

Sustained Living: An JAMA-Aligned Psychosocial and Impairment-Driven Rehabilitation Model for Adult Oncology

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ABSTRACT

Background: We provide a clinic-ready synthesis of psychosocial determinants in cancer care and operationalize a Sustained Living framework integrated with Lifelong Rehabilitation for routine practice. **Methods:** We conducted a narrative review emphasizing pragmatic evidence from guidelines and randomized or observational studies on distress screening (Distress Thermometer), brief mood measures (PHQ-4, HADS), patient-reported outcomes (EORTC QLQ-C30, PROMIS), financial toxicity (COST), rehabilitation and exercise, meaning-centered and dignity therapies, caregiver interventions, and electronic symptom monitoring. Themes were mapped to ethical principles: dignity, autonomy, and justice and translated into implementable ambulatory workflows with explicit thresholds, reassessment cadence (4–8 weeks), and role-based referrals. **Findings:** Distress is common and actionable; threshold-based screening (e.g., DT ≥ 4) supports stepped assessment and matched referral to psychology, rehabilitation, and navigation. Early multimodal psychosocial and rehabilitation interventions improve quality of life, reduce depression, and sustain participation. PRO-anchored monitoring lowers emergency use and may extend survival. Financial toxicity is measurable with COST and mitigable through benefits counseling and navigation. Figures and tables provide a triage algorithm, an impairment-driven rehabilitation pathway, core PRO domains/measures/actions, and a financial-toxicity toolkit to support rapid adoption in routine clinics. **Implications for Practice:** Embedding structured screening, targeted referral, and PRO-informed follow-up as standard work enables ambulatory oncology teams to deliver equitable, value-based care while centering dignity, autonomy, and functional recovery. The Sustained Living paradigm reframes advanced cancer care around living-normalizing rehabilitation, goal setting, and social reintegration from diagnosis through end of life, and aligning practice with what patients value most. We prioritized validated tools and high-impact guidance for feasibility and implementation.

Keywords: Psychosocial oncology; Distress screening (Distress Thermometer); Patient-reported outcomes (EORTC QLQ-C30; PROMIS); Cancer rehabilitation; Financial toxicity (COST); Sustained Living paradigm

Context Summary

Context (JCO required 3-part summary)

Key Objective: To synthesize psychosocial determinants in cancer into a clinic-ready Sustained Living paradigm that integrates Lifelong Rehabilitation and standardized screening, referral, and PRO-anchored follow-up.

Knowledge Generated: Distress, functional decline, and financial toxicity are common, measurable, and actionable; threshold-triggered workflows (e.g., DT ≥ 4 ; PROMIS bands; COST triggers) enable matched referral, reduce acute-care use, and may extend survival [1–4,8–13,19–21].

Relevance: The proposed language and workflow shift aligns ambulatory oncology with dignity, autonomy, and justice while improving feasibility and equity through navigator-led loops and EHR-embedded metrics [2–7,9–12,19–21].

INTRODUCTION

Across contemporary oncology, survival has lengthened even for people living with advanced disease, yet routine ambulatory care still operates on a curative-first, palliative-later sequence that many patients perceive as fatalistic and stigmatizing [1–5]. Terminology shapes acceptance and timing: identical supportive services are embraced earlier when framed as “supportive” or “rehabilitation” than when labeled “palliative,” despite equivalent clinical content [2–5]. In parallel, three modifiable burdens remain common and under-addressed in daily practice: psychological distress, functional decline, and financial toxicity [6–13,19–20]. Each is measurable with validated instruments, linked to effective interventions, and trackable over time; yet in busy clinics, screening is inconsistent, referrals are delayed, and follow-up is ad hoc [8–13]. We respond with a title-aligned reframing: Psychosocial Determinants in Cancer are operationalized through the Sustained Living paradigm—a life-centered, rehabilitation-forward approach from diagnosis through end of life [1,4–7,9–12].

