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Tensions of time at the end (of life)

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ABSTRACT

Perhaps the most valuable asset in our cultural imaginary is time. Yet, this notion of time-as-asset intensifies, is contested, and is often derailed at the end of life. When faced with death, time can become many things, including both personal and interpersonal asset and liability. Bringing the concept of time and dying into focus, this paper draws on qualitative interviews with 15 people nearing death in an Australian specialist palliative care unit. We examine the normative expectations of time and its unravellings in their lived experiences, findings which are critical given time near death has not been extensively studied. We consider five key themes, 'agency and physical decline across time', 'negotiating the time of death', 'the relational affordances of waiting', 'resisting prognostic time', and 'the cost of waiting', all relations to and in time, that were variously woven through people's accounts of the end of life. These themes highlight connections between time and agency, juxtapositions of swiftness and sometimes interminable slowness, and how busyness and paralysis play crucial roles in the practices of dying. Sitting in stark contrast to the rather typical representation of time as a 'good' to be protected or used 'well', especially close to death, more nuanced accounts of dying-in-time emerge, highlighting tensions, troubles, and vitalities as we all collectively confront the end (of life/time).

1. Introduction

Time, writes Barbara Adam, is about "life and death, knowledge practices, and the human condition" (2006: 121). Adam (2004) conceives of time as a fundamental and fundamentally complex phenomenon around which human life is organised. However, time is often understood in more simplistic terms, as an *asset*—to be used wisely. In the words of Benjamin Franklin: "Do not squander time, for that is the stuff life is made out of." Or, in the words of James Clear's now ubiquitous self-help book, *Atomic Habits*, adorning so many shelves and coffee tables, "Time magnifies the margin between success and failure. It will multiply whatever you feed it." Time, we are told, is precious, yours for the taking, and must surely be maximised (Wajcman, 2008).

The logical progression from this cultural valorisation of time as an asset (cf. Preda, 2013) is the pervasive notion that the end of our lives should centre on making the most of the time we have left; that we should 'use' this time to enact the crescendo of our life and intimate relationships in socially meaningful ways (Heidegger and Krell, 1978). The quality of one's 'dying time' appears to approximate the value of the person and the life they have lived. If we don't treasure this time – demand more and 'fight' for it, even (Sontag, 1978; Seale, 2001, 2002; Stacey, 1997) – then ostensibly we don't value the individuals involved, or so the cultural imaginary of dying might hold. We define 'cultural imaginary here as the 'collectively held and often unquestioned beliefs, values, and ideas about what ought to be' (Schelly et al., 2021: 2). As a result, our dying moments often become an accentuated site for matters of, and the mattering of, time, raising the stakes for the moral practice of 'using' one's time left, maximising its duration and actively determining its content if only for the sake of those close to us. Despite the aforementioned cultural valorisation of entrepreneurially and agentically framed *optimal* time, there are many problems with this view of time-as-asset, which become acutely visible in the context of death and dying. This article seeks to bring the concept of time into focus by drawing on qualitative interviews with people close to death to explore how time is lived and understood in the final days of life, an area that has not been extensively studied, and as such deserves renewed attention. Comprehending time, in its full lived complexities, we argue, will be critical for ensuring informal and formal carers are aware of, and resist, the pull of simplistic cultural imaginaries.

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2. Background

One prominent paradox of/in time in the dying process is the valuing time-left vis-à-vis the lived realities of waiting: that is, the (sometimes) slow march of dying time and the waiting involved. The capacity for waiting as a cultural practice is often diminished in the accelerated economies of late modern life (Wajcman, 2008; Siegrist et al., 2004). Yet, dying is so often *all* about waiting—whether that be in discomfort, in uncertainty, or sometimes in celebration of a life well lived. Whatever the 'content' of waiting, waiting for death induces logistical, affective and relational tensions. That is, at least for some—carers and people who are dying alike—waiting is intolerable and an accentuation of things we'd rather rush through, speed up, and even look away from. The waiting of/for dying can be cruel and kind (Berlant, 2011) and everything in-between, offering up, as Ghassan Hage (2009) notes, the strange bedfellows of both a lack of control *and* agency:

> At the most immediate and superficial level one can rush too quickly to say that waiting is a passive modality of being where people lack agency. Waiting at the airport to board a late plane, waiting for an appointment with a medical specialist or waiting on the highway for a mechanic to come and fix our car all involve a large degree of passivity: things are beyond our control, out of our hands, and we can 'only wait' for what we wish to happen, as opposed to actively doing something or another to make it happen. Yet […] there are many cases where agency oozes out of waiting. It is not surprising therefore that the question of agency in relation to waiting is a hotbed of ambivalence (Hage, 2009: 2)

This ambivalent tension between waiting and agency inhabits life acutely at its ends, flowing through the embodied experiences of dying as much as in anticipation of birth at life's beginning (Kowal, 2009).

