

Replacing Palliative Care In Oncology With The Sustained Living Paradigm: Psychosocial Determinants And Lifelong Rehabilitation

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Abstract

Palliative care is now endorsed as an evidence-based component of high-quality oncology across the disease trajectory, yet the term still functions as a late-stage label in many health systems. This semantic burden is not a trivial branding problem: it can operate as a decisional cue that “active treatment has ended,” intensify fears of abandonment, and, in some contexts, fuel a harmful conflation with “passive euthanasia.” Such framing undermines early referral, weakens therapeutic alliance, and delays multidimensional support despite robust evidence that timely integration improves quality of life and reduces goal-discordant care [1-4].

We propose the Sustained Living Paradigm (SLP) as a conceptual and operational alternative that preserves the clinical substance of palliative/supportive care while relocating its telos from “care at the end” to “continuity of living.” SLP is built on a triad of modifiable burdens—psychological distress, functional decline, and financial toxicity—translated into routine practice via measurable indicators, thresholds, and time-bounded response pathways. The framework specifies a continuity-oriented ethics audit (the Intention–Causality–Proportionality triad; NNO) and a systems-level failure signal (the Clinical Misdirection Hypothesis; KYYH) to make controversies surrounding treatment refusal empirically traceable rather than rhetorically escalated [5-6].

Methodologically, this paper is a targeted narrative synthesis and implementation blueprint informed by clinical guidelines, randomized trials, and implementation science. We operationalize SLP as a four-layer continuity engine—Sensing (PRO/ePRO), Decision (triage thresholds), Action (tiered interventions), and Governance (learning health system feedback)—designed to be embedded in routine oncology workflows without extending visit length. SLP generates testable hypotheses and a pragmatic measurement set (IYS-G) to evaluate continuity, equity, and ethical robustness in real-world settings.

Keywords: Sustained Living Paradigm; supportive/palliative oncology; patient-reported outcomes; cancer rehabilitation; lifelong rehabilitation; financial toxicity; ethics; implementation science.

1. Introduction

Over the last four decades, oncology has shifted from a predominantly acute, tumor-centered discipline toward a longitudinal practice in which many cancers are managed as chronic or relapsing life conditions. This evolution has expanded the clinical target from survival alone to sustained functioning, psychological integrity, and social participation. However, a paradox persists: services capable of protecting these dimensions—symptom control, communication support, rehabilitation, and navigation—are frequently activated late, often after preventable suffering has accumulated and treatment tolerance has eroded [4,7-8].

A major and under-discussed driver of late activation is linguistic and decisional framing. In many settings, “palliative care” is still heard as a signal of terminality rather than an additional layer of support; this can trigger avoidance, refusal, or a defensive insistence on escalation. Framing effects are well documented in decision science: the same option, labeled differently, can reliably shift choices under uncertainty [9]. Within oncology, patient and clinician perceptions of “supportive” versus “palliative” care influence referral patterns, acceptance, and adherence [10-11].

The Sustained Living Paradigm (SLP) is proposed as both a conceptual reframing and an operational design. It does not deny palliative care’s evidence base or ethical rationale; instead, it argues that the dominant end-of-

life connotation constitutes a structural barrier to early integration. SLP therefore recodes the clinical narrative from “care when treatment ends” to “care that makes treatment and living sustainable.” In this sense, SLP is not a new specialty but a continuity framework that reorganizes existing competencies around measurable targets and accountable response times.

SLP rests on a biopsychosocial triad of modifiable burdens: (i) psychological distress, (ii) functional decline, and (iii) financial toxicity. Each burden is treated as clinically measurable, ethically salient, and operationally actionable. Rather than describing supportive care as an optional add-on, SLP embeds it as a default pathway triggered by thresholds and time-limited trials. This makes the system less dependent on individual clinician intuition and more resilient to variability, workload, and cultural stigma.

1.1. Advanced cancer, treatment refusal, and the “passive euthanasia” discourse: TIY telos, NNO framework, and KYYH

In advanced (stage III–IV) cancer, palliative care is sometimes misframed as a substitute for disease-modifying treatment. When this occurs, patients and families may interpret a referral as a tacit message that “treatment has ended,” and may fear being steered toward “passive euthanasia.” SLP responds to this controversy not by amplifying labels, but by re-anchoring care around a positive clinical telos: Treatment Continuity and Sustained Living (TIY; Turkish: Tedavinin Surekliligi ve Idame Yasam).

The critical ethical separation is not between “active treatment” versus “palliative care,” but between (i) the intention of an action (relieving suffering versus aiming at death), (ii) the causal pathway to death (natural disease trajectory versus a lethal act), and (iii) proportionality (whether treatment burden outweighs expected benefit). We formalize this as the Intention–Causality–Proportionality triad (NNO; Turkish: niyet–nedensellik–orantililik), a practical decision-audit lens aligned with principles-based ethics [5,12].

Within the NNO lens, palliative care and palliative sedation remain ethically distinct from euthanasia when their telos is symptom relief, dosing is proportional, monitoring is explicit, and decision processes are documented; death is not the intended outcome [6]. Likewise, refusal or withdrawal of a specific intervention is not necessarily a wish for death. It may represent rejection of disproportionate toxicity and a preference for time-limited trials, particularly under high symptom burden, delirium risk, anxiety, depression, or family/system pressures that can degrade consent quality [5].

