

**“Now bounded, now immeasurable”:  
Perspectives on time in disability, suffering, and at end of life**

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Abstract:

Novels, films, poems and visual art can expand our view of time in ways that can be useful in dealing with disability, suffering, and end of life. In particular, they can reveal more complex ways to view time. This can be effective both for the person suffering and those who care for them. Our typical ways of viewing time include linear sequential clock time which progresses in a evenly-parsed ordered unidirectional way, and memory or narrative time—time as we remember it. These two ways of viewing time frequently do not agree. Since these can compete as the best predictors of outcomes in different circumstances, neither can make an exclusive claim to be “real time.” A third view of time that has potential application is one that is multi-layered, extending endlessly, and evidencing expansiveness in each moment. Examples of the usefulness of this third more complex view of time in asthma, pain, end of life and disability are presented. The arts can introduce this more complex view in a way that can help one to fold it into life. All these ways of viewing time in combination can broaden the perspective clinicians take when co-creating with patients good decisions in difficult situations.

Key Terms: time, literature and medicine, arts and medicine, visual arts, disability, end of life, pain, suffering, decision-making.

## **The complexity of time: examples in literature and film**

In a novel by Charles Williams, a woman gripped by her own internal terrors intervenes hundred of years in the past to save a martyr from his terror as he is being burned at the stake. She somehow gives him the internal strength he needs.[1] There is no time travel involved here. The two events go on, apparently at the same moment, the woman's terror and the martyr's death, and the stretching between them happens smoothly. In another part of the book, a battle takes place hundreds of years before the main action of the story, but the trauma and conflict impose themselves on the atmosphere of life in the place of the battle many years later. People from the past and events from the past interact with people in the present of the story, and visa versa.

In another part of that same novel, a building laborer suffers and dies during the construction of a house. Years later, a professor—a key character in the novel—lives there. At one point in the story the two are seen as co-inhabiting the house. “Margaret Anstruther had seen, in her vision, a single house, with two forms leaning from the same window.... Time there had disappeared...propinquity no longer depended upon sequence.”

It was my reading of Charles Williams' novels that started my interest in the practical applications of various views of time. When I finished reading three of his novels, I found myself viewing time differently in daily life, and also as I constructed medical research projects and advised others on study design. Rather than seeing minutes or days ticking by, each having equal duration, I saw the potential for expansiveness of individual moments. Interactions between various moments in life also became more visible. This was particularly relevant to clinical work with patients, and clinical research. In many ways the patients' experiences of their days were not ticking by in equal moments - their past and present seemed to be intertwined in ways that I previously had no concepts for. Williams' writing can help us to make sense of time in daily life, especially at the end of life and in the midst of suffering. The way he describes people relating to death in the context of this multilayered view of time is able to bypass simplistic interpretations of the flow of time and even death itself. I was initially surprised that a work of fiction could have such substantial practical application, and students in my classes have been similarly affected as they have read his novel. W.H.Auden, in a preface to another of Williams' novels, *All Hallows' Eve*, stated that his novels were “good reads,” and this also helps accessibility. The suspense and emotional charge of the writing pulls us in, and coaxes us to reconsider how the world works and how we act in time, providing options of relating to suffering in creative ways. This started me looking at how other works of art might similarly affect attitudes to time in this way.

In the film *Thirteen Conversations About One Thing*,[2] we enter the story in the middle, and are confronted with events in a disordered sequence. A cocky young lawyer is confident about his success in putting a criminal away; he comments on the criminal's stupidity and proclaims to others in the pub that they are responsible for their own lack of success. This scene appears twice in the film, both after and before he apparently kills a woman with his car while under the influence of alcohol. We come to know the woman's life in interspersed segments. We see both the tragedy of the event for her in the short run, but also positive influences of the event for her and for others, including the lawyer who hit her. The film has many stories of different characters going on at the same time. We move between present, past and future, mixing up the order of events, and repeating events, as the structure takes viewers beyond the sequential view of time. Using this mode, it shows how an accident and subsequent disability, which seem pointless, affect the lives of others in positive ways and link to positive parts of life at different

time points. We are disoriented in time by the film's structure; we are forced to take a less linear view of time and view the unfolding situations from a birds-eye view, not constrained by the linear. Good does not necessarily triumph in the short term. Disability, pain and suffering are put in perspective, not always by "turning out well in the end" for the particular person involved, but by fitting into a larger picture, where good extends beyond the immediate situation and spills over into the lives of others.

