, Joan Ablon (2010; 2003; 2002), has studied people with OI. She conducted her study across a variety of states in North America and focused primarily on stigma, identity, and how people with OI are perceived (and perceive themselves) as happier and more emotionally resilient than the general population (see below). Her work also focuses on how OI affects a variety of aspects of life such as education, employment and personal economy, dating, sexual relationships, and marriage. Yet as a chronic condition with bodily fragility as a main feature, studies of OI are part of a far-reaching branch of anthropological literature. Traditionally, chronic conditions have not received much explicit attention in anthropology (Heurtin-Roberts and Becker 1993, 281), but from around the 1990s and onwards, publications with a distinct

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focus on chronic conditions emerged (e.g., Estroffs 1993; Bluebold-Langner 1996; Jackson 2005; Manderson and Smith-Morris 2010). Where chronic conditions now receive explicit attention in anthropology, bodily fragility figures more implicitly, for example in the body of anthropological literature on aging (e.g., Fischer 2015; Lamb 2000). Furthermore, studies of a variety of chronic conditions deal implicitly with bodily fragility. These include studies of physical weakening as a result of cancer and cancer treatment (e.g., Perusek 2012; Hansen and Tjørnhøj-Thomsen 2008), diabetes patients' self-control, self-cultivation, and self-care (e.g., Guell 2012; Ferzacca 2010), and the interrelationship between individual, societal, and medical perceptions of chronic pain (e.g., Greenhalgh 2001; Jackson 1994). Furthermore, studies that focus on narratives and meaning making among multiple sclerosis patients (Robinson 1990), and perceptions of the physical environment among people with multiple chemical sensitivities (Lipton 2004), deal implicitly with bodily fragility. The increasing interest in chronic conditions is also present in studies that take a psychological, experiential, and/or consciousness-related approach. Here, the attention is mainly turned toward emotional aspects and temporal experience (e.g., Samuels 2018; Throop 2017; Weaver and Hadley 2011; Kohrt et al. 2005), again with bodily fragility as implicit subject matter. Hence, the theme of bodily fragility exists in anthropology, yet it lives in the shadow of other thematic and analytical foci. In this article, I deal with some of the themes that the above-mentioned studies also draw on, i.e., the perception of the physical environment, emotion, and temporal experience, taking them as a point of departure in order to draw bodily fragility out of the shadows and stress it and its relation to consciousness explicitly.

A key element in the literature on OI—both anthropological literature, in the form of Ablon's work, and medical literature—is that people with OI are described as being distinctly optimistic, happy, and good at keeping their hopes high in often very difficult situations. Some medical

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literature has argued that this might be genetic: that the genetic mutation that entails the predisposition for fragile bones might also entail a predisposition for optimistic moods (Ablon 2010, 208; Reite et al. 1972; Solomons and Millar 1973). However, this is still questioned and seems to have the status of an unsolved mystery among medical professionals.⁶ Ablon (2003; 2010) has argued that it might not be congenital, but an ability that is developed over time as an effect of enduring continuous emotional and physical suffering. The importance of social and experiential aspects in emotional resilience, as well as the acknowledgement of the co-existence of happiness with emotions such as fear of bone fractures, is also present in newer medical and psychological literature (e.g., Janus et al. 2020, 232; Tsimicalis et al. 2016). I did to some extent encounter optimism and happiness among the people I talked to, despite the distress and hardship they face. They seemingly do, to some extent, have “stout hearts and minds,” to use Ablon’s (2010) words. However, while some stressed that they themselves, and people with OI in general, are just more optimistic than the general population, others told me that they feel like it is a stereotype they must live up to and a mask they put on. The question of how people with OI endure, of how they can be optimistic despite all the hardships they face, is indeed an important and interesting one. Additionally, the tension between experiencing optimism as an unrealistic ideal or as part of one’s personality is worth exploring. However, these themes are not the focus of this article. I will dive into the darker sides of the bodily fragility of people with OI, firstly because I find it important for the understanding of OI, and secondly to recognize the less optimistic sides of the experience of OI on par with the ability to be happy and hopeful.

In the following section, I outline the analytical pillars on which this article rests. Subsequently, I turn to the analysis and discuss how fragments of the past and the future haunt the present lifeworlds of people with OI. Painful past experiences and fearful future scenarios linger on

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the edge of awareness: they flare up momentarily and exist as a continuous weight. Thus, I argue that as bodies fall apart, temporalities collapse, and that this is a central element in the interconnections of emotion, sensorial experience, and shifts in consciousness among people with this chronic condition.

Temporal experience and haunting layers of the lifeworld

“How does life edge along, in time? What haunts people, and why?” (Desjarlais 2012, 101).

To shed light on the intersection of consciousness and chronic bodily fragility among people with OI, I turn my attention toward temporal experiences of lifeworlds via the concept of haunting. I do so because this allows me to flesh out and unfold the nuances of the psychophysical aspects of shifts in consciousness.