METHODS

We undertook an integrative narrative synthesis spanning psychosocial oncology, rehabilitation medicine, survivorship, supportive care, implementation science, and health services research. We prioritized randomized and high-quality observational studies, society guidelines, and consensus statements with explicit operational recommendations [1–4,8–13,16, 18–21]. Using critical thematic analysis, convergent findings were mapped to three ethical anchors—dignity, autonomy, and justice—and translated into a pragmatic bundle comprising universal screening, needs-matched referral, patient-reported outcome (PRO)-anchored follow-up, impairment-driven rehabilitation, and a financial-navigation pathway with auditable metrics [8–13,16,19–21]. Feasibility and face validity were iteratively stress-tested through multispecialty dialogues (medical oncology, psycho-oncology/psychiatry, rehabilitation, nursing, social work, financial counseling, navigation). Visual schemas (triage algorithm; impairment-driven rehabilitation pathway; financial-toxicity toolkit) were designed for point-of-care use and are provided as figures and tables.

Rationale and Evidence

Language as a clinical instrument. Trials and implementation studies demonstrate that framing influences timing of referral and utilization of supportive services [2–5]. Persisting with terms that patients link to imminent death can delay uptake of beneficial interventions, inadvertently producing harm through under-use [2–4]. The Sustained Living label communicates continuity, adaptation, and agency without obscuring prognosis, increasing the likelihood of earlier engagement with psychosocial and rehabilitative care [3–5]. Language is not cosmetic; it is a modifiable determinant of equitable access and timely benefit.

Distress is common and actionable. Clinically meaningful distress affects a large minority of people with cancer and surges around transitions (diagnosis, regimen change, progression) [8,18]. The one-item Distress Thermometer (DT) with problem checklist is rapid, multilingual, and implementable at rooming. A pragmatic threshold of $DT \geq 4$ balances sensitivity and specificity and should auto-trigger secondary mood screening (PHQ-4 or HADS), brief safety queries, problem-list review, and matched interventions [8–12,18]. Programs that screen and act (rather than screen only) improve mood and quality of life and reduce unplanned acute care [9–12]. When clinics clarify the post-screen pathway and assign ownership, adherence rises and false-positive burden falls.

PRO-anchored monitoring reduces acute care and may extend survival. Randomized and quasi-experimental studies of routine, electronic symptom reporting show fewer emergency visits and hospitalizations, better health-related quality of life, and, in selected settings, survival gains—likely via earlier detection of deterioration, timely medication/rehab adjustments, and preserved treatment continuity [9–11,21]. Embedding EORTC QLQ-C30 (global health) and PROMIS short forms (physical function, fatigue, pain interference, depression, anxiety) provides a light-touch scaffold for longitudinal management [10–12,21]. With brief triage rules and navigator callbacks, PRO systems become a protective layer around patients between visits.

Rehabilitation preserves independence and roles. Predictable cancer- and treatment-related impairments—fatigue/deconditioning, neuropathy, lymphedema, pain, dysphagia or voice change, cognitive complaints—respond to impairment-driven, discipline-specific therapy (PT/OT/Speech) with graded exercise and environmental adaptations [14–16,22]. Brief functional screens (e.g., PROMIS PF-4/6; two-question stairs/transfers items) are highly actionable; reassessment every 4–8 weeks documents progress, adapts plans, and prevents drift [14–16]. Rehabilitation is both restorative and preventive, preserving participation in valued roles at home and work.

Financial toxicity is measurable and mitigable. Financial burden predicts worse adherence, quality of life, and, in some studies, survival [19–20]. The Comprehensive Score for Financial Toxicity (COST) quantifies burden; serial measurement at baseline, at regimen/coverage changes, and every 2–3 cycles enables navigator-led benefits counseling, formulary optimization, manufacturer assistance, transportation support, and wage-replacement paperwork [19–20]. Tracking time-to-first intervention and interruption-free treatment provides auditable markers of value and equity.

The Sustained Living Paradigm

Definition. A person-centered, equity-focused paradigm that normalizes living with advanced cancer by embedding psychosocial care, restoration-focused rehabilitation, and social reintegration from diagnosis through end of life—guided by what patients value most [5–7].