The arts provide a vital way to gain access to the space where neither sequentially-ordered, evenly-parsed clock time nor subjective memory gives the definitive answer. This poem, by Rainer Maria Rilke, provides another example from poetry of how the arts can inform and enrich our view of time.[3]

Evening

The sky puts on the darkening blue coat  
held for it by a row of ancient trees;  
you watch: and the lands grow distant in your sight,  
one journeying to heaven, one that falls;

and leave you, not at home in either one,  
not quite so still and dark as the darkened houses,  
not calling to eternity with the passion  
of what becomes a star each night, and rises;

and leave you (inexpressibly to unravel)  
your life, with its immensity and fear,  
so that, now bounded, now immeasurable,  
it is alternately stone in you and star.

This poem is written using a perspective that seems outside of time. This multi-layered, eternal view can help to put our more limited and more commonly held views of time in their place. In some clinical situations, such as end of life, dealing with pain and suffering, and dealing with disability, a multi-layered notion of time might be more valuable than other perspectives in understanding how patients take some views, or some decisions, and not others. The eternal perspective and multi-layered view of time can ease frustration and yield insight as medical results and decisions are conveyed and made. And in the long haul our current suffering might be seen as but a momentary burden in the big picture of eternity. In this situation we are "not at home in either one," as Rilke points out, but somehow experiencing both simultaneously. A fictional work or piece of visual art can open patient and clinician to this perspective, allowing it to permeate life and enabling them to see possibilities in the midst of limitations.

### **Three distinct views of time**

To make the best decisions regarding both treatment management and personally dealing with disease and disability we use various notions of time. How we view time makes a difference to those decisions. **Firstly**, we live in a world where the time that we keep record of with clocks and calendars, **a sequence of evenly segmented days and hours**, is often called "real" time. This time is crucial for both clinical medicine and medical research. A **second view of time**, often captured in narrative, is the retrospective view, held in the memory of the person with disability or disease. If one or the other of these views could be considered "real" time, then we

could base our decision-making on that perspective. However these two views are often mutually exclusive, and although both contribute useful information, neither can be called definitive.

A **third more complex view of time**, the one illuminated by the three literary examples above, is worth the effort of exploration. The arts may be able to illuminate this better than expository description. There are three interacting aspects of this more complex view that deserve our attention here: a) It is “eternal,” not necessarily in a religious sense but as extending infinitely in all directions, beyond what we can see or have direct knowledge of. b) The present moment is more expansive and “full of time” than we assume given its lack of clock-time duration. c) It is multilayered, in that all time may exist simultaneously when viewed from some perspective outside of time and may not flow so simply forward as it seems. This last aspect sees time as multi-layered and part of an infinite or eternal framework in multiple dimensions of space-time rather than establishing a position on a deterministic timeline, or as subjectively relative. In this view, the past, future, and present can be seen as interacting with one another and even possibly existing simultaneously.

One dictionary definition of “eternal” is “time without beginning or end; infinite time,” and this can be a useful concept here. I will be referring here to the complex view of time using the shorthand of “eternal time” or “multilayered time.” When we include this complex view, both the regular progression of minutes and days and the memories of events can be seen as tools that help us to navigate in our lives rather than calling either of them definitively “real” time. Poetry, visual art, and film provide a handle on this way of viewing time.

