Stakeholder perspectives on the term 'time toxicity' to describe healthcare contact time associated with cancer treatments

Short Title: Stakeholder perspectives on the term 'time toxicity'

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Ethics approval
The Sydney Local Health District Human Research Ethics Committee–Concord Repatriation General Hospital approved the conduct of this study (2023/ETH00869). The study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Consent to participate
All participants provided written informed consent for study participation.

Data Availability Statement
The data underlying this article cannot be shared without compromising the privacy of individuals who participated in the study. The qualitative nature of the interviews and experiences of clinicians are personal even if identifying information is removed from individual transcripts, it may still breach confidentiality.

Abstract

Purpose

The labelling of the time-opportunity costs of cancer care as 'time toxicity' has stimulated research into the impact of treatment time on patients, yet stakeholder views on this potentially value-laden term remain unreported. Existing qualitative research highlights significant between individual differences in the perception of burden from treatment-related time. The purpose of this study is to report patient, caregiver, and oncologist reactions to the term 'time toxicity'.

Methods

Semi-structured interviews were conducted with purposively selected adults with advanced gastrointestinal cancers and their caregivers from one metropolitan and one regional centre, as well as gastrointestinal (GI) oncologists recruited from participating sites, email and social media advertising. Interviews were audio-recorded, transcribed, and analysed using thematic analysis tied to a framework approach.

Results

Forty-five people, including patients (n=20), caregivers (n=10) and GI medical oncologists (n=15) were interviewed. Thematic analysis identified three major themes: (1) Critiques of 'toxicity'; (2) Supportive perspectives; and (3) Alternative terminology. While some participants felt that describing time as a treatment-related toxicity was both accurate and provided a potential benefit to health systems optimisation, many felt that the word 'toxicity' conveyed an unhelpful value judgment on time invested for treatment and could overlook positive experiences of care. Alternative value-neutral or positive terms were suggested (e.g. 'time commitment').

Conclusions

We identified divergent perspectives on the terminology used to describe treatment-related healthcare contact time. These differences likely reflect subjective experiences of treatment time. Further research should explore this concept in more diverse populations.

Context Summary

Key objective: This study explored patients', caregivers', and oncologists' responses to 'time toxicity', the nomenclature used to describe healthcare contact time

Knowledge generated: Among individuals with advanced gastrointestinal cancers, their caregivers and oncologists from Australia, views diverged on the appropriate terminology to describe time spent on treatment. Many patients and caregivers preferred value-neutral descriptors of treatment-related time, whereas oncologists were generally more supportive of labelling time as a 'toxicity' of treatment.

Relevance: Findings suggest that the current language used to describe healthcare contact time may not reflect the full range of patient and caregiver experiences. Co-developing terminology that acknowledges the breadth of patient experience may support more meaningful communication about time costs in cancer care.

Purpose

The time-opportunity costs of cancer treatment have been recognized for over 30 years.[1] However, the explicit of framing time costs as time 'toxicity' in 2022 has catalysed a growing body of research attempting to quantify the time associated with cancer treatments, and understand its impact on stakeholders.[2] Qualitative studies support the hypothesis that healthcare contact is often experienced as burdensome by people with advanced cancer and their caregivers.[3-7] However, these studies also highlight that the extent to which contact time is perceived as burdensome varies considerably among individuals, and is often perceived as adding substantial value to care or care outcomes.

The observation that time may not be 'toxic' to all stakeholders has prompted re-evaluation of the most appropriate term to describe time toxicity in the literature. Many researchers have chosen to adopt more value-neutral terminology to describe healthcare contact, such as "contact days".[8]

However, to date, no data reports stakeholder perspectives on the term ‘time toxicity’. As highlighted in the parallel concept of financial toxicity, the language used to describe a concept can influence patient care and the direction of research and policy agendas.[9] To ensure that terminology is fit for purpose, it is important that stakeholder perspectives are considered. In this study, we present the views of patients, caregivers, and oncologists on the terminology used to describe healthcare contact time.

Methods

Study Design, Sample, and Data Collection

Conducted between October 2023 and February 2025, this qualitative study explored stakeholder perspectives on time spent receiving palliative systemic cancer treatments for advanced gastrointestinal (GI) malignancies. The results reported hereafter pertain to one question in the interview guide (Table 1) specifically exploring terminology used to describe healthcare time; the results of other analyses are reported elsewhere[5]. This study was approved by the Human Research Ethics Committee of Sydney Local Health District (Concord Repatriation General Hospital; 2023/ETH00869). It is reported according to the consolidated criteria for reporting qualitative research (COREQ) guidelines (Supplement 1).[10]

At the time of study design (June 2023), there was no published qualitative literature specifically exploring the notion of time as a side-effect of treatment. To achieve adequate information power, we focused on people affected by GI malignancies given the frequent and intense healthcare contact required of patients and their caregivers[11]. Participants included adults with advanced GI cancers and their unpaid caregivers from one metropolitan and one regional cancer centre in New South Wales, Australia serving a geographical area of over 240,000km^2. Purposive sampling was used to capture a variety of experiences with treatment across these two sites. Oncologists were recruited using convenience sampling from these two participating sites, which was supplemented by online and email advertising via the Australian Gastrointestinal Trials Group and Friends of the Sydney Cancer Survivorship Centre. A sample size of 10-20 participants per group was targeted. Interviews continued to thematic saturation.