In anthropology, studies of the temporal experience of people with chronic conditions have focused on hope for (e.g., Samuels 2018) or fear of (e.g., Weaver and Hadley 2001) the future, and despairing moods related to how one’s present situation could be unfolding in alternative ways if one had acted differently in the past (Throop 2017). Instead of looking at how present moods reach back and forth in time, I explore how the past and the future reach into the present.

In doing so, I look at how temporality is experienced and draw on the argument that anthropology must be open to approaches that highlight different aspects of human experience (Willen and Seeman 2012, 4). The concept of experience does not lend itself to easy definitions or a single unified paradigm (ibid., 1), and while a variety of scholars have attempted to define it, I take the following definition of experience as my analytical approach:

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“[Experience is] an open-ended point of departure for robust ethnographic inquiry into the fullness, complexity, and indeterminacy of human life, both individual and collective, as it unfolds in space, over time, across moods and modes, and within multidimensional local worlds that are defined as much by their biographical and embodied particularity as by their intersubjective grounding” (ibid., 5).

Like experience itself, the anthropology of experience does not belong to a unified paradigm. It involves a fluid constellation of themes shared by phenomenological and psychoanalytic schools within anthropology, which have traditionally been regarded as parallel and divergent lines of inquiry (ibid., 1).⁷

I draw on concepts from both traditions. Central to the study of experience in phenomenology is the concept of the “lifeworld,” coined by the founder of phenomenology, the German philosopher Edmund Husserl (Desjarlais and Throop 2011, 91-92; Moran 2000, 181). The concept of the lifeworld has been largely taken for granted in social science, yet a handful of anthropologists have used it explicitly (Bidney 1973; Good 1994; Desjarlais 2011; Duranti 2009; Jackson 2011). The lifeworld in phenomenological terms is the unquestioned, pre-theoretical, practical, historically conditioned, and familiar world of people’s everyday lives (Desjarlais and Throop 2011, 91). Inspired by Husserl, Austrian philosopher Alfred Schütz took up the concept and developed it in *The Structures of the Life-world*, which was published posthumously with the help of his former student Thomas Luckmann. In his work, Schütz’s main interest was in understanding the connection between experience, action, and the social and he is known for bridging phenomenology and social science (Stanford 2018). He dealt with a wide range of aspects of human life including economics, literature, music, and meaning- and

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decision-making. He also explored the interrelationship between consciousness, temporality, materiality, memory, and the body (*ibid.*), which is the branch of his theory this article draws on.

In our lifeworlds, Schütz (1974) stressed, we coexist with other sentient beings to differing degrees of spatial and temporal intimacy (*ibid.*, 3-4, 17, 35-36). There is consequently not a single lifeworld, but multiple intersecting and overlapping lifeworlds (*ibid.*, 5, 61-68). We experience lifeworlds through our bodies: bodies that interact with the environment as well as being part of cultural worlds (*ibid.*, 5-6). Culture, intersubjectivity, the environment, and experiences of the body hence structure lifeworlds in particular ways. Yet lifeworlds are dynamic rather than static. Ever-changing horizons of experience imply that there is a past from which one has come and a future toward which one is heading. However, experience in the lifeworld does not only entail fluxes of awareness from one moment to another. It also involves a less chronological sense of time, what Schütz calls “inner duration,” where several references to the past exist in the present (*ibid.*, 52-56). Experiences hence accumulate over time in a chronological sense, yet they are experienced in a non-chronological way because other points in time influence how they are experienced. I will draw on Schütz’s notion of the lifeworld to capture the multifaceted temporal experience of OI.

While the concept of the lifeworld can help to show that the temporal experience of OI is unchronological, intersubjective, and linked to the body in the physical environment, I draw on the concept of “haunting” to illuminate the details and modes of how this is experienced. In doing so, I will also unfold the subtle yet important difference between haunting and trauma.

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The concept of haunting does not have its roots in a single theoretical tradition, and is hence not a psychoanalytical concept, yet some scholars draw on it with inspiration from psychoanalysis. It is a conceptual metaphor in academia, the meaning of which has emerged from folk tales of ghosts and specters (Blanco and Peeren 2013, 1-2), and it gained popularity in the social sciences with philosopher Jacques Derrida's (1993) *Specters of Marx*, and sociologist Avery Gordon's (2008 [1997]) *Ghostly Matters*. Furthermore, Byron Good (2012) has employed the concept in a psychoanalytical fashion to explore that which is unspeakable yet erupts into awareness in haunting ways. What I deal with is not particularly unspeakable, but I find Good's invitation to look for that which unfolds subtly in haunting ways inspiring. Tine Gammeltoft (2017; 2014; 2013) takes a phenomenological rather than a psychoanalytical approach when she draws on the concept of haunting to show how the past, in the form of repercussions of the Vietnam War, and the future, in the form of the loss of potential lives, haunts the present of pregnant women in Vietnam. I find this use of the concept inspiring in terms of illuminating how the past and future can coexist with the present in haunting ways.