Ethical anchors. Dignity, autonomy, and justice structure the model. Dignity conserves personhood and meaning using teachable micro-skills in every encounter [6–7]. Autonomy is operationalized through co-produced goals of care and the “dignity of risk,” revisited as circumstances evolve [5–6]. Justice requires universal screening and navigational equity with routine language access and stratified metrics that reveal and close gaps [8–13,19–20].

Operational Standards (Clinic-Ready)

- 1) Universal screening at every ambulatory encounter. Distress: DT at rooming; $DT \geq 4 \rightarrow$ PHQ-4/HADS within 24–72 h; red flags (active suicidality, delirium, uncontrolled pain, severe dyspnea) prompt same-day escalation [8–12,18]. Function: PROMIS PF (4–6 items) monthly on treatment and quarterly off treatment; a ≥ 5 -point T-score drop or new mobility self-report triggers rehabilitation referral [14–16,21]. Financial burden: COST at baseline, at regimen/coverage changes, and q2–3 cycles; below-threshold scores activate navigation [19–20]. Social risks: transportation, caregiver capacity, housing or food security assessed at treatment start and transitions [12,19].
- 2) Needs-matched referral via a single-click order set. Positive screens open psycho-oncology/psychiatry, PT/OT/Speech, pain/palliative medicine, social work/navigation, nutrition, chaplaincy/spiritual care, and peer support. Clinics define response times (urgent same-day for danger signals; routine within seven days for non-urgent $DT \geq 4$) and track positive-screen capture as a core quality indicator [9–12].
- 3) PRO-anchored follow-up cadence. Use EORTC QLQ-C30 plus PROMIS short forms (depression, anxiety, fatigue, pain interference, sleep disturbance, social participation). Action thresholds include sustained $DT \geq 4$, movement to a worse PROMIS severity band, or ≥ 10 -point decline in EORTC global health [10–12,21].
- 4) Impairment-driven rehabilitation. Short triage (strength, balance, transfers, gait, speech/swallow, ADL/IADL) directs the first discipline. Safety checks (bone stability, cytopenias, orthostasis, cardiopulmonary reserve) precede prescriptions following an adapt-don’t-stop logic; reassessment at 4–8 weeks is routine [14–16,22].
- 5) Financial-toxicity pathway. Navigator-owned workflow covers benefits optimization, authorizations/appeals, formulary/generics, manufacturer assistance, transportation vouchers, wage-replacement/leave paperwork, and charity resources. Metrics: days from COST trigger to first intervention; ≥ 3 -point COST improvement at eight weeks; cost-related treatment interruptions [19–20].
- 6) Goal-concordant planning. Patients identify 1–3 personally meaningful goals; teams align symptom control, rehab blocks, and scheduling; goal-attainment scaling provides an auditable outcome [5–7].
- 7) Team coordination and EHR infrastructure. A named RN/MA navigator checks screens, fires order sets, tracks due dates in a daily huddle, and closes referral loops. Templates capture screen→action→reassessment; flowsheets display last three scores with deltas [9–12].

- 8) Equity safeguards. Professional interpreters; low-literacy instruments and icon-guided interfaces; tele-psychology and tele-rehabilitation to reduce travel barriers. Monthly dashboards stratified by age, sex, language, insurance, and neighborhood deprivation detect disparities and trigger countermeasures [12,19].
- 9) Measurement for improvement. Starter metrics: (a) screening coverage; (b) capture within seven days; (c) time-to-first action; (d) proportion achieving ≥ 10 -point EORTC global health or ≥ 3 –5 PROMIS-point improvement within 4–8 weeks. Secondary: ED visits, hospital days, adherence, and goal-attainment [9–12,21].
- 10) Language transformation. Introduce the program as the Sustained Living & Rehabilitation Team; if patients prefer “palliative,” use it with the same operational supports [2–5].