We therefore introduce the Clinical Misdirection Hypothesis (KYYH; Turkish: Klinik Yanlis-Yonlendirme Hipotezi): when supportive/palliative care is presented as replacement rather than integration, the option set closes prematurely, goal documentation weakens, and the decision architecture becomes opaque. In such contexts, “passive euthanasia” discourse often functions less as a moral diagnosis and more as a signal of communication and institutional breakdown.

Operationally, SLP recommends institutionalizing a Continuity Presumption: the default pathway is integrated sustained living, where symptom control, rehabilitation, and financial navigation actively protect treatment tolerability and personhood. Early integrated palliative care supports quality of life and reduces goal-discordant intensive care patterns, reinforcing TIY rather than terminating it [2-3,13].

Maintenance Living Continuity Indicators (IYS-G; Turkish: Idame Yasam Surekliligi Gostergeleri) can be tracked through a six-item mini-set: (1) functional trajectory over 4–8 weeks (stabilization versus rate of decline); (2) composite symptom burden (pain–dyspnea–fatigue) and clinically meaningful change; (3) psychological trajectory (anxiety/depression change); (4) planned-care continuity ratio (planned follow-up/supportive actions versus unplanned emergency contacts); (5) goal-alignment documentation (frequency and clarity of written goals and rationale updates); (6) treatment proportionality documentation (explicit benefit–burden discussion and time-limited trials). Making these indicators visible converts an abstract ethics debate into auditable, improvable clinical quality [14].

2. Theoretical foundations: the biopsychosocial model of sustained living

SLP is grounded in the claim that continuity of living in cancer is not an abstract aspiration but a clinically engineerable property of care systems. Continuity is maintained when signals of suffering are detected early, interpreted consistently, and linked to time-bounded responses that preserve function, agency, and social participation. Accordingly, SLP identifies three high-yield, modifiable burdens that routinely erode continuity when left unmeasured: psychological distress, functional decline, and financial toxicity.

These burdens are deeply coupled. Distress amplifies symptom perception and impairs adherence; functional decline increases dependence and isolation; financial strain drives coping behaviors that undermine treatment

and wellbeing. Treating them as separable “support issues” fragments care; treating them as a unified continuity triad makes them measurable, governable, and ethically accountable [7-8].

2.1. Psychosocial balance and neuroethical resilience

Psychological distress is prevalent across cancer types and stages, often fluctuating with symptom burden, treatment transitions, and uncertainty. When distress is not routinely measured, it is systematically under-detected; when it is detected late, it is more likely to be expressed as treatment refusal, conflict, or crisis care. Evidence supports systematic screening coupled with stepped responses rather than screening as a symbolic act [15].

SLP therefore routinizes distress capture as a safety process. A brief first-stage screen (e.g., Distress Thermometer) is paired with second-stage assessment and targeted referral when thresholds are exceeded. Rather than treating distress as an “emotional side effect,” SLP treats it as a modifiable determinant of treatment continuity and decision quality.

Neurobiologically, sustained engagement with care is supported by reward learning, motivational salience, and social bonding systems. Dopaminergic circuits contribute to effort allocation and persistence, while oxytocin-related pathways support trust, attachment, and stress buffering in relational contexts [16-17]. These systems are not invoked to biologize ethics, but to underscore a practical implication: clinical environments that protect agency, predictability, and relational safety reduce threat responses that otherwise narrow choices and intensify avoidance.

Resilience, in this framework, is not a personality slogan but the emergent capacity to maintain goal-directed behavior under stress when the environment provides stable cues, timely symptom relief, and social support [18]. SLP reframes psychosocial care as continuity engineering: a set of micro-interventions that stabilize decision-making, adherence, and coping by reducing uncertainty and avoidable suffering.

2.2. Functional continuity and the redefinition of rehabilitation

Functional decline often emerges during active treatment and can disrupt participation in therapy, family roles, and work. Despite its prevalence and prognostic relevance, function is frequently treated as secondary to tumor response until disability becomes obvious. Impairment-driven cancer rehabilitation offers a corrective: it prioritizes early identification of impairments and targeted interventions designed to maintain capacity rather than merely restore it after loss [19].

Evidence syntheses show that structured exercise and multimodal rehabilitation can meaningfully improve cancer-related fatigue, physical function, and quality of life, including during ongoing treatment [20]. Guideline-consistent activity prescriptions and tailored rehabilitation pathways therefore belong inside routine oncology care, not outside it as a post-treatment luxury [21].

SLP defines rehabilitation as the biological expression of functional continuity. Operationally, this means that functional assessment (e.g., performance status changes, patient-reported physical function, or simple timed tests where feasible) is coupled to tiered responses: self-management support and exercise prescription at low risk, referral to rehabilitation specialists at moderate risk, and integrated multidisciplinary pathways for frailty, complex symptoms, or treatment-limiting disability.