Lastly, I draw on anthropological insights into bodily sensations, as these are an important aspect of understanding the temporal experience among people with OI. As anthropologists have shown, western philosophy and social science have a tendency to divide the senses into categories and deal with these separately, often prioritizing visual sensation (Howes 2003). Moreover, anthropologists have problematized the ways in which medical science and large parts of western philosophy have treated the senses as purely somatic; as detached from mental and social aspects (Geurts 2002; Scheper-Hughes and Lock 1987). However, to understand the workings of the senses, they are best studied as overlapping and interrelated, and as connected to minds, emotions, and sociality (ibid.; Howes 2003; Desjarlais 1992). This is my point of departure in this article for understanding the senses and their mind-body relation.

The past haunting the present

In the opening vignette, I introduced Anna and described how she is both restless and exhausted. Part of what makes her restless and exhausted is constantly keeping an eye on features of the physical environment that can lead to bone fractures. Other people I talked to told me that they do the same. They described how they notice cracks in pavements; bumpy, uneven, and icy roads; wet bathroom floors; slippery tiles; puddles of water in the streets; and high curbstones. What might be unnoticeably small and mundane details in the physical environment for most people can be the source of stumbling and falling, and hence immense pain, long periods of practical challenges, medical complications, and emotional hardships for people with OI. Well into my fieldwork, I talked to Jonas, who at first, in contrast to Anna, seemed calm and at peace with his condition. Jonas has had sixty serious bone fractures and a multiplicity of minor bone fractures throughout his life.⁸ However, he explained how his parents have always encouraged him to not let OI stop him. Thus, all his life, Jonas has engaged in activities that can easily lead to bone fractures such as playing football, skiing, and going out with friends. However, when I asked him if he fears bone fractures, he said:

“I have always had a fear, all my life, of breaking something simply because of the pain and the treatment that follows....So, I have always known that there is a consequence of everything I do physically. The worst consequence is breaking something, and that always lurks in the back of my mind. So, no matter what I have done, if it has been something risky or not risky at all, it always lies latently in the back of my mind that I have to be careful....And I think you take some of the pain with you. When you have had a variety of painful experiences, then you take some of the pain with you. For example, I once fell down the stairs in the tower at Himmelbjerget [a hill in Denmark], you know, I clearly remember what happened in that second. My legs almost collapsed under me.

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And that feeling, or thought, can sometimes reappear when I am walking down the stairs. Then I think, oh, then my body reminds me how it was back then, so I should be extra careful. So, I think such memories of pain lie in you, and they will be there until you die. Well, I think you take something with you every time. And the more you have of such experiences, the bigger the backpack of painful memories becomes, and the more you are reminded, oh, there I slipped on a tiny wet spot or on a slippery floor or something, and then I fell and broke my foot. Well okay, then that is what I take with me, and that means that in the future, I will be a bit afraid of slipping in puddles of water or walking on slippery tiles, for example.” Jonas.

The quote by Jonas is an example of how past experiences of bone fractures stay in the present as painful memories, and that these memories are linked to the physical environment. For example, the pain Jonas experienced from falling down the stairs at Himmelbjerget now connects to the experience of walking down stairs in general. Like Jonas, the other participants gave examples of how past experiences appear in their minds or as bodily sensations, and are thus momentarily brought into the present, when they find themselves in environments that remind them of past fractures. These encounters with the physical environment also become integrated into the body quite literally. While some bone fractures heal after a couple of weeks or months, others keep hurting for years or never heal completely. An encounter with the environment can hence stay in the body as a painful reminder of the past in the present. In addition, the fractures that do heal, and with time leave no pain, can in some cases heal in ways that result in the formation of scar tissue under the skin. Thus, they leave lumps and bulges on the body as visible reminders. Everyday encounters with the physical environment hence turn into mental and bodily memories.

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In the case of OI, visual sensation from the surrounding world, like seeing curbstones or puddles of water, mix with internal bodily sensations that again merge with memories of pain and the voices of family members. Sensing in this case is hence not a purely somatic experience, and as Geurts (2002) argues, the overlap of bodily, mental, and social aspects of sensing creates particular ways of knowing. Jonas knows how to take care when walking down stairs: his mind-body memories tell him what to do. These memories figure as fragments of the past, which flare up momentarily to haunt the present. Moreover, they haunt the present in more persistent ways. They do so in the form of persistent pain and visible marks, but also as a more abstract, exhausting weight of the past in the present. It is the weight of having endured multiple painful instances of fractures, as in Anna's case, and it is the weight of constantly being reminded by memories and bodily sensations to be careful, as in Jonas's case. When I asked Dagmar, whom I introduced in the second vignette, about the pain and the memories of pain, she talked about it as "the undefinable (det udefinbare)"; as always being there as a kind of pain that is both bodily and mental without a clear separation between the two. "It weighs one down (det tynger en)," Dagmar explained, and added that it sometimes makes her very tired—so tired that she cannot gather her thoughts. They become incoherent, she explained. Thus, the persistent weight of multiple fragments of the past in the present figures as a "backpack of painful memories," to use Jonas's wording.