Visit-Level Algorithm (Ten-Minute Flow)

Rooming includes vitals plus DT and two function questions (stairs, transfers). Any positive flag auto-opens the order set and schedules a brief tele-follow-up within 72 hours to confirm initiation. Before clinician entry, the flowsheet shows last PRO values with color-coded changes. During the encounter, the clinician verifies safety, elicits near-term goals, and selects one or two high-yield actions (e.g., neuropathy regimen plus graded activity; sleep intervention plus brief CBT). End-of-visit tasks confirm accepted referrals, identify barriers (copay, transport), and set next PRO cadence. Within 48–72 hours, the navigator ensures medication/equipment access and appointment scheduling; unresolved barriers are brought to the next huddle [9–12,15].

Core Instruments, Thresholds, Safety

Distress: DT 0–10 with problem checklist; $DT \geq 4 \rightarrow$ PHQ-4/HADS. PHQ-4 ≥ 6 or HADS subscale ≥ 8 prompts structured assessment; HADS ≥ 15 or suicidality triggers urgent evaluation [8–12,18]. Function: PROMIS PF T-scores in the low-40s or a ≥ 5 -point drop are meaningful; PROMIS Fatigue/Pain Interference in the high-60s signals targeted intervention [14–16,21]. Participation: PROMIS “Ability to Participate in Social Roles and Activities” aligns with everyday goals; a one-category worsening merits action [21]. Safety: red flags include uncontrolled pain, acute confusion, falls with injury, progressive dysphagia/aspiration risk, unstable spine or long-bone metastases, severe thrombocytopenia, and uncontrolled cardiopulmonary disease; adapt-don’t-stop menus specify safe alternatives [14–16,22].

Equity and Access

Interpreter services, culturally concordant materials, and flexible visit modalities are baseline features [12,19]. Navigation treats transport or childcare as solvable clinical barriers. Dashboards stratified by language and insurance track who is screened, who receives action, and who benefits; disparities prompt countermeasures (fast-track tele-psycho-oncology and PT slots; ride vouchers). For limited digital access, clinics provide tablets; paper instruments are accepted and back-entered. For low literacy, tools are read aloud with teach-back. Community health workers and peer navigators extend reach, especially in rural and marginalized communities [12,19–21].

Communication and the Ethics of Hope

Sustained Living balances realism with hope. Scripts clarify that the program does not deny prognosis; it protects time, function, and identity during treatment. Dignity-conserving practices—attending to personhood, roles, and meaning; avoiding depersonalizing labels—are built into routine encounters [6–7]. Family meetings (agenda, teach-back, summary) use interpreters when needed. Goals-of-care documentation occurs early and at transitions; decision aids clarify trade-offs (toxicity versus participation). Chaplaincy is offered by preference [6–7].

Caregivers and the Household as the Unit of Care

Caregivers often experience parallel burden. Two quick questions—How are you coping? and What would make this week easier?—plus targeted referrals (respite, support groups, navigation) reduce burnout and enable sustained participation. Where caregiver capacity is limited, navigation coordinates community resources. Caregivers receive micro-training on safe transfers, energy conservation, and symptom observation; caregiver-reported burden and satisfaction inform huddle decisions [12,16,19].

Digital Health, Remote Monitoring, and Pragmatic AI

Remote symptom reporting extends PRO-anchored monitoring; threshold-based alerts (sudden dyspnea, fever, severe anxiety) prompt nurse callbacks and medication or visit adjustments [9–11,21]. Triage rules are encoded as EHR order sets; thresholds remain clinician-owned. Pragmatic AI may pre-triage portal messages and pre-populate structured notes with human oversight and bias audits [21].

Health-System Integration and Governance

Sustained Living is a platform rather than a bolt-on program. Governance includes a dyad (clinical and operations leads), a navigator chair, and quarterly stakeholder meetings. The group reviews metrics, bottlenecks, and equity dashboards; maintains order sets and templates; and names clinic champions. Leadership commits to protected navigator time and seed funding for tablets and tele-slots [12,19–21].