### **Strengths and limitations of the first two views of time**

Using multiple perspectives on time is necessary to make good decisions about care and personal decisions in many situations. For example, a particular person in the end stages of cancer needs to have some idea of the projected trajectory in days and weeks—the answer to “How long do I have to live?” But if many of those weeks are spent in a coma followed by a recovery from coma, it is as if that time did not exist for him. His family and the medical staff are very much preoccupied with calendar time. But also for him, interaction with friends and family bring the memory of his past strongly into the present situation. In this situation, time is multilayered. Memory of conflicts from long ago, and attempts at resolution of them, can take center stage in the present. In this context decisions about pain treatment, level of sedation, life prolongation efforts, and how to phrase estimated duration of life, all require a more complex view of time.

#### **Linear-sequential time**

To explore how these views of time can help us make difficult clinical decisions, let us initially look at the usefulness of various views of time. First, the clock and calendar, sequential time of everyday life: As an epidemiologist, this has been my favorite view of time. Its rigor and predictability appeal to my scientific training. One method used in epidemiology is the identification of clusters in time and space, and the accepted best way to do this is to follow a disease prospectively over time and in space, e.g. occurrences of cancer in an area around a nuclear power plant following an accident. It also helps identify likely outcomes. For example, with the skin cancer melanoma, there can be a direct relationship between the time of inception of a melanoma and the depth of the lesion, which in turn predicts the likelihood that the melanoma will metastasize and cause death. By mapping out this progression in many people, we can determine that excising a lesion early in its time course can save a life.

#### **Memory, retrospective, narrative time**

The second view of time is the view from inside the person. Narrative, the story the person tells based on subjective memory, captures some of this, but it can only capture those things in conscious awareness or those we remember or reconstruct. This second view can be essential to inform intervention in a disease such as melanoma that can lead to death if not treated early on in its course. In a study examining why so many people were dying of melanoma in Northern Ireland given the rarity of the disease there, melanoma patients told the stories from memory of their history of discovering the lesion and subsequent treatment. Many told of bringing lesions to the attention of a physician months and years before the diagnosis, only to be told that the lesion was not of significance. This helped alert researchers to the possibility that physicians may be missing diagnoses, and this enabled development of an intervention of physician education that ultimately saved lives as documented in a prospective study.[4] Experienced physicians appreciate how much of medical interview and diagnosis is based on patients' memories of symptoms and potentially causative events.

Memory, however, can be inaccurate when compared with sequential clock time, and we often assume that sequential time should trump memory in our decision-making. An example of where this might be appropriate tells that, "laboratory studies have shown that current mood states influence the kinds of memories that people tend to retrieve: in happy moods, recollections of positive experiences spring to mind more readily than recollections of negative experiences; the opposite tends to occur in dark moods." [5] In these cases memory is often deemed "unreliable." There have also been studies showing that "false" memories can be encouraged in people by various strategies and contexts.[6]

#### ***Conflicts between linear and memory time***

But the sequential view of time cannot always be considered most reliable. Implicit or explicit memory of events rather than the sequence of occurrence can drive our decisions and actions. An excellent example of this is a study by Redelmaier and Kahneman on pain during colonoscopy.[7] The study asked patients to give measures of perception of pain at various points during two different colonoscopy procedures. Then afterwards they were asked to tell which of the two procedures they would prefer to have the next time. Although procedure number one was longer and more painful than procedure two as assessed by the patient in sequential time (recorded moment to moment as the patient experienced it), it was still the procedure preferred. This was because although treatment one was longer and contained more subjectively reported pain, it had a less painful ending and less intense peak pain. The total pain as measured by minutes of pain times intensity was actually worse for the first colonoscopy. But for the patient, the memory of the distress of the procedure was not determined by overall pain—the pain was remembered as less severe overall if the maximum intensity was less and the denouement more long and drawn out. The patients' memory rather than the moment-to-moment assessment was the crucial factor that led the patients to prefer the longer procedure with the greater total quantity of pain. So although sequential time is often referred to as "real" time, our actions can also be preferentially driven by retrospective assessment. In this sense, time as seen by our memories can also be thought of as "real." The authors concluded by asking which is the real pain, that remembered or that momentarily experienced?