Written consent was provided via Research Electronic Data Capture (REDCap) eConsent.[12,13] Semi-structure qualitative interviews were then conducted for approximately 45 minutes by a

male medical oncologist trained in qualitative interviewing. Questions in the interview guide were informed by the clinical experience of in the research team, treatment burden literature, and existing literature on perceptions of time during cancer treatment[14,15]. Interviews were conducted with one participant at a time, either online or in-person. They were audio-recorded, transcribed verbatim using TRINT (www.trint.com), and corrected by two researchers (SS, EE) prior to analysis.

Data Analysis

De-identified transcripts were inductively coded by two researchers (SS, EE) using a constant comparative method. Thematic analysis was conducted in NVivo 14, employing a framework approach (Supplement 2)[16], informed by grounded theory. Emergent themes were iteratively refined in consultation with senior researchers (JS, JV; Supplement 3 and 4). Illustrative quotes are references with patient/caregiver/oncologist (P/C/O) followed by participant number.

Results

We interviewed 45 participants: 20 patients, 10 caregivers, and 15 oncologists (Table 2). Among patients and caregivers, 87% were native English speakers, 80% were Australian-born, and 50% had tertiary education. Among oncologists, two-thirds practised exclusively in metropolitan settings, and half had over 10 years of consultant experience. Participant responses reflected three themes: (1) Critiques of the term 'toxicity'; (2) Supportive Perspectives; and (3) Suggested Alternative Terminology.

Critiques of the term 'toxicity'

Most participants, especially patients, caregivers, women, and less educated participants, expressed a focused critique of using the word 'toxicity' to describe healthcare time (Supplement 4). They suggested the term 'time toxicity' was negatively value-laden and overlooked positive experiences of illness or treatment, which some described as *"life giving"* (P-37) or beneficial to social wellbeing. In addition, patients felt that the terminology implied a value judgement on their decision to undergo treatment: *"I'm here for a reason… I'm not here wasting my time"* (P-1).

Caregivers were primarily concerned that the negative framing of treatment time could increase treatment burden for patients. This was raised in three ways: first, by reinforcing negative thought processes around cancer treatment; second, by drawing attention to the amount of time sacrificed by caregivers to provide care; and lastly, by providing a contextual reminder of their loved one's limited survival time.

> *"I didn't think (a negative term) was necessary. There's enough negativity and mental health (concerns) anyway, without another term."* (C-16).

> *"I haven't really dwelled on (time) because otherwise you could kind of go down a bit of a tunnel of like, feeling, I guess, deeply frustrated." (C-15)*

Several participants contended that using 'toxicity' to describe time was semantically inaccurate: *"time can't be toxic"* (O-58). However, others felt the word choice was appropriate, but too jargonistic to be used in patient care: *"amongst your medical colleagues, that's a term you would use. With everyday people…. that makes it sound even more scary."* (C-6). Overall, many participants felt that time was better viewed as a neutral construct, focusing instead on the trade-offs that were an inherent part of receiving treatment:

> *"This is a situation that calls for this kind of action. That action may lead to this, that and the other. So I don't see it as a 'toxin', I see it as a trade off…."* (P-11)

Supportive Perspectives

Supportive views centred around two subthemes. First, participants felt the term 'toxicity' appropriately captured the impact of time as a side-effect of cancer treatment:

> *"I think it says a lot… toxicity adds a level of negativity to it. But having to come in and do chemo for six hours–it's not a positive thing to do."* (P-17)

> *"I can definitely relate to that… it is toxic to our time, because to be honest, it's all you can think about."* (C-7)

Although some oncologists argued that 'toxicity' should be reserved for describing biological effects, most agreed it was appropriate to treat time as a toxicity, noting that treatment time is *"an added issue the patient has to deal with that they wouldn't otherwise"* (O-20). This view related to a second subtheme: that the use of provocative language ('toxicity') could help to optimise the patient experience. Many oncologists felt that the label 'time toxicity' could draw attention to under-recognised burdens from treatment:

> *"It's a really important concept for us to think about how much good time we're giving patients."* (O-65).

