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A New Paradigm in Psychosocial Oncology: Integrating Lifelong Rehabilitation and Social Reintegration into Cancer Survivorship

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1. Abstract

1.1. Background

Patients with Stage III and IV cancers often encounter a care model labeled “palliative care,” which traditionally focuses on comfort in the face of life-limiting illness. Growing evidence indicates that this terminology and approach can inadvertently undermine patient hope and engagement (pmc.ncbi.nlm.nih.gov). This article argues that the term palliative care is conceptually and ethically problematic for advanced cancer patients, as it is frequently perceived as synonymous with imminent death and cessation of active living (pmc.ncbi.nlm.nih.gov).

1.2. Purpose

We propose a transformative paradigm shift in psychosocial oncology - replacing “palliative care” with a Sustained Living paradigm (“Idame Yasam” in Turkish) centered on dignity, agency, psychosocial presence, and continuity of life for patients with advanced cancer. We introduce a Lifelong Rehabilitation Model, integrating continuous rehabilitation and social reintegration into cancer survivorship from diagnosis through end-of-life. Methods: A comprehensive narrative review and critical analysis of literature was conducted, spanning psychosocial oncology, palliative care, rehabilitation medicine, and bioethics. Key themes were identified regarding shortcomings of the current paradigm and the potential benefits of an integrated lifelong care approach. Results: Three principal findings emerged: (1) The term “palliative care” carries stigma and misconceptions that deter its early uptake and effectiveness (pmc.ncbi.nlm.nih.govpubmed.ncbi.nlm.nih.gov); (2) Advanced cancer patients have substantial unmet psychosocial, rehabilitative, and social needs under current care models (spcare.bmj.commascc.org); (3) A rehabilitative, life-affirming approach can improve quality of life, emotional well-being, and even survival in advanced cancer (nejm.orgbiomedcentral.com). Building on these insights, we delineate the Sustained Living paradigm and Lifelong Rehabilitation Model as a unified framework. Discussion: We explore how this model reframes end-stage care as a continuation of survivorship, preserving patient dignity and autonomy. We present conceptual schema options (layered, circular, longitudinal) to visualize the model, and discuss policy implications for adopting Sustained Living globally. Conclusion: The Sustained Living paradigm represents a new global approach to advanced cancer care - one that rejects the passive connotations of “palliative” in favor of an active, person-centered continuum of care supporting patients to live fully, with dignity and agency, until end of life. Adopting this paradigm could harmonize medical, psychosocial, and rehabilitative efforts, transforming cancer survivorship and end-of-life care worldwide.

2. Introduction

Modern oncology has achieved significant advances in prolonging survival even for advanced (Stage III and IV) cancers, yet the psychosocial and philosophical framework of end-stage care remains rooted in a paradigm that many patients and providers find problematic. The term “palliative care” has traditionally been used to describe care for patients with life-limiting illness, focusing on symptom relief and comfort when cure is no longer possible. However, a growing body of literature critiques this terminology and its implied approach. Patients often perceive “palliative care” as meaning “you’re going to die”a message of finality that can strip away hope and engagement (pmc.ncbi.nlm.nih.gov). Zimmermann et al. (2016) found that many advanced cancer patients and caregivers see the label palliative as stigmatizing, associating it with giving up active treatment(pmc.ncbi.nlm.nih.gov). In a randomized study, Maciasz et al. (2013) demonstrated that patients viewed the name “supportive care” far more favorably than “palliative care”, despite identical services offered(pubmed.ncbi.nlm.nih.govpubmed.ncbi.nlm.nih.gov). These findings underscore that terminology profoundly shapes patient attitudes and willingness to utilize services (pubmed.ncbi.nlm.nih.gov). Conceptually, the Latin root of palliative (“palliare” - to cloak (pmc.ncbi.nlm.nih.gov) hints at care that “covers up” or masks suffering, rather than actively fostering life. Ethically, deploying this term for Stage III/IV patients—many of whom may live with cancer for months or years-can be seen as incongruent with the principles of patient-centered care and autonomy. It may prematurely orient care towards death, rather than life, causing distress and a sense of abandonment in patients who are still striving to live with cancer (pmc.ncbi.nlm.nih.gov).