This work has subsequently been confirmed by others, finding that for rheumatology patients, memory of pain a week later can be predicted by the intensity of peaks and troughs.[8] In clinical medicine and health care planning, various methods have been devised to attempt to measure not only quantity but also quality of life. One way of trying to assess the value of life and to help make decisions about life prolongation measures and health care planning has been

to ask people how much time they would be willing to trade off for various improvements in circumstances. This approach to quantifying the quality of life has been shown to be sorely lacking.[9] We cannot use simplistic algorithms of intensity or quality time duration to assess the often ill defined concept of “what makes life worth living” for individual people, even though it would make life and decisions much easier.

### **Adding in the eternal, multilayered perspective**

#### ***Time at end of life***

The limitations of the two more usual ways of viewing time were brought home to me by the case of a 50-year-old man with end-stage cancer. As he made decisions about how to prioritize activities in his final days, he was facing both the abbreviated nature of his clock-time life and the unknown future. His days and those of his family were influenced by memories and unresolved relationship issues that had to be dealt with in the context of those memories. Past, present and future were crashing into one another for this patient. Like the poet Rilke, he found himself at once "bounded" and "immeasurable."

A dying person may choose to endure two weeks in pain, if that decision provides an opportunity to resolve relationship conflicts or estrangements or find peacefulness in other ways. The decision about pain management is not determined by clock time multiplied by intensity, but is informed by a more complex relationship in which the eternal perspective plays a part. In end-of-life situations, decisions based on clock time and supposedly “rational” considerations are often in conflict with emotions and feelings. Trying to oversimplify time only obscures good decision-making.

Although it is unscientific to accept specific religious beliefs as true for all, it is equally unscientific to deny that for many people, part of their world-view includes a notion of a life beyond the constraints of that which we can see or touch. Eternity as used in this article may not coincide with particular religious understandings of what takes place after death—heaven or hell or reincarnation or merging with the cosmos, for example. But many people do believe there is some kind of life after death, and this can influence how they view the time spent alive. And also, many people who do not adhere to particular faith traditions nevertheless believe that life continues in some form after death. The ways of viewing eternal time mentioned in this article can help people to combine religious views with the typically scientific views of time. In an article on the definition of health, Kenneth Boyd articulates well how important it is not to exclude the religious view.[10] A recent study of “burn-out” in professional caregivers in end of life settings showed that one of the factors most predictive of decreased burnout was a sense of ordinary spirituality that accompanied people through the day.[11] The arts can, for those with religious views or without, enlarge the possibilities of ways time might be conceived. The more complex view of time and the notion of eternity as used in this article, extend beyond the particularities of belief. Those without traditional views of life after death can still relate to the multi-layered, endless views presented through the arts, and find some usefulness of it for life choices.

### **The arts can provide ways to envision multilayered time**

An example of a person using poetry to help understand time at end of life is Peggy Rosenthal.[12] She optimistically wrote: “There is no greater gift than getting the diagnosis of a life-threatening illness while you feel perfectly healthy and are assured that you probably will continue to feel fine for several years,” which was the situation she found herself in. She

expresses how she was touched by a poem by Yehuda Amichai, beginning:

A man doesn't have time in his life  
to have time for everything....

She says "...as the poem stretches language beyond time, it stretches my being along with it. For stretching language beyond time is what poetry essentially does."

J.R.R. Tolkien, a master of creative fiction, wrote about the interface of fiction with the real, which has relevance for various views of time:

Fantasy is a natural human activity. It certainly does not destroy or even insult Reason; and it does not either blunt the appetite for, nor obscure the perception of, scientific verity. On the contrary. The keener and the clearer is the reason, the better fantasy will it make. If men were ever in a state in which they did not want to know or could not perceive truth (facts or evidence), then Fantasy would languish until they were cured. If they ever get into that state (it would not seem at all impossible), Fantasy will perish, and become Morbid Delusion.[13]

Fiction, even that which is fantastic, can highlight that which is real in practical ways, as those of us who have seen useful comparisons to our own lives in Tolkien's fantasy stories can attest to. An example relevant to this discussion of time is that although Gandalf knows to some extent what is going to happen throughout *The Lord of the Rings*, he still is not sure of it, and is called on to make decisions that might change that same outcome. Undergraduate students, on reading Charles Williams' thrilling novel, saw a way around a fatalistic world view, which many of them had adopted implicitly. Fatalism is inextricably connected to the sequential uni-directional flow, as well as other beliefs. When that narrow perspective was called into question through the novel, the students were able to consider viewing circumstances in their lives as less deterministic, and with more fluidity. As they lived through the events with his characters, they were able to vicariously perceive time in a different way.