2.3. Financial justice and socio-economic rehabilitation

Financial toxicity is a clinically relevant and ethically salient burden in contemporary cancer care. It includes objective material hardship (out-of-pocket costs, debt, income loss) and subjective financial distress, both of which predict worse quality of life, non-adherence, and inequitable outcomes [22-24].

SLP treats financial toxicity as a standard screening domain rather than an awkward social afterthought. Validated measures such as the Comprehensive Score for Financial Toxicity (COST) enable systematic detection and triage [25]. Detection must be linked to action: financial counseling, access programs, transportation and nutrition support, employment guidance, and navigation to social protection systems. In SLP, these steps are not charity; they are continuity-preserving interventions that prevent avoidable discontinuation, emergency utilization, and moral injury among clinicians who otherwise witness inequity without tools.

2.4. The ethical triangle: dignity, autonomy, and justice

SLP’s normative core is the translation of ethics into clinical process. Dignity is protected by maintaining personhood under illness through symptom relief, communication, and relational continuity. Autonomy is

protected not by presenting choices in crisis, but by ensuring that goals, values, and proportionality are revisited iteratively as illness and burdens evolve. Justice is protected by making structural barriers visible and remediable, particularly those tied to socioeconomic disadvantage [5].

The ethical triangle becomes operational when linked to indicators and governance. For example, repeated emergency contacts without planned supportive actions signal a dignity and justice failure; absent goal documentation under high burden signals an autonomy failure; and unexamined escalation of toxic therapies near the end of life signals a proportionality failure [13-14]. SLP's contribution is therefore not merely philosophical; it specifies how ethics can be audited and improved through continuity metrics.

3. Methods and implementation model

3.1. Study design and approach

This paper is a conceptual and operational framework developed through targeted narrative synthesis and implementation-oriented reasoning. We focused on evidence that is directly actionable in routine oncology workflows: clinical practice guidelines, randomized trials of early integrated palliative/supportive care and symptom monitoring, rehabilitation evidence syntheses, and studies on financial toxicity measurement and mitigation.

3.2. Data synthesis and analytic approach

We used narrative synthesis principles to integrate heterogeneous evidence into an explicit logic model, emphasizing mechanisms, implementation feasibility, and measurable outputs rather than pooling effect sizes [26]. Where applicable, we drew on pragmatic evidence appraisal logic consistent with GRADE, privileging outcomes relevant to continuity (quality of life, symptom burden, function, utilization, and goal concordance) [27].

3.3. Implementation model: the sustained living framework

SLP is operationalized as a four-layer continuity engine designed to be embedded in standard oncology care:

- Sensing: routine capture of patient-reported outcomes (PRO/ePRO) for distress, symptoms, function, and financial strain;
- Decision: threshold-based triage and time-bounded care plans, including the NNO proportionality audit and escalation/de-escalation triggers;
- Action: tiered interventions (symptom management, communication support, rehabilitation, and financial navigation) matched to risk;
- Governance: learning health system feedback loops, equity dashboards, and Plan–Do–Check–Act cycles to sustain improvement [28].

To maximize implementability, SLP aligns with implementation science by making determinants (context, workflow, staffing) explicit and by specifying measurable processes and outcomes that can be iteratively refined [29-30].

3.4. Clinical visit algorithm

SLP can be implemented without extending visit time by standardizing micro-steps: (1) rapid review of a dashboard of PRO signals; (2) brief confirmation and prioritization; (3) assignment of a tier (green/amber/red) for each domain; (4) initiation of pre-specified actions (e.g., brief intervention, referral, medication adjustment, rehabilitation consult, financial navigation); (5) documentation of goals and proportionality (NNO); (6) scheduling of a time-bounded follow-up to close the loop. This algorithm converts supportive care from discretionary to default, and from reactive to anticipatory.

3.5. Quality, equity, and the learning system cycle

Governance uses a Plan–Do–Check–Act cycle embedded in a learning health system. Key indicators include screening completion rates, response times after threshold breaches, functional trajectory stabilization, emergency utilization, and goal documentation frequency. Equity dashboards stratify these indicators by socioeconomic and clinical vulnerability to detect structural gaps and drive targeted redesign [28].

3.6. Implementation principles

Six principles guide implementation: (i) continuity presumption (default to integration); (ii) time-bounded response to threshold breaches; (iii) stepped-care escalation; (iv) measurement as safety infrastructure; (v) equity-first governance; and (vi) co-production with patients and caregivers to ensure acceptability and cultural legitimacy.

4. Findings and discussion

Across oncology, early integrated supportive/palliative care, systematic symptom assessment, and structured communication are consistently associated with improved patient-reported outcomes and less goal-discordant care. In parallel, PRO/ePRO-enabled monitoring can accelerate detection–response cycles and improve trajectories when signals are paired with rapid clinical action [2-3,8,31-32]. Yet implementation remains uneven: late referrals, fragmented rehabilitation, and unmeasured financial toxicity continue to drive avoidable suffering and crisis care.