However, only two patient participants, themselves healthcare workers, identified with this idea, with one affirming that it was *"good this gets a name"* (P-10), and another suggesting that the concept of time as a toxicity could inform the consent process: *"we should be open about all the benefits and all of the potential negatives, which include time."* (P-44)

Suggested Alternative Terminology

Several participants suggested alternative terms (Table 3). Many were value-neutral–e.g. *'time commitment'*. Others emphasised the burdens or opportunity costs of treatment, offering such terms as *'time burden'*, *'time lost'* or *'time cost'*. In contrast, some advocated for more positively framed language, highlighting either perceived treatment benefits or the value of less healthcare contact, e.g. *'time invested'* or *'time away from doctors'*.

Discussion

As highlighted in discourse on the parallel concept of financial toxicity[9], language shapes how clinicians, researchers, and policymakers understand and respond to phenomena. This study describes patient, caregiver, and oncologist responses to terminology used to describe healthcare contact in cancer care. Several perspectives emerged. First, many participants felt that 'time

toxicity' was an overly negative descriptor for time spent receiving care, with the word 'toxicity' often criticised as being inaccurate or jargonistic. Second, the potential for this terminology to add burden to patients or caregivers participating in treatment was highlighted. Third, several participants–principally oncologists–viewed the term as useful for framing the additional time required for treatment as a side effect warranting attention. Last, several value-neutral descriptors were suggested as alternatives for describing the time burdens of treatment in practice.

Our results indicate divergent views on the optimal terminology for describing time spent in treatment-related activities. Although no prior study has addressed the language used to describe treatment time, existing evidence suggests patients with advanced cancer highly value how and where they will spend their time. In a secondary analysis of patients' attitudes towards palliative systemic treatments that prolonged progression-free, but not overall survival, nearly half of participants spontaneously identified time burdens as a concern.[17] Other qualitative studies underscore the sense of burden associated with time spent on care.[3-5,15] However, these studies also highlight that perceptions of burden are highly individual and shaped by personal circumstances.

Consistent with this evidence, participants reacted strongly to the use of the word '*toxicity*', perceiving it as casting healthcare time in an unduly negative light. Several participants went further, identifying potential unintended harms: conveying a value judgement on patients' treatment decisions; exacerbating psychosocial burdens associated with prognostic uncertainty; and potentially straining patient-caregiver dyads. Beyond these impacts, framing time as a treatment toxicity may be counterproductive for three reasons. First, unlike financial toxicity, healthcare time cannot be shared with other 'payers'. Second, efforts to reduce healthcare time may risk undertreatment, particularly for marginalised groups, who may require more healthcare time to overcome barriers to treatment. Third, time costs are experienced subjectively, and reductions may not reflect optimal care for all people.

In contrast, several participants emphasised the value of applying negative terminology to describe healthcare time. Consistent with Gupta et al.[4], these participants–often oncologists or highly educated patients–felt the label 'time toxicity' could draw attention to, and ultimately reduce unnecessary healthcare time. Their familiarity with clinical jargon and practice in

engaging with abstract concepts may have contributed to this preference. Ultimately, many participants favoured the use of value-neutral terminology, such as 'time commitments', reflecting a broader trend in the literature towards terms like 'contact days'. It was suggested that framing time toxicity in a positive light–emphasising time spent away from healthcare–may offer a more patient-centred way to communicate about time burdens in practice.

Taken together, these findings support framing time as a trade-off to be optimised rather than a 'toxicity' to be managed. Additionally, these data underline a subjective component of time toxicity that goes beyond healthcare contact days alone. As identified in previous work, time spent on care is often viewed as investment in future health, and its value varies according to their experiences, goals, and treatment benefit.[5] Further, subjective burden is dependent on individual- and system-level factors.[3] The results of this study do not suggest that patients or caregivers dispute the potential value of trying to understand and mitigate unnecessary time burdens associated with treatment. Rather, they argue for describing the temporal impacts of care in ways that reflect the full range of meanings patients ascribe to them.

Original definitions of 'time toxicity' focused on the *added* time burden of one treatment over another where outcomes were similar.[2] This was–and remains–a fair base assumption: additional healthcare time should offer a benefit to patients. However future work should investigate ways in which time toxicity can take into account both objective and subjective time burdens of care, as has been proposed in financial toxicity.[18] Before doing so, further mixed methods research involving more diverse populations and healthcare settings is needed, as most existing studies have been conducted in Western nations and have focused primarily on palliative systemic therapy and gastrointestinal cancers[3-7,17].