Visual art can offer other insights into the multi-layered approach to time. Marcel Duchamp's *Nude Descending a Staircase* shows a figure in cubistic abstraction at multiple points on the descent, all seen simultaneously in the picture. What Duchamp was trying to do in this piece was part of the Futurism manifesto on painting, developed in 1909. This manifesto reveals that these artists were conflating various aspects of vision into what they called "a process of interpenetration - simultaneity-fusion." [14] Not only did these artists take various spatial perspectives on the same object and represent them in one painting, but also, as this painting demonstrates, various points in time are shown on one canvas, and we view it in one single moment. In fact, this painting was partially inspired by multi-exposure photography.

In the brochure for the 2004 Chicago Humanities Festival, Douglas Druick, curator for the Art Institute of Chicago's exhibit on Seurat's "A Sunday on La Grande Jatte - 1884", writes about the painting's radical expression of time—its paradoxical sense of the momentary and the permanent; the evanescent and the eternal—and posits that this is the key to the picture's initial notoriety and lasting fascination. This wall-sized, pastel-toned yet vivid, pointillist painting connects you both to a moment of people wandering in a park in the past, very much in history. But it can also touch within each of us something that is very much "here and now." It may be possible that the introduction of paintings such as these into a clinical setting might be able to put momentary suffering in a wider context, creating a peaceful connection through the painting and its moment in the past to an eternal sense in the present moment.

### **“What does it all mean?”**

We are continually trying to make sense of life, to find meaning in the various events and feelings and interactions. Memories of the past few days and memories from the distant past color our feelings about our bodies, our human relationships, and our desires. Our memories may not relate appropriately to our current feeling state, or to what has happened as described by linear sequential time. The arts that give an eternal perspective on time can help us to sort thoughts and feelings and enable us to make decisions in harmony with the values that give our lives meaning. Meanings and values are often implicit—we are not always aware of them.[15] The arts can help us to give form to these in a way that can help us fold these effectively into our lives, or draw them out for the person who is ill. Reading fiction, and viewing films or pieces of art can help both those who are ill and those caring for them to envision how the time of illness and even time at end of life fits into the whole of life, helping to more accurately see relative values.

### **Time in the context of chronic disease and disability**

Living with chronic disease, disability or impairment especially highlights some issues regarding time. When disabled, one of the most frustrating things is the inability to meet time pressures adequately. It takes longer to do many things when one is blind, or missing an arm, or in a wheelchair. We live in a “faster is better” society.[16] When we refuse to measure the quality of our lives by how fast we are going on the track, and envision both moments and total extent of time differently, this challenges the norm. In a book researching chronic disease and time, Kathy Charmez summarizes her views and those of others: “Being ill gives rise to ways—often new ways—of experiencing time.”[17]

The frustrations of time pressures that accompany disease, and the experience of caring for others with disease and disability, can have positive effects on our capacity to view time in complex ways. The “living fully in the present moment,” approach gives more value to the experience while we live it rather than regarding it as just something to get through. Notions such as that of Ralph Waldo Emerson, that “Each day is a miniature eternity,” can be helpful in wrapping our minds around this possible way of viewing time. It is the “smelling the roses” and reveling in the details of life like the colors of the evening sky, that can take a second of passing time and allow it to expand into something that is perceived to be something of longer duration and of great worth. Albert Einstein said, “There is something essential about the now which is just outside the realm of science.” In a book written by the spouse of a disabled woman, and filled with drawings of New York City street buildings and dirty dishes, the drawings themselves open your eyes to what can be missed if we are living the present moment just in order to get to the next.[18] It is not the text that inspires in this regard, so much as the line drawings on each page of the book, of teacups and crumpled bits of paper that are beautiful although not perfectly drawn. In the process the author shares the visual images of life with us as he works through the sufferings and metaphysical questions brought on by his encounter with disability in one he cares for. An interesting personal experiment on this front that we can all try is, at the end of the day, to run past oneself a “film” of some of the high points of the day. It is interesting to see how much passed by without much notice while it was happening. If that was “real time,” was I not there? In this way at least, we can mine in retrospect, what we missed in the moment.