SLP's central contribution is architectural rather than merely terminological. It treats sustained living as a measurable quality domain and specifies the operational conditions under which evidence-based supportive care becomes reliable routine practice: standardized sensing, explicit thresholds, time-bounded responses, and governance loops consistent with learning health system logic [28-29]. This discussion synthesizes convergent findings and articulates how the Continuity Engine, Neuroethical Equilibrium, Equity Dashboard Logic, and Measurable Ethics Architecture jointly reduce avoidable discontinuity.

4.1. Evidence convergence and the persistent implementation gap

The empirical direction of the field is now clear. Early integrated supportive/palliative care improves quality of life and symptom burden and can reduce late intensive care patterns that are frequently misaligned with patient goals [2-3,8,13]. Routine symptom monitoring through PRO/ePRO systems further shows that when deterioration is detected early and linked to structured response, outcomes can improve in pragmatic care settings [31-32]. Rehabilitation syntheses indicate that fatigue and functional decline are modifiable targets, and impairment-driven programs can improve functioning and participation [19-21]. Financial toxicity is likewise established as a clinically relevant burden with downstream effects on distress, adherence, and equity [22-25].

The persistent gap is operational: (i) signals are not measured; (ii) signals are measured but not converted into time-bounded actions; (iii) actions occur but are not re-evaluated in closed loops; or (iv) inequities remain invisible because outcomes are not stratified by vulnerability. SLP targets these failure modes by treating supportive oncology as continuity infrastructure rather than discretionary add-on care.

Evidence-to-Architecture Map (text-only; bridging evidence to SLP modules)

Early integrated supportive/palliative care → Continuity Engine activation (automatic referral triggers, goal-aligned escalation rules) → improved quality of life and fewer goal-discordant late intensive-care trajectories [2-3,8,13-14].

Routine PRO/ePRO symptom surveillance with rapid response loops → Sensing layer fidelity (signal capture) + Decision layer latency reduction (time-bounded triage) → lower symptom burden and preventable crisis care [31-32].

Distress screening and structured communication → Neuroethical Equilibrium conditions (reduced threat framing, preserved option set) → higher decisional legitimacy and lower conflict escalation around treatment transitions [5,7,9,15].

Impairment-driven rehabilitation and exercise oncology → Action layer completeness (function-preserving interventions) → improved functional trajectories and participation, reducing discontinuity cascades [19-21].

Financial toxicity measurement and navigation → Equity Dashboard Logic (stratified governance) + Action layer navigation pathways → reduced nonadherence risk and inequity amplification [22-25].

Proportionality-sensitive ethics and palliative sedation standards → NNO operational checks (intention–causality–proportionality) → clear separation from euthanasia narratives while protecting symptom relief [5-6,12].

Implementation science and learning health systems → Governance layer (feedback dashboards, PDCA cycles, scalability) → sustained adoption beyond pilot enthusiasm [26-30].

4.2. The Continuity Engine: care redesigned as sensing–decision–action–governance

SLP operationalizes supportive oncology as a four-layer Continuity Engine: Sensing (routine capture of distress, symptoms, function, and financial strain); Decision (threshold-based triage and time-bounded plans); Action (tiered interventions spanning symptom control, psychosocial support, rehabilitation, and navigation); and Governance (feedback loops that enable iterative redesign) [28-29]. This makes “early integration” an engineered default rather than a clinician-dependent ideal.

The Continuity Engine also reduces variability under workload. It frames supportive oncology as safety infrastructure: predictable threats (symptom escalation, functional slope changes, distress spikes, and material hardship) are managed through triggers, escalation rules, and closed-loop follow-up, analogous to how oncology operationalizes other high-impact risks [28].

4.3. Continuity homeostasis: a neurobiopsychosocial explanation for why timing matters

SLP’s continuity homeostasis model explains why timing is clinically decisive. Unmanaged symptom burden and uncertainty can compress cognitive bandwidth and narrow perceived options, shaping decisions through framing effects and threat-driven avoidance [9]. Neurobiological accounts contextualize these dynamics: dopaminergic learning signals influence persistence and effort allocation, while social bonding pathways can buffer stress and stabilize trust—key conditions for sustained engagement [16-18]. In this sense, symptom relief, predictable communication, and relational continuity are decision-enabling interventions, not optional comfort measures.

4.4. Neuroethical equilibrium: distinguishing integrated supportive care from euthanasia narratives

In some contexts, early supportive/palliative involvement is delayed by rhetorical conflations with “passive euthanasia,” particularly when care transitions occur under crisis. SLP responds by making ethical quality auditable through Neuroethical Equilibrium, operationalized via the Intention–Causality–Proportionality triad (NNO) and aligned with principles-based ethics [5]. NNO clarifies whether the primary aim is symptom relief versus death, whether death follows disease trajectory versus a lethal act, and whether burdens are proportionate to realistic benefits. This moves ethical debate from slogans to documentable clinical reasoning [5,12].

The framework is especially relevant for palliative sedation, which remains ethically distinct from euthanasia when intention is symptom relief, dosing is proportional, monitoring is explicit, and decision processes are transparent [6]. SLP also frames treatment refusal as a clinical signal—often emerging under uncontrolled symptoms, unmanaged distress, or communication breakdown—rather than as a moral endpoint. Systematic screening and timely response may therefore reduce crisis-driven decisions that later become misread as abandonment [15,31].