The temporal management of death, and the tensions of waiting and agency therein, reflects an important part of what Elizabeth Grosz (2004) calls the 'temporal economy'—articulating the organising (time-centred) norms which inhabit subjects (and subjects inhabit) as well as practices of resistance therein. For instance, the concept of the 'good death' (cf. Collier and Chapman, 2023; McNamara, 2004) has routinely been infused with notions of *enough* time but not *too* much (not 'too drawn out', not 'lingering', not suffering for 'too long'). In the pursuit of the 'good death', the art of waiting also becomes a moral imperative and virtuous activity, illustrative of 'good patienthood', being a 'good carer', even 'good care' that is neither overly interventional nor overly laisse-fair. To rush death is to be callous but to draw it out is to be cruel—a Catch-22 of the palliative/dying milieu (Lawton, 2002; Pollock et al., 2024). Time and its moral contours are omnipresent in dying; time is on everyone's mind and yet often unspeakable ('when will it end', 'how long have I got', 'can we speed it up'). Whilst a distant observer might with confidence say these times can be measured as 1 week, 1 day, or however many hours, quantified duration often has little connection to its temporal 'feel' and how it is experienced by those bound together in waiting.

Such intensities around time in the context of dying render the practice of waiting and *waiting time* as an evaluative measure—whether implicit or formalised. This temporal evaluative 'feel' imbues dying, with *time taken* used to assess the relative 'success' of *all* subjects in the choreography of death (patients, families and professionals alike), in relation to the normative frames and expectations of the 'good' death (Collier and Chapman, 2023). Death is often talked about and evaluated by the collective, —'mercifully quick' or 'painfully slow', or 'long enough to say goodbye'—with lay and professional evaluations often resting on the (admittedly impossible) tightrope walk between avoiding lingering and orchestrating timeliness. Such an understanding reflects Hage's contention that "waiting is not only shaped by the person waiting; it is also shaped by those who are providing whatever one is waiting for" (Hage, 2009: 3) This time is thus intersubjective.

The relational experience of being *in* time at the end of life is also mediated by forms of privilege and marginality (Tobin et al., 2022). Whose time *matters*/is valued is bound up in relations of gender, class, ethnicity, race, and their intersections (Greer et al., 2021). The end of life is no different, necessarily contoured by structural conditions that can influence who is worth waiting for, whose life is worth extending, and to what degree people feel valued at the end of their life. Whether situated in formal structures (i.e., whose family has the assets and work-related entitlements to visit and care at the end of life) or informal structures (i.e., who has the cultural capital—or literacy—and capacity to access supportive care, welfare and so on), the politics of time in the last few weeks and days is inseparable from structural dynamics, particularly the broader politics of waiting. Hage attunes us to this idea when he notes:

> The multiple and ambivalent forms in which agency takes shape in relation to waiting render it a particularly unique object of politics. There is a politics around who is to wait. There is a politics around what waiting entails. And there is a politics around how to wait and how to organise waiting into a social system. Waiting can, for example, define class and status relations in the very obvious sense of 'who waits for whom', which also means: who has the power to make their time appear more valuable than somebody else's time? (Hage, 2009: 2)

As we explore below, the politics and moralities of time render the lived realities of death and dying as simultaneously both deeply biographical and structural. In our engagements with interview participants, for instance, the experience of lingering and limbo are deeply embedded in their personal experience of value, entitlement (for care and celebration, and a life well lived), and sense of (ongoing) worth. That is, the final days and how this time is viewed and treated are always inextricable from broader social and cultural factors, contouring how life and death are conceived and lived-out to the end. The dominating idea of time-as-asset fails to capture these complexities and interferes with comprehending more nuanced (and complicated) lived realities of how time is experienced at end of life.

3. Methods and analysis

This qualitative study explored the experiences of 15 people receiving care at a specialist inpatient palliative care unit/hospice, focusing on those within the last few weeks, or in some cases days, of life. The palliative care unit was part of a sub-acute care hospital, and ethics approval was granted by the hospital ethics committee. The palliative care unit has 20 beds, and people receiving care at the unit, including those who participated in this study, had received diagnoses of various life-limiting illnesses, most particularly forms of cancer or chronic obstructive pulmonary disease (COPD). In Australia, the average length of stay for patients admitted to palliative care units such as the one at which this study was conducted is 11 days, and 3 in 5 people admitted to palliative care units are aged 75 or above (AIHW, 2024). In this study, participants ranged from 61 to 84 years of age. Of the 15 in-depth interviews completed, 6 of the participants were male and 9 female, and of the 15 participants, 13 were Anglo-Australian.