As mentioned previously, Dagmar explicitly used the word "fragments" to talk about her experience with OI, which made me realize that "fragments" is a useful term to unravel what is at play in my empirical material more generally. During a later interview, I asked Dagmar about "the metaphor of fragments," as I termed it; she interrupted me as I was asking the question and specified that:

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“I don’t think it is a metaphor!...to me it is like, when that is how my body is, then I think it in some way influences my mind. You know, there are times when I think everything becomes way too, well, you can be standing in the middle of chaos to above both of your ears; suddenly become hospitalized, and suddenly taken out of your everyday life, and suddenly have to solve a lot of problems while you are lying there...everything dissolves and becomes fragmented.” Dagmar.

Dagmar continued by telling me how her social life, thoughts, and memories become fragmented as an effect of her bone fractures. I came to understand that fragments are more than a metaphor to communicate the experience of OI. Fragments are a real and quite concrete element of the experience of OI: the fragments of physical and emotional pain. Fragments have thus more to do with the ontology than the epistemology of OI. It is a way of being in the world, not only a way of understanding that kind of being in the world. Hence, painful past experiences have a fragmenting effect on the temporal experience. Regarding chronic pain, Good (1994) has noted that “time itself seems to break down....Time caves in. Past and present lose their order” (ibid., 126). The experience of bodily fragility also seems to break down time, and I became interested in the specifics of this in relation to OI.

I started wondering if the weight of multiple fragments of the past in the present exists as a continuous force or if it varies over time. I got the impression that, on an everyday basis, it is possible to shift one’s attention away from it by doing or thinking about something else, yet it is always present in the back of the mind.

In terms of life course, it seemed to vary as well. The number of bone fractures is rarely consistent, meaning that most people with OI experience periods with many bone fractures and

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periods with few or no fractures at all.⁹ Dagmar, who is now in her fifties, had periods without fractures from her late twenties to her early forties. She explained that:

“You could almost forget it, or well, every time there was something, because it could be other things that were hurting or rendered difficult. I had a lot of problems with my teeth. That is also a part of the condition, right, and I am one of those who have had it very severely....And every time I had a fracture in relation to my teeth, then it was kind of like, then my whole set of reflexes woke up again. You know, oh, oh, oh no! Even though it was limited to the mouth....But the fear, it is there. It is there. It lies just below the surface, right, that is what I believe. But not in a way that kept me from traveling, for example, because I thought: it will be okay. I would not dare that today.” Dagmar.

In the periods where fractures were few, Dagmar could almost forget OI, yet it was never completely absent from her awareness. She would still be reminded, yet it would not hold her back to the same extent as in the periods with many fractures. As I started talking to other people about the presence of emotional and physical pain, memories, and fear, what Dagmar calls “the undefinable,” it seemed that it was not a question of it being there or not being there. It was rather a matter of intensity, in the sense that it is always there, but that it is sometimes above and sometimes below the surface of consciousness; never far away, figuring as a companion who is always latently present on the edge of awareness. As Schütz (1974) notes regarding inner duration, it has a horizon of the past and a horizon of the future, but how the horizons of the past and future are experienced depends on the present situation (ibid., 53, 111). There are no shores upon which one can crawl and observe the stream of time consciousness from a distance. One always lives in the stream of time consciousness,¹⁰ which is the context for reflections and experiences (ibid., 55, 111-116). How the past figures in the present is bound

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to how the present unfolds, meaning that the present is not only characterized by the past, but that the past, too, is characterized by the present. While fractures of painful memories flare up and enforce themselves as a weight of the past in the present, the intensity of this weight is dependent on the present situation. The present situation is also very much linked to how the future figures. It is sensed in a psychophysical fashion, and following Desjarlais (1992), I will argue that this results in a particular way of being in and engaging with the world. Concerning the overlap between psychological and physiological aspects of illness, Desjarlais has suggested that sensing can be approached as:

“a lasting mood or disposition patterned within the workings of a body. A sensibility is occasioned by the specific (and often shifting) concerns marking a person's world. It denotes a particular way of being and so shapes how a person feels and engages with that world” (ibid., 150).

Past experiences with bone fractures result in a particular way of engaging with the world for people with OI; a way of being that shifts as it is informed by fear, pain, perseverance, and (sometimes) the willingness to take risks. I will elaborate on this further. Before I do so, I will add two further aspects I find important in understanding the way the past figures in the present lives of people with OI.