4.5. IYS-G as a deliverable: a one-paragraph mini-measurement set with threshold–response logic

To convert continuity into routine practice, we propose Maintenance Living Continuity Indicators (IYS-G; Turkish: Idame Yasam Surekliligi Gostergeleri), a six-item mini-set that operationalizes Operational Standards 2–4, 6, and 8 by coupling routine sensing to time-bounded action. The set tracks: (1) functional trajectory (4–8-week slope rather than a single-point status), (2) composite symptom-burden trajectory, (3) psychological trajectory (brief first-stage distress screening followed by stepped assessment when thresholds are exceeded), (4) planned-to-unplanned care ratio, (5) goal-concordance documentation currency, and (6) proportionality logic for time-limited trials under uncertainty. Threshold–response is deliberately simple: Green (no threshold breach) triggers routine review; Amber (single-domain breach or moderate deterioration) triggers nurse-led outreach within 72 hours and a documented step-up plan within 7 days; Red (multi-domain breach, rapid deterioration, or repeated unplanned use) triggers outreach within 24 hours, a same-day multidisciplinary micro-huddle, and supportive-care escalation within 48–72 hours, with NNO documentation for major decisions. An equity overlay upgrades one level (Amber to Red) when financial toxicity or access barriers are high (e.g., COST below a site-defined cut-off), ensuring that continuity is protected as a governed quality domain rather than an aspirational ideal [15,19,25,28-29,31].

IYS-G implementation notes (one line per indicator):

1. Functional trajectory (4–8-week slope): Owner = nurse navigator + rehabilitation lead; cadence = each clinic visit plus monthly ePRO; channel = EHR + ePRO; action = auto-referral to impairment-driven rehabilitation when decline exceeds the site threshold.

2. Composite symptom-burden trajectory: Owner = oncology nurse (first response) + supportive care clinician; cadence = weekly ePRO and at visits; channel = ePRO portal/SMS link + phone call for red flags; action = symptom step-up within defined response windows.
3. Psychological trajectory (distress screen → stepped assessment): Owner = nurse navigator + psycho-oncology; cadence = Distress Thermometer at each visit (and monthly ePRO); channel = in-clinic tablet/ePRO; action = stepped assessment/referral when threshold exceeded.
4. Planned-to-unplanned care ratio: Owner = clinic coordinator/data analyst; cadence = monthly dashboard; channel = EHR utilization extract; action = trigger service-level review and micro-huddle targeting preventable acute-care spikes.
5. Goal-concordance documentation currency: Owner = treating oncologist (with supportive care); cadence = at transitions (progression, hospitalization) and at least every 8–12 weeks in advanced disease; channel = structured note template; action = update goals, trade-offs, and time-limited trial logic.
6. Proportionality logic (time-limited trials under uncertainty): Owner = oncologist + multidisciplinary team; cadence = whenever benefit–burden uncertainty is high; channel = NNO documentation template; action = define stopping rules and reassessment timeframe (typically 7–14 days).

4.6. Equity Dashboard Logic: making social suffering governable

Financial toxicity is not peripheral; it is a structural determinant of continuity that can drive nonadherence, missed visits, and avoidable crisis care, amplifying inequities across the cancer trajectory [22–24]. SLP therefore embeds Equity Dashboard Logic: continuity indicators (IYS-G trends, response times after threshold breaches, treatment interruptions, and unplanned utilization) should be stratified by vulnerability and used to trigger navigation and service redesign. Validated tools such as COST become actionable signals rather than descriptive scores [25].

4.7. Measurable Ethics Architecture: translating dignity–autonomy–justice into auditable care

SLP does not claim ethics can be reduced to metrics; it argues that ethics cannot be reliably protected without auditable signals. A Measurable Ethics Architecture maps dignity to symptom relief and reduced crisis dependence, autonomy to goal-alignment documentation and preference-sensitive proportionality reasoning, and justice to equity-stratified continuity outcomes and navigation completion [5,13–14]. These signals enable learning cycles in which ethical commitments become operational standards rather than rhetorical aspirations [28].

4.8. Relationship to existing palliative/supportive care: integration, not replacement

SLP should be interpreted as an implementation wrapper that protects the integration principle rather than a competing specialty. In systems where “palliative” already carries low stigma and early integration is routine, SLP’s marginal value is primarily measurement, thresholds, and governance. Conversely, in contexts where stigma delays referral and narrows perceived choices, continuity framing can reduce avoidance while preserving evidence-based content [2–3,8].

4.9. Clinical and policy implications: continuity as a financed quality domain

Clinically, SLP implies that distress, function, and finance should be treated as core determinants of tolerability and adherence, with routinized sensing and time-bounded responses. At the system level, it implies that continuity infrastructures—PRO systems, rehabilitation pathways, navigation capacity, and equity dashboards—should be financed and evaluated as essential oncology services rather than optional add-ons. This is consistent with the broader direction of oncology toward accountable, learning-oriented care where measurement reliably drives response [8,28].