The criteria for recruitment were that the participant was over 18 years of age, was an inpatient of the unit, was cognitively able to undertake an interview, was not in significant pain, and was capable of providing informed consent. Clinicians made informed decisions based on their knowledge of the people in their care as to whether they fit this inclusion criteria, paying particular attention to whether they were cognitively able to undertake an interview and not in significant pain. If deemed appropriate by the treating clinician, participants were approached by their treating clinician who provided an information sheet and, if the participant agreed, contacted the lead author. The lead author then spoke to the participants in more details about what was involved, and then gained informed consent and completed the interviews. It was emphasised (in written and verbal communication) that non-participation or withdrawal from the research project would not affect any ongoing clinical relationship with other members of the research team. All interviews took place in the participant's own rooms in the unit, and lasted between 30 min and 1 h, depending on onset of (additional) pain/tiredness. Interviews were loosely structured, exploring the following broad concerns: a) experiences of/at the end-of-life; b) issues of identity and social relations at the end of life, c) experiences of being cared for, both formal and informal; and d) experiences of social change and evolving institutional practices in shaping end of life experiences.

Data analysis was informed by Charmaz's (1990) approach to qualitative analysis, emergent from the principles of constructivist grounded theory, as well as quasi-deductive approaches to qualitative research analysis (Robinson, 2001). The process of analysis was iterative, beginning during data collection and providing an opportunity to establish initial themes and look for other similar or divergent cases, complicating our initial observations, and retaining the complexity of the data. While an interview schedule was used across interviews informed by thematic grouping of questions, we ensured that the semi-structured nature of the interviews allowed for participants to move the interviews in various directions, in line with what Trundle et al. (2024) term an 'ethnographic disposition' in qualitative interviewing. After the interviews had been transcribed, we approached the analysis initially by systematically reading through each interview several times and noting patterns within the data collected. Within this process, we continually sought to retain the complexity of the respondents' experiences, documenting atypical cases, conflicts, and contradictions within the data. Once we had identified a theme, we would search through the transcripts for other related comments, employing constant comparison to develop or complicate these themes further. This process meant that events that we initially viewed as unrelated could be grouped together as their interconnectedness became apparent. The final step involved revisiting the literature and seeking out conceptual tools that we could use to make sense of the patterns that had been identified in the data. All data presented here uses pseudonyms in line with participant's requests for anonymity.

4. Results

We now turn to the qualitative interviews to explore five key themes related to how time is experienced and understood in the last weeks and days of life. We highlight how participants experience time across five key themes; 'agency and physical decline across time', 'negotiating the time of death', 'the relational affordances of waiting', 'resisting prognostic time', and 'the cost of waiting'. (p. 7).

4.1. Agency and physical decline across time: '… the end of that part of my life'

> Audrey: [the body is] not playing the way it should. I mean, I put music on and my feet will start wanting to dance …

Audrey, a woman in her eighties, had been the primary carer for her husband before she was diagnosed with a terminal brain tumour. She drove him to his medical appointments and looked after their garden and home. When we spoke to Audrey just a few months after her diagnosis, she was unable to walk. Time, for her, had moved swiftly into her final days and yet was now glacially slow. "*Well, I want it all to be over. I'm sick of it. <crying>",* she said when the lead author stepped into her room. Unable to reach the glass of water placed on her side table by the nurse, the pain of losing this ability was obvious as we undertook the interview. She did not want it handed to her, but wanted 'it' —her life—to end. Time often presented itself in terms of the swift sense of falling into the last few weeks and days, and few were prepared for this. Audrey, for example, went from being illness- and disability-free, living a "normal life," and caring for her ill husband, to not being able to move her legs. She woke up one day and not only could not move, but was also suddenly aware of her death nearing:

> Audrey: There's a lot going on in my life […] Yeah, so everything happened with me from June. I went from being able to mow my own lawn, doing everything, changing light bulbs, because my husband couldn't do it. I've gone from that to someone that can't even get out of bed. <crying> It's just frustrating.
>
> Interviewer: Incredibly [frustrating].
>
> Audrey: It's just so frustrating. I mean, I might just want something from that table [points to side table] and there's no way I could get there. The other day I thought, "I've had enough of this. I'm not going to have all my life lying on my back looking at things," but I can't walk because this leg.
>
> Interviewer: And this has happened in a very short period of time.
>
> Audrey: Yes, since June.
>
> Interviewer: I mean, that's literally just a few months.
>
> Audrey: It is. I just woke up one day [and this happened]

For Audrey, the rapid pace of the loss of her mobility was intimately entwined with her sense of diminishing agency, an experience she repeatedly referred to as "frustrating". Having gone from someone who could mow the lawn to someone who "can't even get out of bed" within just a few months, the speed of Audrey's physical decline was striking. A similar scenario confronted Barbara, who suddenly collapsed during a routine day shopping, to never return home and be living her final days in the palliative care unit. Barbara, also in her eighties, recounted the moment when her legs gave way at the supermarket:

> Barbara: It has happened quickly. I could feel my leg getting weaker, and I probably shouldn't have gone to the shops that day, but we went anyway, and we were just walking and my legs just gave way and I just fell to the floor and that was the end of that part of my life.