Firstly, I found that it is not only fragments of bone fractures that have occurred that stay in the minds and bodies of people with OI. Additionally, fragments of events which could have led to bone fractures but did not come to haunt the present. For example, Esther, who is in her sixties, told me about an instance long ago, when she was a young woman. It was a warm summer day, and she and a friend had gone for a bike ride in the countryside. There were not many cars on

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the small roads between the fields, and occupied with talking to her friend, Esther entered a crossroad without noticing a car approaching from the other side. Surprised and frightened, she fell off her bike. Luckily, she did not get hit by the car and furthermore, she did not break anything from the fall. Yet she fearfully remembered the incident every time she was in the area. Like Esther, other participants told me about incidents that did not lead to a bone fracture, yet stayed with them as fearful memories linked to the physical environment. Fractures that did not take place are thus as much a part of the lifeworld and temporal experience of bodily fragility as instances of actual fractures.

Secondly, the past in the present has an immanently intersubjective aspect. For example, Esther's father also had OI, and he was always afraid of bone fractures. So was Esther's mother, who feared to see her loved ones in pain. Thus, "Be careful!" was not an unusual phrase in her childhood home. When I met Esther, she had just had a fracture in the lower part of her spine. It was her first serious fracture since her early youth. She had been careful all her life. She had been worried many times during her adult life when she fell, bumped into things, or felt pain in some part of her body. Yet, every time she went to the hospital, the doctors told her that there were no fractures, that she was fine, and that she could go home. But Esther kept being careful and fearful. During my interviews with people with OI, the voices of family members surfaced as echoes from the past. They were a continuous underlying tone and seemed to be the soil from which reasonings regarding how to handle risks grew. For example, even though Jonas is worried and carries a lot of pain, he keeps engaging in activities that can potentially lead to fractures, explaining that "it is what they [his parents] taught me." This is not to say that the people I talked to blindly follow what their parents taught them, but that social relations populate and shape lifeworlds in varying ways. The cases of Anna, Jonas, Dagmar, and Esther are examples of how the past collapses into the present in haunting ways. In this regard, their

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temporal experiences of bodily fragility have shared features. However, Jonas's and Esther's stories are examples of how parents' approaches to OI color experiences and give lifeworlds personal nuances.

However, the voices of family members might not only be memories, but also integral to the present, being what Gammeltoft (2017) terms "spectral kinship": vividly present traces of the past and the future in social relations. In his account of experience, Schütz (1974) argues that though the experience of time and space varies from person to person and is thus individual, it is intersubjectively constituted via biography (ibid., 56-58). Whereas it might be possible to place oneself in the exact same spot as another person, one would not perceive the surroundings in the same way, partly because one might have other bodily premises for the experience (Schütz uses the example of nearsightedness), and partly because one has another biography (ibid., 40). Biography refers to one's lived experiences as they are influenced by the social relations and the history of these experiences over time (ibid., 56-59). Memories are therefore closely related to bodily experiences. These bodily experiences are related to the wider material and social world, as bodies interact with the physical environment and exist among other people, both of which influence and shape experiences and memories. It is hence a circular motion of psychophysical experience in time, through space, and among other people, when the past collapses into the present and comes to haunt the present.

The future haunting the present

"I have a tendency to, when, you know, it is in periods, where I think that in that specific place, I could fall. I can see myself fall all the way down the stairs, just by making some little movement. I can see the whole chain of events. Now I am laying down there [at

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the bottom of the stairs]. You just have that picture inside your head, but then I think, try to calm down, you know, nothing has happened.” Olivia.

This quote from a young woman named Olivia is an example of how the present is not only infiltrated by what has happened and what could have happened in the past, but also what might happen in the future. Olivia has had serious cases of bone fractures 20 times and multiple minor fractures; 65 in her fingers and hands alone. She got them from doing sports, going out with friends, and a variety of other events, but she has never fallen down any stairs. Nevertheless, the mental image of an event that has not led to a fracture haunts her present as a fragment of what the future might hold. The future also haunts the present in a less concrete, yet more constant way, as the continuous deliberation of when to be careful and when to take risks. For example, Olivia said:

“When I was younger, my mother and father kind of cocooned me in terms of saying you cannot do that and that and that. It was of course for my own sake....Now, my parents have come to a point where, of course, [I am] 23 years old....I must care for myself, so now it is kind of like, now you must figure out for yourself if you want to go roller-skating or skiing. I was never allowed to do that before....They will just advise me not to do it, but it is up to me now to make the decisions about what I want, because it is like my body, my life. You know, they give me advice and guidance, and I do of course appreciate that, but I have to make the decisions on my own. And I haven't done anything crazy yet [laughs a little], and it isn't something I plan on doing. But still, if I am given the opportunity to go skiing, for example, I actually think I will take it. Because I also want to experience life. I don't want to look back when I am 80 years old, and am in a wheelchair or what do I know, then I don't want to look back and think,