The eternal perspective and multi-layered view of time can also ease the anger and frustration of disability and chronic disease, and yield insights for the medical professional, as medical results and decisions are conveyed and made, as well as insights for the person afflicted.



In disability, the “me that was fully active” is simultaneous with the “me who now can move very little.” The disability does not define me. The nature of the self is multi-layered in time, rather than merely defined by memory or sequential perception. Like the multiple self-portraits of Rembrandt, “me” is located across time and space. The arts can provide a service as they open this perspective and allow it to invade life. Returning to the *Thirteen Conversations* film example, the film’s bird’s eye view from beyond linear time could help a person deal with the seeming senselessness of something like spinal cord injury and help provide motivation to engage and live a full life. The film shows how things that may seem senseless at the time can have a positive place in a fabric of life. Seeing life as multi-layered, as part of an infinite whole, may give a perspective that enables the disabled person to better see what is most important in life for him or her, and therefore be able to make appropriate decisions.

The arts can enable us to live with apparently paradoxical situations. Poetry has a special capacity to effectively capture paradox and can put it in a way that makes it more understandable or useful to us. The visual arts can do the same. This is especially true if we approach these works with a willingness to be open. They can introduce us to ways of thinking that can enable us to handle the often paradoxical elements of time we are faced with in disease and disability.

### **Time and Asthma**

One final concrete example of the variability of ways of looking at time and their potential practical impact, is in dealing with asthma- or COPD-induced shortness of breath. Speaking from experience, personally and clinically, I know how distressful and panic-inducing it can be. And its distress is enhanced by duration in clock time. For an asthmatic, the longer severe bronchospasm lasts, the more dangerous it is to life and limb. Internally the asthmatic needs to track this clock time to estimate whether to call an ambulance or wait it out with oral or nebulized medications. In the midst of this acute awareness of clock time there also exist memories of previous asthma episodes, and the course they took. Having survived a number of these acute episodes, the person’s memory of them can soften the event, enabling him to respond to them with increased calm. But in addition, a vivid awareness of the present moment can help him to focus on the relaxation of the airways and place out of direct focus thoughts of past dangers or clock time passing. The present moment carries the awareness of other moments in a multi-layered way. And the eternal time perspective can help to remove some of the fear related to the event, seeing it all in perspective, and help create a detached state where the emotions can be more controlled. The big picture of life has a perspective-giving quality that can enable a person to transcend the immediate or remembered panic. Pulling all three views of time together can inform practical action.

### **Complexity of time for complexity of decisions**

All three views of time are important and have useful information to convey. They each can effectively guide interventions and actions when used alone in specific situations. However in some of the more complex decision-making quandaries, we would be well-advised to triangulate these views, and the arts provide a lens that can help us and those we care for to do this.

Kenneth Rexroth, at the end of Part One of “The Signature of All Things”[19] remembers his past under a summer tree:

My forty summers fall like falling  
Leaves and falling water held  
Eternally in summer air.

The arts can help us to understand more fully how we exist in time and better enable important values to be seen and concretely addressed for the person who is ill. What is a day worth? Its worth cannot be measured in hours. What gives life its meaning, and how can decisions be informed by that meaning? One exquisite moment may be worth days of suffering in the waiting for it. These are not simple equations.

Reading certain works of fiction and poetry and viewing particular films or pieces of art can provide a perspective on time that may be able to enrich our way of experiencing time, and provide a potential resource to help many deal more effectively with disability, pain, suffering, and end of life. Continuing to explore, catalog, and test the effectiveness of these resources has potential to bear fruit for those experiencing serious illness and disability and those who care for them.

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