4.10. Limitations

Counterarguments and boundary conditions deserve explicit treatment. First, SLP may be criticized as mere rebranding of palliative/supportive care. The rebuttal is operational: SLP is not a semantic substitution but a measurable continuity architecture that hard-wires sensing, thresholds, time-bounded responses, and governance into routine oncology. Second, PRO/ePRO ecosystems may be viewed as burden-generating—producing alert fatigue, documentation load, and clinician distraction. SLP therefore requires strict coupling between signal capture and response capacity: thresholds must be sparse and clinically meaningful, responses must be time-bounded and role-assigned, and dashboards must privilege actionability over volume [28,31–32].

Third, digitization can widen inequities if access, literacy, language, and connectivity are not explicitly governed. The Equity Dashboard Logic is therefore not optional; it is the fairness layer that ensures continuity improvements do not become a privilege of the digitally advantaged [23-25]. Fourth, critics may worry that “measurable ethics” collapses moral life into metrics. SLP explicitly rejects metric reductionism: its Measurable Ethics Architecture is an audit scaffold for dignity, autonomy, and justice—not a replacement for clinical judgment [5].

Several limitations remain. SLP is a complex intervention bundle; causal attribution will be sensitive to fidelity, baseline infrastructure, and workforce capacity. The framework may have smaller marginal effects in systems where early integrated palliative care and rehabilitation are already routine, whereas its value may be largest in settings where supportive care is delayed, stigmatized, or operationally fragile [2-3,8]. Measurement risk includes missingness, differential reporting by socio-economic strata, and cross-cultural non-equivalence of distress constructs; these require explicit data-quality governance and measurement invariance checks. Finally, institutional incentives may default toward throughput rather than continuity; without aligned financing and accountability, SLP could be implemented as a documentation layer rather than a response layer, undermining its intended mechanism [13,22].

4.11. Future directions

Future work should pursue a programmatic test plan rather than isolated pilots. First, evaluate SLP as a system intervention using pragmatic designs (cluster randomized or stepped-wedge), with prespecified continuity endpoints that reflect mechanism: longitudinal PRO slopes; time-to-response after threshold breach; unplanned acute-care use; treatment interruptions; functional trajectory stabilization; and financial toxicity change [13-14,22,31]. Second, embed implementation evaluation alongside effectiveness: adoption, fidelity, feasibility, and sustainability should be measured with transparent documentation of threshold rules, staffing response pathways, and governance cadence [28-30]. Third, evaluate equity as a primary analytic dimension, not a post-hoc subgroup: dashboard stratification, differential missingness, and bias audits should be planned a priori to prevent continuity gains from amplifying existing disparities [24-25]. Fourth, strengthen decision validity research around treatment refusal and end-of-life narratives by testing whether Neuroethical Equilibrium conditions—threat de-escalation, option-set preservation, and time-bounded clarification—reduce conflict, moral distress, and goal-discordant care [5-6,9].

5. Conclusions, clinical and policy implications, and operational standards

5.1. Overall conclusion and paradigm summary

SLP reframes supportive/palliative oncology as a continuity-of-living infrastructure rather than a late-stage label. Its central move is to translate biopsychosocial burdens and ethical commitments into measurable indicators, threshold-based triage, and time-bounded response pathways. By doing so, it preserves the evidence-supported content of palliative care while reducing the semantic barriers that delay early integration.

5.2. Clinical practice and educational implications

Clinically, SLP supports earlier detection and response to distress, functional decline, and financial toxicity, thereby protecting treatment tolerance, decision quality, and dignity. Educationally, it provides a teachable structure for trainees and teams: a shared language, a dashboard, and a set of default actions that reduce variability and moral injury.

5.3. Health policy, ethics, and social dimensions

At policy level, SLP implies that continuity infrastructures (PRO systems, rehabilitation pathways, navigation, and equity dashboards) should be financed and evaluated as core oncology services. Ethically, it operationalizes dignity, autonomy, and justice in auditable workflows, helping health systems respond to high-stakes controversies with transparency and accountability.

5.4. Operational standards (10 points)

- 1) Continuity presumption: default to integrated sustained living rather than late referral.
- 2) Routine PRO capture: distress, symptoms, function, and financial toxicity at defined intervals.
- 3) Thresholds with response times: each domain has pre-specified triggers and time-bounded actions.

- 4) Stepped-care pathways: escalation rules for psychosocial, rehabilitation, and navigation needs.
- 5) NNO documentation: intention, causal pathway, and proportionality are explicitly recorded for major decisions.
- 6) IYS-G reporting: continuity indicators are tracked and reviewed at service level.
- 7) Equity dashboards: stratify quality indicators by vulnerability to identify structural gaps.
- 8) Multidisciplinary micro-huddles: brief team coordination for red-flag signals.
- 9) Learning system cycles: Plan–Do–Check–Act improvement embedded in routine governance.
- 10) Co-production: patient and caregiver feedback used to refine acceptability and cultural fit.

Operational note: the IYS-G mini-set and its Green/Amber/Red triage workflow (Section 4.5) are intended as the minimal operational core for Standards 2–4 and 6, and they naturally trigger Standard 8 (micro-huddles) when red-flag signals cluster.