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why didn't you take any chances? Maybe I will have a fracture, but isn't that fracture worth it, if you get that experience? But then again, when I was younger, I had some fractures that could just be put in a cast for a couple of weeks and then everything was fine. It is only the two newest fractures I have had where they [the doctors] have had to operate and there have been some complications. So, you must also keep the risk of complications in mind. So that is where I am kind of in doubt again....Nevertheless, it is, well, something you must think about. If I get osteoarthritis or rheumatoid arthritis early and my mobility is reduced, can I then work? You know, is it then worth going skiing, if you might lose ten years of your working life? So, it is always that unexpected, you know, one can always be unlucky, and extra unlucky if you have OI, because the degree of risk is just higher. So, it is about balancing pros and cons all the time. Is it clever, what I am doing right now? Should I join my friends for a night out, where I know there will be a lot of drunk people acting foolishly, or should I just sit at home and watch a movie like I do all the other nights? You know, I have to get out and be part of life. So, it is, yeah, finding a balance.” Olivia.

The future exists in Olivia's present attempt to find a balance between the risk of future bone fractures and the risk of missing out on life. As Deborah Lupton (2013) has argued, risk is often associated with fear and vulnerability, yet it is important to note that risk also relates to desire and self-actualization. In the case of OI, I will argue, these are interconnected as risk simultaneously relates to the fear of pain and bone fractures, and the fear of not living life to the fullest and becoming the person one desires to become. These two kinds of risk and fear play out as multiple future scenarios that infiltrate the present and persistently haunt it. It was an ongoing theme when I talked to people with OI, and the aspect of uncertainty was a central element of the fear. In this regard, Dagmar explained that:

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“I compare it to...what it feels like to live in a warzone, where there are landmines. Because it is like living on a minefield, right? You never know when it will explode or, when you step on it, if it will explode a little bit ahead of you. You never know quite how, but you know that it is dangerous to walk there. Still, you must walk there, because you have to move around and get food and do what you need to do. You cannot just stand still. But that is what erodes (tærer på) you. That is the feeling that kind of erodes you sometimes. That you always live like that.” Dagmar.

By comparing the risk of fractures to the risk of encountering landmines in a warzone, Dagmar stresses how the constant balancing of risk “erodes” her in the present. As with the weight of the past, the weight of the future carves into the present of people with OI to haunt and erode them. So far, it might seem as if the ways in which the past and future haunt the present are similar. However, there are differences, which I will unravel by pointing to the differences between trauma and haunting.

One could argue that the recurrence of pain has associations with the concept of trauma, which is characterized by the repetition of painful memories. What separates trauma and haunting, however, is that haunting is more than repetition (Blanco and Peeren 2013, 10-15; Gordon 2008 [1997], xvi, 22). What is haunting is always both revenant (invoking what was) and arrivant (announcing what will come). It not only entails the unbidden parts of the past in the present, but also facets of the future that are always already imbued with possibilities derived from the past (Blanco and Peeren 2013, 10-15). Unlike traumatic repetition, haunting refers to figures of surprise that do not necessarily reappear in the same manner or guise (ibid., 13). Haunting is emergent and distinctive for producing a something-to-be-done (Gordon 2008 [1997], xvi,

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22, 201). It is hinted at in these definitions, I will argue, that haunting entails a creating and creative ability. I want to stress this feature, as it is a prevalent aspect of how the temporal experience of OI is haunting. It produces scenarios that have never happened and crafts particular versions of possible futures, as the quotes by Olivia show.

Good (2012) and Gammeltoft (2017; 2014; 2013) unfolded how the past and the future can fall into the present, come to coexist and erupt into awareness in haunting ways. They do so by focusing on close social relations and political conditions. As should be clear by now, my contribution is an analysis that follows the same train of thought, yet takes bodies as the point of departure for studying haunting. As I have shown, however, close social relations shape bodily experience when it comes to the past in the present. They are also an inherent part of the future in the present.

For example, Olivia's father, who also has OI, got a serious bone fracture in his back a couple of years ago, which was followed by a lot of complications. The doctors who treated him told him that it has now healed as much as possible. Yet the pain remains, and he now lives off early retirement benefits. I have described how the voices of family members are like echoes from the past into the present. This is indirectly visible in Olivia's reflection that her father's present condition is part of how she fears her own future might be in terms of her working life. It is thus an example of how these echoes of family members not only linger in the present, but also reside in future scenarios.