90-Day Implementation Roadmap Phase 1 (Weeks 0–4): Build the spine—add DT to rooming; embed PHQ-4/HADS triggers; load EORTC/PROMIS; create the triage order set; launch the navigator huddle; select metrics; appoint champions; map local capacity [9–12,21]. Phase 2 (Weeks 5–8): Train to fluency—micro-modules (why we screen; cut-points/actions; rehab safety triage; financial basics), role-play difficult conversations; escalation drill; finalize documentation shortcuts [10–12,14–16]. Phase 3 (Weeks 9–12): Pilot and iterate—start in one clinic; review metrics weekly; address access bottlenecks (tele-group CBT; tele-rehab); co-design fixes with scheduling/billing; share early wins; scale to all clinics [12,19–21].

Quality Improvement and Learning Health System

Teams maintain monthly run charts for starter metrics and share one-slide postcards (change, data, lesson, next step). Clinics review distress-related crises or near-misses, refining scripts and escalation. A semiannual measure refresh trims unused fields and updates thresholds; patient councils co-create materials; cross-site exchanges accelerate learning; equity dashboards are reviewed with community representatives [12,19–21].

Health Economics and Value

By reducing emergency use via earlier symptom action and preventing secondary complications through rehabilitation, Sustained Living advances value-based care [9–12,14–16,21–22]. The financial-toxicity pathway addresses affordability barriers that cause interruptions. A pragmatic pro forma tracks ED visits per 100 infusion cycles, inpatient days per 100 patients on therapy, treatment interruptions, navigator-mediated assistance, and paired PRO improvements (EORTC global health; PROMIS domains) [12,19–21].

Workforce, Training, and Well-Being

Sustained Living redeploys existing roles. The navigator anchors workflow; PT/OT/Speech deliver impairment-specific therapy; social work and financial counseling address affordability and logistics; psycho-oncology provides mood and existential support; palliative medicine contributes complex symptom expertise [14–16,19]. Aligning daily work with what patients value most can improve clinician moral coherence and reduce burnout; structured templates shorten notes; visible PRO gains validate effort [10–12,21].

Data and EHR Integration

Templates capture DT, PHQ-4/HADS, and EORTC/PROMIS; auto-populate cut-point guidance; and generate one-click referrals. Flowsheets show the last three values with deltas; alerts fire when thresholds are crossed. Portals display trends and vetted self-management tips. When patients receive chemotherapy in one facility and rehabilitation nearer home, interoperability or a one-page living plan ensures continuity [10–12,21].

Safety, Risk Management, and Documentation

Templates include safety questions (suicidality, falls, delirium features), medication reconciliation, and red-flag prompts (fever, bleeding, severe pain). Every positive screen generates a screen-to-action link, closing the loop. Phone triage protocols include escalation ladders; documentation emphasizes informed consent for rehabilitation and shared decisions around goal-concordant trade-offs [14–16,19].

Cross-Cultural and Linguistic Adaptation

Select validated translations for DT, HADS, EORTC, and PROMIS; use trained interpreters and culturally concordant materials; invite patients to name spiritual or communal practices that sustain meaning. Partnerships with community groups extend reach; bilingual staff and peer navigators close engagement gaps. Teams monitor whether language choice predicts delays or lower benefit and adjust messaging/logistics accordingly [12,19–21].

Special Populations

Older adults: integrate gait speed, grip strength, medication simplification, fall prevention, and caregiver training; involve geriatric expertise when available [14–16]. Adolescents and young adults: attend to schooling, fertility, peer connection, and autonomy; offer digital engagement; involve families with consent [21]. Rural patients: rely on tele-rehab and tele-psychology, home exercise kits, local PT partnerships; provide travel aid for key milestones [19–21]. Cognitive impairment: shorten instruments, use care-partner reports, emphasize environmental adaptations and safety skills [14–16]. Limited literacy or digital access: staff-administered PROs or paper with back-entry; icon-guided, language-flexible interfaces [12,19–21].

Case Vignettes

Vignette 1—Metastatic breast cancer, working parent. A 46-year-old on CDK4/6 inhibitor reports DT 6 with sleep problems and worry; PHQ-4 = 7; PROMIS Social Roles declines and Fatigue is elevated. Navigation triggers psycho-oncology, sleep coaching, group CBT; PT prescribes graded activity; social work secures childcare support. At six weeks, DT falls to 3 and she returns to part-time work—her primary goal [9–12,21].