Several important limitations should frame our interpretation of these results. First, this study captured the viewpoints of individuals affected by gastrointestinal cancers within a single health system and sociocultural context, and we would caution against generalizing these results to redefine the concept of *time toxicity*. Instead, this should prompt us to pay closer attention to the role of language in describing healthcare contact time, and direct future research toward exploring the terminology of time toxicity among individuals with a broader range of tumour types, treatment modalities, geographic, cultural, and linguistic contexts. Second, patient and

caregivers were asked to reflect on labelling treatment time as a toxicity of treatment via an analogy with treatment side-effects. As many were currently receiving treatment, optimistic perceptions of its benefits could have biased responses toward a rejection of that label[19]. Patients and caregivers may have been more willing to view time as a toxicity if informed *a priori* of treatments with small benefits. Third, reactions to the interview question were impressionistic and do not represent a comprehensive exploration of all terminology that could describe healthcare time. Last, participants were informed that the interviewer was a practicing oncologist, which may introduce response bias if this caused them to moderate criticism of terminology.

In summary, while the term 'time toxicity' may serve a valuable role in highlighting the potential time burdens of care, our findings highlight potential downsides associated with the use of this terminology to describe all time spent on care. Whilst potentially appropriate for research or interprofessional discourse, participants in this study favoured the use of neutral or positively framed terminology to describe healthcare contact time in clinical practice. As our understanding of treatment-related healthcare contact time grows, future work should focus on co-developing such language with patients, caregivers, and clinicians, and evaluate its impact on shared decision-making and perceptions of treatment burden.

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Tables

Table 1: Interview Question for Analysis

Patients and Caregivers: *Sometimes we use the word 'toxicity' to talk about the side effects of a treatment. The term 'time toxicity' has been used to describe the impact of the time associated with receiving cancer treatment. What are your reflections on this term?* - *Probe: would you propose an alternative term?* Oncologists: *The term 'time toxicity' has been used to describe the impact of time associated with receiving cancer treatment. What are your reflections on this term?* - *Probe: would you propose an alternative term?*

Table 2: Demographic Characteristics of Interview Participants

Characteristic	Group	Patients, n (%)	Caregivers, n (%)	Oncologists, n (%)	Total, n (%)
Gender	Male	12 (60)	3 (30)	8 (53)	23 (51)
	Female	8 (40)	7 (70)	7 (47)	22 (49)
Age (years)	18-34	1 (5)	2 (20)	2 (13)	5 (11)
	35-54	3 (15)	2 (20)	11 (73)	16 (36)
	55-74	13 (65)	5 (50)	2 (13)	20 (44)
	≥ 75	3 (15)	1 (10)	0	4 (9)
Geographic Location	Metropolitan	10 (50)	5 (50)	9 (60)	24 (53)
	Regional	10 (50)	5 (50)	5 (33)	20 (45)
	Both	NA	NA	1 (7)	1 (2)
SEIFA Quintile[a]	1	5 (25)	1 (10)	Postcode not asked	6 (20)
	2	6 (30)	2 (20)		8 (27)
	3	5 (25)	3 (30)		8 (27)
	4	3 (15)	1 (10)		4 (13)
	5	4 (20)	3 (30)		7 (23)
Born in Australia	Yes	16 (80)	6 (60)	Not asked	24 (80)
English spoken at home	Yes	18 (90)	8 (80)	Not asked	26 (87)
Level of education	High school	10 (50)	5 (50)	Not asked	15 (50)
	Diploma	7 (35)	2 (20)		9 (30)
	Bachelor Degree	1 (5)	2 (20)		3 (10)
	Masters Degree	2 (10)	0 (0)		2 (7)
	Doctoral Degree	0 (0)	1 (10)		1 (3)
	Specialist Experience (Years)				
			< 5 years	4 (27)	4 (27)
			5-10 years	5 (33)	5 (33)
			11-20 years	5 (33)	5 (33)
			> 20 years	1 (7)	1 (7)

[a]: Socio-Economic Indexes for Areas (SEIFA) Quintile: ranks postcodes according to their relative socio-economic advantage, with higher scores indicating advantage and lower scores indicating relative disadvantage

Table 3: Alternative Terminology for 'Time Toxicity' As Reported by 45 Stakeholders

	Suggested Terms
Value-neutral	*"Time commitments"* (C-16; O-19; O-20; O-25; P29; P-45) *"Time impacts"* (O-63) *"Time receiving treatment" (*O-19) *"Time requirements"* (O-25) *"Time spent administering healthcare"* (O-56) *"Time spent doing these things when you could be doing something else"* (O-55) *"Time spent on treatment away from other things"* (O-55) *"Time spent on treatment"* (O-58) *"Time trade-off"* (P-11)
Positive	*"Healing time"* (P-2) *"Time investment"* (C-12) *"Supportive time"* (C-15) *"Time away from doctors"* (O-56) *"Time of independence"* (O-56) *"Good quality time"* (O-56)
Negative	*"Time cost"* (P-10; P-11; C-16; O-58) *"Time burden"* (O-20; O-60) *"Time lost"* (O-26; O-58) *"Inconvenience of treatment"* (O-25) *"Time spent feeling sick"* (P-5)