Lifeworlds are, however, not only populated by familiar characters. Some told me how their fear of future fractures affects their view of strangers' bodies. For example, Anna said:

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“When I am in Føtex [supermarket chain in Denmark], and there is a child in a shopping cart, in that little room, you know, and the mother of the child is a bit inattentive, and the child is like [Anna moves from side to side], sometimes, I choose to stand close enough that I can catch the child if it should fall. At other times, I simply have to walk away. Because I do not feel like, well, you must be careful, because this mother could be furious with me, if I suddenly grab her child, because I think it is falling. So, I avoid situations very, very often, where I can see that I cannot, because I cannot handle it. ... There are also situations which I cannot avoid. There was a cyclist who fell one day when I was driving along [a bike lane], and of course he fell right in front of me. They [the cyclists] drove in such a slow line near the school, and then he slid or something and rolled around. One must stop. You know, my heart was racing, and I was shivering all over my body. I cried hysterically afterwards, and I just cannot not handle it. It is a person, I don't know! And it does not matter if he gets up afterwards and drives away. I get SO affected by it. I cannot handle it. So, I have to walk away from situations very often, because it stays with me. ... It comes in periods, it is not too bad at the moment, but it has been really bad. I had to see a psychologist and things like that because it takes up so much space in my mind.” Anna.

This is an example of how the fear of fractures among people with OI can affect their view of other people's bodies. It is part of future scenarios, as Anna prepares for the child to fall, even though she does not know the child, and the child most likely does not have OI, and will therefore not be seriously injured if he or she should fall. Furthermore, as the person on the bike falls, Anna knows that he most likely will not be hurt, yet the fear is almost unbearable. In addition, even when he gets up and rides away, perfectly well and safe, she takes the experience of an event in which another person could have had a bone fracture, even if it did

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not happen, with her. As she says, it stays with her and affects her. This is again an example of the creativeness of haunting experiences. Just as Olivia has never fallen down any stairs, Anna has never seen a baby fall from a shopping cart or a man getting seriously injured by falling while on his bike, nor has she experienced these events herself or for her children. Yet these scenarios haunt her. It comes in periods, as Anna explains. Yet it is an example of a period where the fear is very intense.

As I discussed in the previous paragraph, fear continuously lingers on the edge of awareness. The fear and the undefinable pain of the past hence flows with varying intensities through time: from lingering below the surface of awareness in periods where fractures are few to being so tormentingly intense that it fills up the mind, overflows the boundaries of it, and reaches out to unknown bodies. Drawing on the work of philosopher Henri Bergson, Schütz (1974) argues that lived experiences can have varying modes of “tensions of consciousness” (ibid., 25). Tension of consciousness refers to the degree of attention to life or reality (Schütz uses both words). Action while being wide awake is the highest form of tension of consciousness and relation to the real world, while dreaming is linked to what is unreal and is therefore the lowest form of tension of consciousness (ibid., 25-34). I find this concept useful in illuminating the specific workings of haunting in the case of OI. However, Schütz does not address that which lingers on the edge of awareness. Including that which lingers on the edge of awareness adds an important and necessary dimension, especially in combination with his account of intensity. Schütz uses the term intensity to attend to the depth and strength of lived experience (ibid., 112). In combination, these concepts of consciousness contribute to an amplified understanding of the haunting layers of lifeworlds in cases of OI.

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As I have shown, the weight of the past and future is always lingering on the edge of awareness. However, when it is very intensely felt, it moves from the edge of awareness to the highest degree of tension of consciousness and reaches out to the world. When it is less intensely felt, it inhabits a lower level of consciousness; it does not reach outwards to the world as forcefully. During these times, the tension of consciousness can still be on a high level, yet it reaches out to the world in a way that is characterized by other moods: joy and curiosity, for example. As Dagmar explained, when the fractures are few, it is possible to attend to the world in a mood that is less fearful and evokes the courage to travel, for example.

The edge-of-awareness layer of the lifeworld is where haunting resides most of the time, it seems. I got the impression that from there, it stretches outwards to the world in varying intensities, drawing on different regions of the past and the future in divergent degrees of fragmentation and tenaciousness. This, I argue, is how emotional and sensorial experiences shape the lifeworlds of people with OI over time, and thus how shifts in consciousness among people with this chronic condition occur.

Concluding remarks

Anna tries to live in the present moment. However, she cannot help but look back, forward, and a little bit to the sides in order to be constantly prepared as fragments of her painful past and the weight of future scenarios filled with fear come to haunt her.

In this article, I have examined the temporal experience of living with the rare, chronic condition osteogenesis imperfecta (OI). I have shed light on how the bodily fragility of OI shapes temporal experience in a particular way: the past and the future exist in the present in the form of bodily and mental pain, and fear that comes to haunt momentarily and stays as a

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continuous weight, fluctuating through time in varying intensities. Thus, I have illuminated how the past and the future collapse into the present as bones fracture and bodies “fall apart.”