During the conversation, the speed of Barbara's physical decline was the overwhelming sensation to which she returned, and her telling of her time in the palliative care unit was accented with descriptions of time stopping and parts of her life ending:

> Barbara: Okay. So how does it feel for me [being palliative]? It's totally life changing because I'm going to be in a chair, I'm not going to be able to physically stand up and do anything. I can't - <crying>
>
> Interviewer: It's okay.
>
> Barbara: Sorry.
>
> Interviewer: Don't be sorry.
>
> Barbara: I can't do anything. Now I can't even just get up and go to the toilet, I can't get up and go open the blinds, get a drink of water. That part of my life has stopped
>
> Interviewer: Don't worry about me. I'm happy with the tears. It's fine. I just want to hear what's going on for you.
>
> Barbara: It's just I don't know how I'm going to cope, but I'm being positive about it. I know that I can't do those things and there's no good worrying about it. I have to learn to do things differently […] physically, I feel well. It's just that I can't walk and it's just made that whole, big difference.

When asked to talk more about the sensation of parts of her life stopping, Barbara responded that, "*you notice that when older people are dying, they say about the clock stopped. You think they're just stories, but these things do happen at the end of things."* She gave the examples that within a very short space of time she had stopped driving, stopped walking, and the plants in her garden "won't even grow". She summarised this series of sudden endings by saying that:

> Barbara: It's just snowballed. It's just ridiculous how fast this has developed.

> Barbara: I'll just say this […] I feel like I've lost control of what's happening to me. You know? I just feel like someone else is totally in control and this is a watershed [moment]. It's a huge change.

Susan also described her path to the palliative care unit as one of swift decline. She, like Audrey and Barbara, understood the pace of her physical decline as being connected to her sense of agency:

> Susan: Yeah. Life, you mean? I had a good life. I lived in a, I lived in a nice little cottage in amongst the gum trees and the koalas.

> Interviewer: And then what happened? What happened that moved you in here?

> Susan: Out of the blue, I lost my, my ability to do things. I woke up one morning and I thought, "What's up with me? I haven't got my full ability anymore." I knew that but …

> Interviewer: Did you, did you know much about palliative care before you came in here?

> Susan: Not really, no.

> Interviewer: What did you know? What, what was your understanding?

> Susan: Well, it was end of life, you know. Once you get into a place like this, it's more or less your end of, end of life, you know. That's, that's my understanding. And I thought, "Shit! I'm in a bloody place where all the, all the dead readies are." Yeah.

Susan's sudden, "out of the blue" physical decline propelled her to consider the speed of dying. Susan had quickly moved from a place in the bush to what she saw as a place where everyone was 'readying' for death to arrive. For Audrey, Barbara, and Susan, rapid physical decline and a 'crash' into the palliative care unit were entangled with experiences of losing control and agency, evidenced in their reflections of moving from gardening, mowing the lawn, and living independently to not being able to walk or get out of bed and finding oneself in a place which represented, in Barbara's case, a series of cascading endings, and in Susan's case, the place where "dead readies" reside.

The initial-onset 'speed' of dying was often accompanied by a jarring form of limbo and, for some, a relation of lingering (explored below). The palliative care unit, and entrance into it, often "hit the brakes" on the swift and out-of-control acceleration into death, through acts of (temporary) stabilisation. While Barbara noted in her comment above a loss of control as related to the swiftness of physical decline and an acceleration towards death, other participants experienced challenges to their sense of agency when faced with this emergent slowness or institutionally-supported lingering. Both out-of-control acceleration and the sense of being in limbo (between life and death) were part of the tussle and trouble of the scene.

4.2. Negotiating the time of death: ' … gone in 48 hours'

For some participants, an experience of lingering prompted requests for help from professionals to 'speed up' their dying process, an increasingly common request in the authors' current context, given the recent legalisation of voluntary assisted dying (VAD) throughout Australia. We note, however, that we speak here not about VAD specifically, but point to the everyday, informal requests to be eased into death—those often messy practices of soothing, comforting, and sedating, which all form part of the complex scenes of life at its edges, whether in formalised clinical guidelines, or simply 'in clinical reality.' Yet, these practices remain fraught and tense. For example, John said:

> John: I'd rather it sped up rather than slow down, I think. It's, you know, I've done the advanced [care] directive and said no to all the life-prolonging actions that could be performed. But, you know, of course, there are limits on doctors. They're not gonna give me a pill to put me to sleep permanently. But, yeah, I think, as I originally said, if it was inevitable, then there's no point hanging around.

Another participant, Steve, described how his father's death had been hastened and that when he brought this up with his palliative care team, he interpreted their response as pushback in relation to the religiosity of the institution:

> Interviewer: So, what's the plan from here?

> Steve: Well, I can't get [it] out of them [what the plan is for me]. I might have upset them in here yesterday because they're religious [and I asked about speeding up my death] … But I know when my old man went down, they just increased his morphine until [he died]. […] But I asked them about that and they said, "No, no, you can't do that anymore," and I think because they're a religious side to the church arm, I think they don't like doing that.