Meanwhile, the field of psychosocial oncology has illuminated the extensive emotional, social, and existential challenges faced by cancer patients across the disease trajectory. Advanced cancer patients frequently report high levels of unmet needs in domains such as psychological support, information, daily living assistance, and social connection (spcare.bmj.com). For example, a Dutch study of patients with advanced cancer and their families identified psychological issues, along with financial and informational concerns, as the most prevalent unmet needs (spcare.bmj.com). Globally, up to one-third of all cancer patients experience clinically significant distress, and this proportion is even higher among those with late-stage disease (thelancet.com). Yet under current models, psychosocial support and rehabilitation services are often introduced late, if at all, in the illness course. Palliative care services—when offered-do encompass psychosocial and spiritual care in principle, following the World Health Organization’s definition of palliative care as an approach to improve quality of life for patients and families facing life-threatening illness. In practice, however, referrals to palliative care typically occur very late (e.g., only in the final weeks of life), and many patients in Stage IV never receive dedicated supportive care beyond ad-hoc symptom management (pmc.ncbi.nlm.nih.gov). Zimmermann et al. (2022) argue that the prevailing model of palliative care is “neither widely known by patients and their caregivers nor consistently practiced” as early as it should be (pmc.ncbi.nlm.nih.gov). This gap leaves many advanced cancer patients in a liminal state-no longer pursuing cure, but not receiving the comprehensive support they need to live as well as possible.

The central argument of this article is that a new paradigm is urgently needed to reframe care for advanced-stage cancer patients. We contend that the term “palliative care” should be critically re-evaluated and ultimately replaced for this population. Instead of a paradigm implicitly centered on dying, we propose one explicitly centered on living: a concept we term “Sustained Living.” In Turkish, this concept is captured by “Idame Yasam,” meaning “ongoing or maintained life,” highlighting a commitment to continuity and endurance of life’s qualities even in the face of terminal illness. The Sustained Living paradigm posits that patients with advanced cancer remain cancer survivors - a designation traditionally reserved for those post-treatment - and that they are entitled to ongoing rehabilitation, meaningful social roles, and life-affirming care until death. This notion builds on the National Cancer Institute’s broad definition of a cancer survivor as encompassing anyone from the moment of diagnosis through the remainder of life (journalofethics.ama-assn.org). By viewing late-stage patients as survivors living with cancer, rather than as terminal patients simply awaiting death, we can unlock a more empowering approach to care.

In this paper, we introduce the Lifelong Rehabilitation Model, which integrates medical, physical, psychosocial, and community support in a continuous care pathway for advanced cancer patients. This model treats rehabilitation and social reintegration as ongoing processes parallel to oncologic treatment, not as post-curative afterthoughts. Our approach is informed by emerging trends in oncology and palliative medicine. Notably, there have been calls to consider metastatic cancer as a chronic condition in need of long-term supportive management, given that many Stage IV patients now live for extended periods due to improved therapies (mascc.org). The Multinational Association of Supportive Care in Cancer (MASCC) and American Society of Clinical Oncology (ASCO) recently convened an expert panel that emphasized the unique needs of people with advanced or metastatic cancer and the importance of survivorship care standards for this group (mascc.org). This signifies a paradigm shift acknowledging that survivorship principles (such as rehabilitation, health promotion, and coordinated care) should apply concurrently with treatment for advanced disease, not just after remission (mascc.org).

Furthermore, innovative approaches within palliative care itself have laid groundwork to build upon. The concept of rehabilitative palliative care championed in hospice settings focuses on enabling patients to “live fully until they die,” emphasizing goals like autonomy, functional maintenance, and personal priorities (hukstage-new-bucket.s3.eu-west-2.amazonaws.com). Tiberini and Richardson (2015) note that the priorities of people living with advanced illness revolve around choice, autonomy, and dignity (hukstage-new-bucket.s3.eu-west-2.amazonaws.com). These values align closely with the ethos of Sustained Living. However, rehabilitative palliative care has struggled to gain widespread implementation, partly because it remains under the umbrella of “palliative” terminology. By contrast, our proposed Sustained Living paradigm seeks to mainstream such rehabilitative and psychosocial efforts by removing the conceptual barrier of the palliative label and embedding rehabilitation and social support as core components of standard care for advanced cancer.

This article is structured as follows. We first describe our methods in developing this paradigm, including literature synthesis and conceptual modeling. We then present key results of our analysis, identifying critical shortcomings of the traditional approach and evidentiary support for our proposed model. Next, we provide detailed dedicated sections on the Lifelong Rehabilitation Model (with suggested schema for its design) and the Sustained Living Paradigm, elaborating their philosophical and clinical foundations. In the Discussion, we compare this new paradigm to existing models, address potential challenges in implementation, and highlight its implications for patients, clinicians, and health systems. We also outline specific policy recommendations to facilitate a global shift toward Sustained Living in oncology care. Finally, we conclude with a call to action for integrating lifelong rehabilitation and social reintegration into cancer survivorship, thereby ensuring that even in the advanced stages, cancer care remains about living and not only about dying.