This article has provided the reader with an insight into life with OI, a rare and rarely studied condition, as Anna and other people with the condition experience it. It is an ethnographic contribution to the intersections of the fields of consciousness and chronic conditions, by which I have sought to highlight how life with a chronically fragile body can be experienced. My aim has been to show that chronic conditions are not only dynamic in the sense that the condition itself can change over time. Focusing on consciousness has allowed me to explicate that when bodily fragility is a central part of a chronic condition, socially-influenced temporal and psychophysical experiences of it can be affected, which can result in shifts in the experience of the condition, (sometimes) unrelated to somatic or treatment-related changes. This adds another layer to the understanding of how chronic conditions are dynamic. I hope that the insights from this article can be of use in future studies of consciousness in relation to other chronic conditions that have an aspect of bodily fragility, even though the bodily fragility might figure in different ways compared to OI.

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Notes

1. The physical consequences of the condition differ greatly from being only slightly more fragile compared to people without OI to breaking bones from sneezing or pressing a button. Hence, how easily people with OI break a bone differs accordingly.
2. A minority of people with OI in Denmark live off early retirement benefits and a few do quite physically demanding jobs. However, my impression is that the majority do a wide variety of full- or part-time sedentary work: for example, working as a secretary, engineer, or radio host, sometimes in spite of dreams of having physically active jobs such as being a police officer or a construction worker.
3. Even though many people with OI have children, pregnancy can be impossible or entail great risk for both the mother (if she has OI) and/or the child (if it has OI). Therefore, some people with OI cannot have children, some choose not to have children, and some adopt children, while those who choose to have children are often followed extra closely by medical professionals during pregnancy and might have to have a caesarean section.
4. Since OI is a very rare condition, it is hard to find a more homogeneous group of interlocutors. Even though age, gender, and socioeconomic factors shape experiences of OI, I found that there are aspects regarding the temporal experience of bodily fragility that exist across age, gender, and socioeconomic status.
5. Chronic bodily fragility, either as part of a condition or as an effect of treatment of a condition, for example, exists to varying degrees in cases of cardiovascular diseases, immune diseases, diabetes, hypersensitive pneumonitis, hemophilia, multiple chemical sensitivity, cancer, and stroke.
6. Ablon (2010; 2003) refers to medical articles from the 1970s (e.g., Reite et al. 1972; Solomons & Millar 1973), yet I encountered the same view in 2017 among the doctors I

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talked to; that people with OI are particularly happy and emotionally resilient. However, most of the doctors I talked to viewed genetics as just one out of several possible explanations, and they agreed that social factors could be at play too.

7. Phenomenology and psychoanalysis both have their origins in the early 20th century and are both results of discontent with the traditions they belong to (philosophy and psychology, respectively) (Willen and Seeman 2012, 7). They both deal with human experience from a first-person point of view in the present moment in relation to shadows of the past and the future (Hollan 2012, 37). Except for Alfred Irving Hallowell's (1955) work during the 1950s, and Clifford Geertz's (1966) and David Bidney's (1973) explorations during the 1960s and 1970s, phenomenology was integrated into anthropology from the 1980s onwards, whereas psychoanalysis appears throughout the history of anthropology, yet in very different ways and following no straightforward path (Gammeltoft and Segal 2016, 400-403; Willen and Seeman 2012, 7-8).
8. Some of the people with OI I talked to categorize the bone fractures they have had into various categories. Hence, I found that when asked how many bone fractures they have had, some would say that they have had x amount of "serious," "real," or "registered" bone fractures, and then add that they of course have had a multiplicity of minor fractures. Most would count the number of "serious" bone fractures: meaning the bone fractures that result in a lot of pain, required surgery and/or hospitalization for longer periods, and meant that they could not engage in everyday life. Minor fractures were often not counted because as most people told me, they "did not count," meaning that they were not very painful, did not require surgery or hospitalization, and did not limit them in terms of engaging in their everyday activities. A minor, uncounted bone fracture is, for an example, a fracture in a finger or in a toe.

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9. A period without fractures means several years, yet how many years differs greatly with each case. Many of the medical nuances of the condition are still unknown, yet a comprehensive study of the number of bone fractures among people with OI in Denmark found that the fracture rate was highest in people with OI aged 0-19 and lowest in people with OI aged 20-54 (Folkestad 2016, 52; Folkestad et al. 2016). The fracture rate for people with OI older than 54 was higher compared to people with OI aged 20-54, but lower compared to people with OI aged 0-19 (ibid.). The high number of fractures in early life might be a result of fractures due to falls when toddlers learn to become more mobile, and increased fracture risk during growth spurts in puberty (Folkestad et al. 2016, 127). The increasing number of fractures in later life might be a result of postmenopausal bone loss for women and age-related bone loss in men (ibid.). Yet the number of fractures also relates to life choices (Folkestad pers. comm. 2020), i.e., if the person with OI chose to live life in a way that increases the risk of bone fractures.

10. The theoretical term “time consciousness,” as I understand Schütz, is an entry point to explore how consciousness is shaped by temporal experiences and should hence not be understood as the consciousness of time.

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