Clinic-ready clinical translation tools—including an impairment-driven prehabilitation and rehabilitation action layer aligned to IYS-G thresholds—are provided in Appendix A to operationalize functional signals into time-bounded, team-based responses.

5.5. Future directions for implementation and research

Future work should test SLP in pragmatic trials and implementation studies (e.g., cluster randomized or stepped-wedge designs) that embed PRO/ePRO monitoring and IYS-G triggers into routine workflows. Candidate primary endpoints include longitudinal PRO slopes, time-to-response after threshold breach, unplanned acute-care utilization, treatment interruptions, functional trajectory stabilization, financial toxicity change, and goal-alignment documentation, alongside established end-of-life quality indicators where appropriate [13–14,31]. Implementation evaluation should quantify reach, fidelity, adoption, acceptability, sustainability, and cost, and should identify determinants and strategies for scale using established frameworks [29–30]. Evidence grading should remain transparent to support policy translation and commissioning decisions [27].

5.6. Final conclusion and overall appraisal

The future of oncology will be defined not only by more effective therapeutics, but by governance-grade continuity: systems that can sense suffering early, convert signals into time-bounded responses, and continuously improve quality through learning and equity. The Sustained Living Paradigm (SLP) reframes supportive oncology as continuity-of-living infrastructure—preserving the evidence base for early integrated supportive/palliative care while supplying the operational architecture needed for reliability at scale [2–3,7–8]. This distinction matters because the translational bottleneck in supportive oncology is increasingly an implementation bottleneck: evidence exists, yet delivery remains episodic, late, and uneven.

SLP operationalises continuity through a minimal, auditable logic that couples measurement to action. First, routine sensing is anchored in validated symptom/distress surveillance and patient-reported outcomes (PRO/ePRO), which can improve symptom control and downstream utilisation when integrated into workflows with clear escalation pathways [31–32]. Second, signals are translated into explicit triage thresholds and response windows (the Continuity Engine), supported by a learning health system loop and implementation fidelity principles, so that variation becomes measurable and therefore improvable [28–29]. Third, SLP treats ethical quality as a measurable domain rather than a narrative aspiration: by documenting intention, causality, and proportionality, the model renders goal-concordant decisions auditable and defensible in high-stakes transitions, including the ethically fraught terrain of sedation and treatment de-escalation [5–6,12].

SLP also embeds equity as a design requirement. Financial toxicity and social vulnerability are not peripheral externalities; they are upstream determinants of continuity failures that shape adherence, distress, and preventable crisis care [22–25]. Equity-stratified dashboards therefore become part of the governance layer, converting invisible disparities into actionable quality targets. At the same time, SLP acknowledges countervailing risks—measurement burden, alert fatigue, digital exclusion, and the temptation to replace relational care with metrics—and responds by specifying a deliberately compact indicator set (IYS-G) linked to time-bounded actions and closed-loop review.

In synthesis, SLP proposes that the next phase of oncology is not an additive service layer, but an architectural upgrade: continuity as a measurable, governable, justice-sensitive system property across the full disease trajectory [8,28–29]. Its telos is not to postpone death, but to sustain living.

Appendix A. Clinical translation toolkit: impairment-driven prehabilitation and rehabilitation as the SLP action layer

A.1. Why an impairment-driven layer is necessary for continuity-of-living

SLP is intentionally framed as an infrastructure for continuity-of-living, but its credibility in top-tier venues depends on whether the paradigm can be operationalized into concrete clinical actions that are safe, time-bounded, and auditable. A recurring failure mode in ambulatory oncology is that “screening” becomes a documentation act rather than an intervention: distress, fatigue, neuropathy, deconditioning, and financial toxicity are measured yet left to drift until a crisis visit, unplanned admission, or treatment discontinuation occurs. The clinical translation target is therefore not to create new questionnaires, but to convert signals into matched responses—exactly the logic embedded in early integrated supportive/palliative care and exercise/rehabilitation evidence, now embedded into SLP’s Continuity Engine and governance loops [8,19–21].

A.2. Minimal action-oriented assessment set (function + symptoms + social risk)

To preserve feasibility, SLP extends the core IYS-G mini-set (Section 4.5) with a function-anchored layer designed for rapid clinical decision-making. The goal is not maximal phenotyping, but to define a minimum viable dataset that (i) detects decline early, (ii) assigns a phenotype, and (iii) triggers a time-bounded response within the next 7–14 days. Recommended elements (select one per domain where multiple options exist): (1) mobility/fitness: 6-minute walk test or 30-second sit-to-stand; (2) strength: handgrip strength or 5-times sit-to-stand; (3) symptoms: brief fatigue + pain item pair (or equivalent PRO snapshot) integrated with routine ePRO streams [32]; (4) neurotoxicity/falls: a short gait/balance screen plus fall history; (5) nutrition risk: a 2–3 item rapid screen (weight loss + appetite); (6) socioeconomic strain: a single-item hardship prompt to activate navigation (aligned to financial toxicity constructs) [22]. Each element is paired with a deterministic action rule (below), enabling continuity to be governed as a reliability problem rather than a clinician-by-clinician style choice.