Steve continued by saying that he would be *"quite bloody happy to go home and take a few days [to die]. It'd be all over then … but anyway, we'll see what they [the care team] come up with. They might have a meeting tomorrow. It's just a drag on …"*. For Steve, who had undergone treatment for a life-limiting illness for two years before moving to the palliative care unit, the limbo of his decline led to a desire to attempt to negotiate the timing of his death. He shared how specialists had prepared him for slowness, *("they said it would be slow, said it's started off as only slow proceeding, said it could skyrocket or it could just doodle along like that for ages"),* but that he nonetheless experienced this lingering time as drawn-out, a "drag on", bringing with it relational risks. Steve's experience of the treachery of slowness was very much centred on concerns around how others would respond to what he understood to be the burden of the drawn-out death, with fears that the love and intimacy of partners, family, and friends would suffer from the dying process, and he would end up being "hated":

> Steve: My wife's cousin, he died of bloody motor neuron disease. You don't want to get that.

> Interviewer: No, you don't.

> Steve: His wife said she ended up hating him in the end before he died because of problems all the time. Looking after him, she could never get any rest. […] And so, I said to my wife, "I don't want you bloody hating my guts by the time I leave [die]."

> Interviewer: What did she say?

> Steve: Yeah, she knows after seeing what he went through. So anyway …

Similarly, Paula reflected on the relational strains that might eventuate through a lingering death. She told us that her decision to reduce active treatment for her life-limiting illness was related to not wanting her daughter to see prolonged suffering:

> Paula: The specialist said to me he couldn't guarantee me any time. So I thought, "Well, why put my daughter through watching me be very, very ill?" I thought it might be best to do it [cease active treatment].

For Paula and Steve, attempts to negotiate the time of death were intimately intwined with a sense that waiting or lingering could have costly impacts of their relatives, as seen in Steve's concerns about being "hated" by his wife and in Paula's wish to shield her daughter from watching a process of illness and physical decline. Here, we see how time at the end of life is relationally implicated (intersubjective, as we noted above) and not just felt and experienced solely by the person who is dying, leading to complex negotiations of how it will be lived (out).

4.3. The relational affordances of waiting at the end-of life: ' … a good opportunity'

A central reason to critically explore time at end of life is to capture the vitality of diversity in lived experience and thus work against any simplistic assumptions about the contours of death. In much the same way that notions of time as an asset jarred with many of the experiences above, experiences of 'lingering' were similarly polysemic. For some participants, waiting at the end of life was experienced as a "good opportunity"—offering time to share intimate moments with loved ones, celebrate the completion of a life, or organise one's affairs. This was hardly straightforward but was also *appreciated time*. For example, while Audrey acknowledged the difficulty inherent in raising the topic of her death with her family and friends, saying that often *"they don't want to know about it sort of thing",* she ultimately expressed that the waiting time allowed her an opportunity to communicate love, as her own mother had previously done:

> Audrey: Well, I get teary too. Yeah. But it's a good opportunity. You can tell them how you feel about them. When you know something's happening, you can tell people how you feel about them and let them know that you love them.
>
> Interviewer: It's an opportunity isn't it?
>
> Audrey: It's so often you hear about these people that get murdered. They haven't had the chance to tell their family how much they love them.
>
> Interviewer: Exactly.
>
> Audrey: And it means a lot. It means a huge amount. Yes. So, I've been fortunate that I've been able to do that. And I've written things. I've got a couple of books that I just jot down what's happened that day and let them know that I love them. Yes. ….[later] When my mum died, it was 23 years ago now, but it was weeks afterwards I was going through - Mum always kept a diary. Not a written [record] of every day, but the dates that she had things on. Anyway, I was going through this diary ages after Mum had passed away and I found "I love you" written in it. And that's why I want to write these, because it was ages [ago] and it was lovely. <crying> Yeah. So that's why I thought, "No, I'll let them know how I feel." […] So no, you've got to tell the people you love, you love them. It's not a sign of weakness or anything.

Here, Audrey, who initially faced a very swift physical decline and rapid entrance to the palliative care unit, discusses how waiting to die had afforded her an opportunity to write messages to her family and friends, highlighting that though there is a cost to waiting, there is also an opportunity in that time. Another participant, Paula, told us how she had been encouraged to write letters as well, saying "*my son-in-law, he said that I should write letters for special occasions and things like that.*" When asked by the interviewer if she had taken up her son-in-law's suggestion, and how it felt to write the letters, she said she had written "*a couple*", then hesitated, stating that, "*oh, well it's sad. It is quite sad*". When the interviewer followed with "*hard on you?",* she replied, "*yes, it is.*" We might complicate the notion of relational affordances and opportunities in waiting at the end-of-life by questioning from whom these affordances emanate, and whether there are normative expectations at play, in this case in the form of a relative's suggestion for Paula to 'use' the time she had left in a 'positive' way by writing letters to her relatives.