3. Methods

This work is a conceptual analysis and model development study informed by a narrative review of the literature and expert insights from psychosocial oncology, palliative care, rehabilitation, and ethics. We followed an integrative methodology with the following components:

3.1. Literature Review

We conducted a comprehensive search of academic databases and gray literature focusing on advanced cancer care, including keywords such as “palliative care stigma,” “advanced cancer rehabilitation,” “psychosocial needs advanced cancer,” “cancer survivorship and Stage IV,” and “dignity in end-of-life care.” High-impact publications and guidelines were prioritized, including clinical trials, meta-analyses, and consensus statements. Notably, we reviewed evidence on outcomes of early palliative/supportive care interventions (nejm.org, studies on patient perceptions of palliative versus supportive terminologypubmed.ncbi.nlm.nih.govpubmed.ncbi.nlm.nih.gov), and emerging guidelines on survivorship care in metastatic cancer (mascc.org). We also drew from foundational works in palliative care philosophy (e.g., dignity-conserving care models (pubmed.ncbi.nlm.nih.gov).

3.2. Critical Thematic Analysis

Using an inductive approach, we extracted recurrent themes and gaps from the literature. We specifically examined (a) ethical and conceptual critiques of palliative care; (b) documented psychosocial and rehabilitative needs of advanced cancer patients; (c) proposed models of care delivery (e.g., integrative oncology-palliative models, rehabilitative palliative care, chronic illness frameworks); and (d) patient-reported priorities and values (such as maintaining normalcy, autonomy, social connectedness). These findings were mapped to identify misalignments between patient needs and existing care paradigms.

3.3. Concept Development

Based on the identified gaps, we engaged in an iterative process of concept development for a new care paradigm. This involved formulating the Sustained Living concept as a guiding philosophy and outlining the Lifelong Rehabilitation Model as a practical framework. We drew on principles from multiple disciplines: from rehabilitation medicine (emphasizing function and adaptation), from survivorship programs (emphasizing continuity of care beyond acute treatment), and from psychosocial oncology (emphasizing holistic support for emotional, social, and spiritual well-being). We also incorporated insights from chronic disease management models and disability studies, which promote enabling environments and patient empowerment despite health limitations.

3.4. Expert Consultation (Conceptual)

While no formal Delphi process was conducted for this paper, the first author (and colleagues in oncology, psychiatry, palliative care, and public health) engaged in collaborative discussions to refine the paradigm. These discussions functioned as informal expert consultations, challenging and stress-testing the model against realworld clinical experience and ethical standards. Feedback from these interdisciplinary dialogues helped shape the model's components (for example, highlighting the necessity of including family/caregiver support and community reintegration as key elements).

3.5. Schema Design Proposals

As part of the model development, we generated proposals for at least three conceptual schematics to represent the Lifelong Rehabilitation Model. These schema designs - described in a dedicated section below - were devised to facilitate visual thinking and can be refined in collaboration with the article's co-authors and future stakeholders. Designing multiple representations (layered, circular, longitudinal, etc.) ensures that the model can be communicated and understood from different perspectives.

3.6. Ethical Review

Given the ethical dimension of proposing to discard an established term ("palliative care"), we reviewed ethical guidelines and commentaries on end-of-life care terminology and practice. We ensured that the proposed paradigm upholds ethical principles such as beneficence (by improving supportive care), non-maleficence (by avoiding the harm of stigma or abandonment), autonomy (by centering patient agency), and justice (by aiming for equitable access to life-enhancing care for advanced cancer patients).

No human subjects were involved in this study; thus, institutional review board approval was not applicable. This research is rooted in analysis of published literature and theoretical synthesis. The Methods above culminated in the formulation of the Sustained Living paradigm and Lifelong Rehabilitation Model, which are presented in the Results and dedicated sections to follow.

4. Results

Our analysis yielded a set of key findings that inform the need for a new paradigm in advanced cancer care. These findings highlight fundamental problems with the status quo and point towards elements that a successful new model must incorporate. Below, we summarize these findings before elaborating on the proposed Lifelong Rehabilitation.

4.1. Model and Sustained Living paradigm

4.1.1. Terminology and Stigma

There is compelling evidence that the language used to describe end-stage cancer care significantly influences patient perceptions, acceptance, and even utilization of services. The term "palliative care," while intended by professionals to denote an added layer of support, often invokes fear and a sense of hopelessness in patients and families(pmc.ncbi.nlm.nih.gov). Zimmermann and colleagues (2022) reported that patients find the introduction of "palliative care" traumatic, interpreting it as a signal of "no hope" and an end to active life (pmc.ncbi.nlm.nih.gov). In quantitative terms, Maciasz et al. demonstrated that simply renaming a service "supportive care" improved advanced cancer patients' understanding of and willingness to use that service (pubmed.ncbi.nlm.nih.gov). Patients hearing "supportive care" had significantly more favorable impressions and higher perceived need for the service than those hearing "palliative care"(pubmed.ncbi.nlm.nih.gov). These results indicate that the traditional terminology is not a neutral descriptor; it carries emotional and existential weight that can negatively impact care. From an ethical standpoint, persisting in using terminology that provokes dread and potential disengagement could be seen as maleficent, in that it may inadvertently cause psychological harm or delay beneficial intervention. This finding underpins our recommendation to retire or radically redefine the term palliative care for Stage III/IV patients. It also suggests that any new paradigm must be framed in language that empowers and comforts rather than alienates patients.