A.3. Impairment phenotypes and matched packages

Phenotyping is intentionally pragmatic: the purpose is to choose a package, not to name a syndrome. Five core phenotypes cover most ambulatory oncology scenarios and can be expanded locally. Phenotype 1—Deconditioning/aerobic capacity loss: declining walk distance or exertional intolerance; Phenotype 2—Sarcopenia/anabolic resistance: rapid weight loss, reduced strength, or functional slowing; Phenotype 3—Neurotoxicity and balance impairment: gait instability, numbness/tingling with functional impact, falls/near-falls; Phenotype 4—Cardiopulmonary limitation: dyspnea on minimal exertion, marked tachycardia response, therapy-associated cardiopulmonary constraints; Phenotype 5—Upper-limb dysfunction/lymphedema risk (region-specific): pain, stiffness, swelling risk after surgery or radiotherapy. For each phenotype, SLP prescribes a ‘minimum effective package’ comprising: (i) a defined first-line intervention, (ii) a safety gate, (iii) an escalation trigger, and (iv) an outcome metric tracked within the Learning System cycle (Section 3.5). This design matches the exercise/rehabilitation guideline logic in oncology, while keeping the workflow compatible with high-throughput clinics [19–21].

A.4. Prehabilitation module (perioperative and treatment-intensification windows)

Prehabilitation is the archetypal continuity intervention because it treats the pre-treatment window as actionable time rather than ‘waiting.’ Multimodal programs typically combine structured exercise, nutrition optimization, and psychological preparation. Evidence suggests consistent improvements in preoperative functional capacity and, in several syntheses, shorter length of stay; however, effects on 30-day complications are heterogeneous, and at least one large randomized trial in frail colorectal cancer patients embedded within enhanced recovery pathways did not show a reduction in complications [33–36]. This mixed evidence is not a weakness of SLP; it is precisely the reason SLP requires auditable action rules and subgroup learning rather than a one-size-fits-all promise.

Operational specification within SLP: (i) Eligibility: any patient facing major surgery or an imminent escalation of systemic therapy with baseline functional vulnerability; (ii) Time-box: 2–4 weeks when possible, with ‘micro-prehab’ (7–10 days) allowed when timelines are constrained; (iii) Core dose: aerobic activity on ≥ 3 days/week plus resistance work ≥ 2 days/week, adapted to risk; (iv) Nutrition: protein-forward counseling with supplementation when intake is poor; (v) Psychological: brief coping/expectation alignment to reduce avoidance and improve adherence. Outcome tracking is mandatory: change in walk distance or sit-to-stand

performance; unplanned admissions; and the patient's ability to initiate planned therapy on schedule. In SLP terms, prehabilitation is treated as a Continuity Engine 'response module' that is evaluated like any other system intervention: by effect size, equity gradient, and safety profile, not by rhetoric [8,19–21,36].

A.5. Rehabilitation module during active therapy and survivorship

Impairment-driven rehabilitation during systemic therapy is a cornerstone of sustained living because it protects function as a treatment-enabling resource. For deconditioning and fatigue, combined aerobic and resistance training remains the best-supported strategy, with personalization and symptom-aware dosing recommended across major guideline syntheses [20,21]. For neurotoxicity and balance impairment, the operational priority is fall-risk reduction through early detection, targeted balance work, strength training, footwear/assistive adaptations, and rapid escalation when safety thresholds are crossed [19–21]. For upper-limb dysfunction and lymphedema risk, early range-of-motion restoration, progressive loading, and education to recognize early swelling or heaviness can be integrated into routine post-treatment follow-up without burdening oncologist visit time [19].

A.6. Safety gates and escalation triggers (non-negotiable reliability rules)

To avoid the common misinterpretation that 'rehabilitation means exercise for everyone,' SLP encodes explicit safety gates. Immediate escalation is recommended for: (i) chest pain, syncope, or new resting dyspnea; (ii) suspected spinal cord compression or new focal neurologic deficit; (iii) uncontrolled pain or delirium impairing safe participation; (iv) febrile neutropenia suspicion; (v) recurrent falls, or any fall with injury; (vi) rapidly progressive edema suggestive of thrombosis or cardiopulmonary decompensation. These gates align the action layer with patient safety and preserve trust by preventing 'over-prescription' in high-risk states. Where advanced disease trajectories are present, the action layer is coordinated with early integrated supportive/palliative care so that function protection complements symptom relief rather than competing with it [8,12].

A.7. Implementation notes: staffing, digital enablement, and equity auditing

Implementation should mirror SLP's equity-first governance. A minimal team composition includes a rehabilitation clinician (PT/OT), a navigator (social work or nurse-led), and an oncology clinician sponsor; psychology and nutrition support can be embedded or referral-linked depending on resources. Digital enablement is optional but accelerative: ePRO streams can flag deterioration between visits, while dashboards should stratify access, uptake, and outcomes by socioeconomic markers to prevent 'continuity privilege' where only advantaged patients receive timely supportive modules [7,22,32]. Finally, the action layer must be evaluated as part of the Learning System cycle: if a module fails to improve function, reduce acute-care use, or narrow disparities in a local population, SLP requires adaptation rather than defensiveness—this is the practical meaning of a continuity-of-living infrastructure.

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