Further still, other participants relayed how waiting at the end of life provided opportunities to plan their departures in specific ways. Chelsea, for example, who was in her sixties and whose spirituality had become increasing important to her as she approached death, shared that while waiting to die she was actively planning her "*celebration of life*", something which her children were *"grateful that I have done":*

> Chelsea: It actually felt uplifting, if I can say, because I know … Here I go <cries>. I know where I'm going when I've passed. I'm a very spiritual person and I just know that my dad and my brother will greet me when I'm, I'm gone. I'm actually gonna do a eulogy as well for my celebration of life, is what I call it, and it's gonna be filmed. I'll get my daughter to, or the guy that's arranging all of the, the video and music, and, and all the rest of it, to do it, so I can just say my last piece.

Barbara and Kate also discussed how they were organising administrative aspects of their deaths, such as power of attorney documents, funeral planning, and even cancelling the phone-carrier plan (Telstra), to ease the potential burden on their respective children to navigate these tasks after death:

> Barbara: I've been trying to get everything done. I was trying to get all my paperwork in order before I got to this stage, because I knew this stage was coming, up to a point. Not the inability to do anything, but I was trying to get all my paperwork in order, made the will. And I didn't have the power of attorney and all that done, but it's done now. But I didn't have it done, but I was trying to get all those things done so that it was easier for them [the children]. So, I think that's why a lot of people prepare their own funerals these days, because the kids don't know [what to do].
>
> Kate: I'm happy I have the time to sort out some business stuff too. I'm the one that handled all the finances at home. My older son's taking over all that. But there's still things that have got to be done, like Telstra for instance, and the car is in my name, and things that have got to be done, still. It's good that I can help them do that now, rather than they have to deal with that later. I'm finding anyway.[…] I said to the kids, "You've got to remember, I've had a really good life. I had a lovely childhood, I had no worries about being beat up and malnourished."

In her statement that "*it's good that I can help them do that now*", Kate echoes Audrey's comment that waiting at the end of life can be understood as a *"good opportunity"*. Importantly, for these participants, experiences of waiting at the end of life as being uplifting, time for clarity, organisation, or celebration, are intimately tied to their sense of value, of having led a life 'well lived' *("you've got to remember, I've had a really good life"),* their support from others, and to the material conditions within which they were spending their final days.

4.4. Resisting prognostic time: "I'm going to ignore that"

Another intriguing dynamic around time was one of resisting institutional or prognostic time. Some participants talked about enjoying time left despite calls to be preparing for the end, and others actively challenged predictions (from professionals and family) about time-left. These orientations to time pushed up against perceived institutional perceptions (here to die) and personal ambitions (here to live). One participant described this sense of institutional time in reference to the "eye-roll" that she received from staff when challenging prognostic timeframes:

> Louise: I might be being a little bit more optimistic than what the doctors are. I mean, because you've got to believe the doctors. But when I've asked them approximately how long, they roll their eyes and say, "We really don't know." But when I said, "Well, I'm going to be here for two years," and one of them just rolled their eyes again and I thought, "Oh, I'm going to ignore that." Because what else can I do? … I mean, it's going to happen one day, sooner or later, so I'd rather it was later. So, maybe I'm just being over - I don't know what the word is. Over impractical.

Here, the implicit assumption that death is soon approaching (although without being explicitly spoken about) clashes with Louise's assertion that she will "be here for two years", with the eye-roll encapsulating the contested nature of time in this moment. Louise continued:

> *Louise: But anyway, I mean, I consider myself lucky, and I don't believe the doctors when they say I've got two years at the most to live. So, that's what I'm working on at the moment. I'm trying to keep positive.*
>
> Interviewer: Who said to you that you've got two years to live?
>
> Louise: The doctors basically said, when I said, "How long?" and they said, "Well, we can't guarantee you more than two years." I said, "No." Because I'll be 80 in two years' time. I'm going to see that. I'll be 40 years married in two years' time, so I want to see that through as well.

Louise's simple "no" demonstrates how time in a palliative care unit is not a stable phenomenon, but is instead embroiled in relational struggles such as negotiation, or, as in this case, resistance and refusal. While resisting prognostic time was, for Louise, an affective and assertive move—maintaining that she would 'see (time) through' to her 80th birthday and 40th wedding anniversary—for other participants, such as Chelsea, the body resisted the time of the institution. When the lead author spoke to Chelsea, she was mobile and valued day visits to see her family and friends, saying that such outings to attend birthdays and appointments were permitted by the unit, yet that "*they [staff] turn on me with that*". When asked to explain more, Chelsea told him about a time when she had felt pressured into returning home:

> Chelsea: And what I think they don't understand here is, you know, they say, "Well, you look well," you know. "You get around." And I have to; otherwise, I'd go stir-crazy. But I'm not a true, palliative-care patient. So, I left a couple of weeks back. I went home on the Saturday and I actually felt like I was bullied into going home. And I stated that, and I said, "And I don't use that term lightly." Nothing was ready for me[…].
>
> Interviewer: So, let's, let's wind back a little bit. Why do you think you were pushed out? What happened? What was going on?
>
> Chelsea: Because I'm not, because I'm mobile. Pretty much because I'm mobile.
>
> "Am I not dying quick enough?" is what I said to them. That's what I said. "Am I not dying quick enough for you?"