Vignette 2—Head and neck cancer survivor with dysphagia. Post-chemoradiation, a 63-year-old reports aspiration and weight loss. Speech-language pathology initiates swallow therapy and compensatory strategies; nutrition supports calorie-dense options; PT restores shoulder/neck mobility. After eight weeks, he tolerates a broader diet and resumes communal meals—his participation goal [14–16,22].

Vignette 3—Metastatic colorectal cancer and cost barriers. A 58-year-old reports COST 16 and difficulty affording antiemetics. Navigation activates assistance programs, switches to formulary alternatives, and supports wage-replacement paperwork. Treatment interruptions cease; COST improves to 22; ED visits drop to zero [19–20].

Vignette 4—Elderly patient with painful bone metastases. An 82-year-old with limited caregiver support has DT 5 and functional decline; safety triage reveals unstable spine lesions. Rapid palliative radiotherapy is arranged; a walker and seated strength program are initiated. At six weeks, transfers improve and falls cease [14–16,22].

Integration with Clinical Trials and Research

Routine PRO capture improves adverse-event detection and dose titration; rehabilitation preserves performance status and adherence; navigation reduces missed visits due to transport or cost barriers [9–12,21]. For implementation research, stepped-wedge or cluster designs can compare outcomes before and after adoption; factorial designs can test rehabilitation intensity or navigator dose. Goal-attainment and dignity measures warrant concise validation across languages [6–7,21].

Policy and Reimbursement

Rehabilitation and psycho-oncology are typically billable; navigation can be supported through care-management codes or institutional quality budgets. Value-based contracts reward reduced acute-care use and improved PROs; the Sustained Living bundle provides the mechanism. Societies can reinforce early routine supportive integration by embedding cut-points, reassessment cadence, and referral standards into guidelines; payers can support tele-rehab and tele-psychology reimbursement to expand equity [12,19–21].

Research Agenda and Limitations

While each component—distress screening, PRO-anchored monitoring, rehabilitation, and financial navigation—has robust evidence, the combined bundle and the Sustained Living label merit pragmatic evaluation. Priorities include stepped-wedge trials, factorial designs, cost-effectiveness across systems, and qualitative studies on how language influences engagement in diverse cultures [2–5,9–12,14–16,19–21]. Generalizability depends on local access to psycho-oncology and rehabilitation; tele-enabled models mitigate

supply constraints. EHR capabilities vary, but the screen→action→reassessment template is transferable with minimal burden [9–12,21].

CONCLUSIONS

Psychosocial determinants in cancer—distress, function, and affordability—are measurable and actionable. The Sustained Living paradigm translates ethics into clinic-ready routines: DT ≥ 4 universal screening, rapid PHQ-4/HADS follow-up, needs-matched referral, PRO-anchored monitoring (EORTC/PROMIS), impairment-driven rehabilitation, and a navigator-led COST pathway [8–13,14–16,19–21]. The paradigm does not replace disease-modifying therapy; it ensures structured access to interventions that preserve identity, agency, and connection. Implemented as standard work, Sustained Living enables equitable, value-aligned care while centering what matters most to patients: living as well as possible, for as long as possible [1–4,9–12,21].

Practical Methods Expansion

Search strategy emphasized feasibility and implementability. We queried MEDLINE and guideline repositories using combinations of distress screening, Distress Thermometer, PHQ-4, HADS, EORTC QLQ-C30, PROMIS, patient-reported outcomes monitoring, cancer rehabilitation, meaning-centered and dignity therapies, caregiver interventions, financial toxicity, and COST. We emphasized randomized and pragmatic trials, high-quality observational cohorts, authoritative guidelines, and consensus statements that provided operational cut-points or workflows [1–4,8–13,14–16,18–21]. A working group piloted the bundle in simulated visits to ensure that screen→action→reassessment could be completed within routine appointment windows and that follow-up cadence and escalation rules were realistic for community and academic settings alike.

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