For Chelsea, her mobility represented a rupture in the time of the institution, whereby her presence in the palliative care space was underscored with a sense that she was "*not a true palliative-care patient*" because the pace of her physical decline and time-toward-death was not accelerating in a way that might be implicitly expected. Chelsea summarises this feeling of being 'out of time' with the time of the institution through the exclamation "*am I not dying quick enough for you?*". Through both Louise's affective response to staff regarding living beyond prognostic time and Chelsea's mobility, we see how institutional or prognostic time is something which both seeps into the everyday of the unit but is also actively resisted.

4.5. The cost of waiting: "I don't have much of a choice"

For some participants, waiting at the end of life came with significant emotional and financial costs.

Evelyn, for example, entered the palliative unit swiftly, and then her condition became stable, or in other words, she entered a period of waiting. She described her situation as one of being "in limbo", and her history of post-traumatic stress disorder and financial struggles were deeply implicated in her experience of waiting as one of distress, rather than it being a "good opportunity". When asked how it felt to be in the palliative care unit, Evelyn replied:

> Evelyn: How do I feel about being in it? I feel like it's, I feel like a person like me that's struggled to get my autonomy, I feel like it's really restrictive. I think the time, I think it, I think that directly relates to my soul, I feel. My soul hasn't been fulfilled yet by being locked-up in here.
>
> Interviewer: Is that how it feels; [Yeah] it feels like being locked-up? Do you feel like you have a choice to be here?
>
> Evelyn: Oh, well, I don't have much of a choice, financially. If I want to go into aged care, I'd have to pay for it. And I'd have to pay a lot of money for it. […] I feel pressured. I feel very pressured to come up with some sort of an answer that's going to compliment them [the palliative care unit].

For Evelyn, an extended period of waiting for death—which had resulted in conversations about her leaving the palliative care unit without a clear plan of where to go—manifested as pressure rather than a period of time that afforded opportunities. For Barbara, who had been the primary carer for her husband until she arrived in the palliative care unit, extended waiting time was experienced in terms of loneliness. Having cared for her family, she found that no one was accompanying her in her waiting for death.

> Barbara: I did the driving, the shopping, everything. And then for the next five years I basically, even though I could hardly get around myself, I looked after him and I was there for him for everything. I'd take him to the doctor's, make all his appointments, do his cooking and cleaning, and whatever. He had someone helping him, and now that I need help, there's no one. He can't help me anymore. But the family, even his family, weren't helping him. It was just me, and I was able to do it and happy to do it. And now that it's my turn, there's nobody. That's what hurts.
>
> Interviewer: It hurts a lot. And it's actually an extremely common gender story as well.
>
> Barbara: That's the worst. <crying> That is the absolute worst

In Barbara's statement that "*now that it's my turn, there's nobody*", it is evident that periods of waiting or lingering at the end of life can be painful if the waiting is unaccompanied. Her history of gendered care for her husband and family made the loneliness of waiting time especially difficult. In contrast, Audrey told us how her family had taken the care load once she arrived in the palliative care unit, something she reflected on as a lucky experience:

> Audrey: The kids are good and they're helping. Making sure that my husband's got meals and the washing's done and the house is cleaned. And, I mean, I'm very lucky in so many ways. Because there are families that couldn't care two hoots about their parents.

Here, there is a striking difference in how these women reflect on their final days, and it is important to bring attention to how structural differences such as gendered care burdens in the case of Barbara and financial insecurity in Evelyn's case are known and felt, impacting the lived realities of how waiting time is experienced differently at the end of life.

5. Discussion

The fraught issue of time at the end of life is not a new area of concern or focus. Many scholars have discussed it, families wrestle (and often 'bargain') with it, professionals seek to manage it through navigating "clock time", and people have to live with/in it (Scruton, 2012; Pasveer, 2019; Gupta et al., 2022). Time is experienced subjectively, and this subjective understanding is always-already embroiled in how the "human condition" is lived and felt (Adam, 2006). For some, time drags along, for others, time speeds and careens ahead. As our participants demonstrate, time at the end of life cannot be considered in singular or linear terms. Further, experiences of time surrounding death and dying may be different in other locales outside of a specialist palliative care unit, the purview of this study. Previous work by the authors has shown how space and place condition experiences of death and dying in particular ways (Collier and Broom, 2021). Yet, whether in a palliative care unit, at home, or in other spaces, certain simplicities and normative constraints have dominated how time at the end of life is thought about. In the broader cultural sphere, time is conditioned by certain normativities and positioned as that which must be productively optimised—used wisely and in line with certain conventions or expectations (Ehlers et al., 2024). In such a context, where time is figured as an asset, 'time left' at end of life is afforded often-unquestioned value. Added to this, in both social and professional/clinical arenas, ideas about the importance of *not* lingering or acquiring *more* time are elevated in relation to death. What is often not captured in many scholarly accounts or appreciated in broader understandings, however, are the *complexities* of time: the ebbs and flows of time at end of life, the enactments of agency within times of waiting as death approaches, and the unique contours and problems of/in time that individuals face. Limiting our ways of conceptualising time is problematic for a number of reasons.

In the first instance, reductive or simplistic ideas about time can enact harm. When they implicitly or explicitly inform clinical guidelines, such approaches to time have the potential to assume certain trajectories have inherent value whereas others do not. Of perhaps more concern, especially in the context of legal changes such as the rise of VAD, is the idea that if dying time is deemed 'unproductive' and lingering viewed as a cost rather than opening up other realities or possibilities, considerable cultural consequences emerge.

Second, social factors condition time at end of life; how people experience this time and whose time is viewed as valuable is inevitably impacted by broader cultural factors and relations of power. We have marked specifically how gendered expectations can condition how dying time is experienced: for instance, if women are positioned as primary caregivers, this can mean that such care is absent in their own final days. While not evident in our sample or addressed directly in this paper, further social factors such as race, class, and access to health care may impact how time is experienced and valued and deserve further attention. The disparate impact of income inequality, cultural literacy (and subsequent capacity to advocate for specific needs), and access due to demography, race, and ethnicity, can lead to vast disparities in the (times of) end of life (Buck et al., 2020; Gao et al., 2011). For instance, a systematic review of studies of adult patients in the UK, Australia, New Zealand and Canada receiving inpatient, day, outpatient and community hospice care, found that minority groups are less likely to receive this form of care than majority populations (Tobin et al., 2022). In Australia, First Nations people are less likely to receive palliative care, as are people with an informal carer from a non-English speaking background. In the UK, South Asian and Caribbean/African groups are under-represented in specialist palliative care (Tobin et al., 2022: 145). Moreover, there is lower hospice/palliative care available for people living in areas of lower socio-economic status or in rural and deprived areas, simply due to resourcing. among other factors (Collier and Chapman, 2023). Given these complexities, there is a need then to question whose dying time is actually valued if time at end of life is not recognised (and cared for/attended to) in the first place through specialist care. Dedicated time to die is indeed a certain kind of privilege that not all can access.

6. Conclusion

Through exploring the accounts of our participants, it is clear that rather than being simple, singular, or linear, time at end of life is instead marked by a range of tensions. Our participants demonstrate how time at the end of life can be variously experienced as an opportunity, a cost, and a tension – sometimes concurrently – to be negotiated in particular and complex ways. Returning to the cultural imaginary of dying time, the complexities of time highlighted by our participants are often erased through the culturally fetishised narrative of the peaceful, timely death, surrounded by loving family and friends. Such valorisations of company and depictions of the 'timely death' do little justice to the *lived unfolding* and the *felt occupying of time* in relation to dying. Even when individuals are able to access specialist palliative care, we see the *multiplicities* of felt time at end of life. Time can appear (and be felt) to stop, but simultaneously rush forward with a sudden or quick decline that might then be temporarily stabilized in palliative care. Alternatively, time might move interminably slowly, drawing out seemingly exponentially and producing concerns about relational strain—that is, the effects the long lingering death might have on those close to the individual who is dying. Simultaneously, such lingering can lead to a desire to speed up time, to resolve the waiting through intervention. These ambivalent experiences of time are countered with other views, such as appreciating time and its affordances or resisting the ostensible tyranny of time as it is 'contained' in prognostications of 'time left.'

A renewed focus on time at the end of life as being a subjectivity, and far from a linear or 'stable' experience, is particularly important not only in order to bring to the surface the lived experiences of those nearing death, but also to open space for healthcare providers, carers, and families/people close to those who are dying to be aware of and resist the pull of dominant cultural imaginaries of time as an asset when supporting people at the end of life, a narrative which may enact harm by assuming certain trajectories have inherent value whereas others do not. Ultimately, what becomes evident through this analysis is a need to question the dominating narrative of 'time left as a valuable asset' and instead ask: for whom, under which conditions, and when is it not?

CRediT authorship contribution statement

Alex Broom: Writing – review & editing, Writing – original draft, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Katherine Kenny:** Writing – review & editing, Writing – original draft, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Nadine Ehlers:** Writing – review & editing, Writing – original draft, Conceptualization. **Henrietta Byrne:** Writing – review & editing, Project administration, Data curation. **Phillip Good:** Writing – review & editing, Resources, Investigation, Funding acquisition.

Ethics approval statement

This study has received ethics approval from the St Vincent's Health and Aged Care Human Research Ethics Committee and the St Vincent's Hospital Human Research Ethics Committee.

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The data that has been used is confidential.

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