4.1.2. Unmet Psychosocial and Rehabilitative Needs

Advanced cancer patients often experience a complex array of needs beyond tumor-directed medical treatment. Our review confirms that psychosocial needs (emotional support, mental health care, coping with existential distress), informational needs (understanding illness, prognosis, and care options), practical needs (managing symptoms, daily activities, financial concerns), and social needs (maintaining relationships, roles, and inclusion in society) are prevalent and insufficiently addressed. For instance, a systematic review of supportive care needs found that across cancer types, psychological and informational needs are among the most commonly unmet during the survivorship trajectory pmc.ncbi.nlm.nih.gov). In advanced disease, these needs are magnified as patients cope with greater symptom burden and uncertainty. Physical symptoms like pain or fatigue can lead to functional decline, yet access to rehabilitation services (physiotherapy, occupational therapy, pain management beyond medications, etc.) for advanced cancer patients is sporadic. Many advanced cancer patients are left to contend with mobility issues, weakness, or cognitive changes on their own or with minimal guidance, whereas a rehabilitative approach could help maintain function and independence longer. The literature on palliative rehabilitation suggests significant benefits: Nottelmann et al. in Denmark incorporated rehabilitation into oncology care for advanced cancer (the "Pal-Rehab" trial) and observed improvements in patients' quality of life and emotional well-being with a 12-week tailored program (biomedcentral.com). Likewise, a hospice-based rehabilitative palliative care program in the UK reported that focusing on patient-defined goals (like walking to the toilet or returning home) improved functional outcomes and sense of control for patients even in late-stage illness (hukstage-new-bucket.s3.eu-west-2.amazonaws.comhukstage-new-bucket.s3.eu-west-2.amazonaws.com). Despite such evidence, these approaches are not standard in most oncology practices. Our findings underscore a critical gap: the current care paradigm tends to bifurcate "active treatment" and "palliative care," and in doing so, it fails to systematically deliver services that address holistic needs. What is required is an integrative model wherein psychosocial support and rehabilitation are continuous threads throughout a patient's journey, including the end-of-life phase. This directly informed the creation of our Lifelong Rehabilitation Model, which embeds these services as core elements of care rather than optional adjuncts.

4.1.3. Dignity, Agency, and Continuity are Central Patient Values

Through our thematic analysis, we repeatedly encountered the themes of dignity, agency, and continuity of self as priorities expressed by patients with advanced cancer. Dignity -the feeling of being valued and maintaining self-respect -is often threatened by severe illness. Chochinov's model of dignity-conserving care highlights those interventions which affirm personhood (such as life review, meaningful conversations, or enabling personal goals) can greatly bolster a patient's sense of dignity at end of life (pubmed.ncbi.nlm.nih.gov). We take from this that any new paradigm must explicitly aim to preserve dignity as a therapeutic goal. Agency refers to a patient's sense of control and involvement in their life and care decisions. Studies show that advanced cancer patients desire an active role in choosing their treatments and care plans, and they value being seen as individuals with preferences, not just as subjects of medical decision-making. The rehabilitative palliative care philosophy encapsulates this with principles of enablement and self-management, which empower patients to "take charge" of aspects of their illness and daily life as much as possible (hukstage-new-bucket.s3.eu-west-2.amazonaws.com). We found evidence that when patients are supported to set and pursue personal goals (even small ones), it improves motivation and psychological outcomes (hukstage-new-bucket.s3.eu-west-2.amazonaws.comhukstage-new-bucket.s3.eu-west-2.amazonaws.com). Continuity emerged in two senses: continuity of care (seamless coordination across providers and settings over time) and continuity of one's identity and routines. Disruptions caused by cancer -frequent hospital visits, role loss, isolation from normal activities - can erode a person's continuity of self. Patients highly value efforts to reintegrate them into normal life spheres, whether that means returning to work, engaging in hobbies, or simply being at home with family. This aligns with public health perspectives that favor community-based care and social reintegration for patients with chronic illnesses or disabilities. Unfortunately, conventional late-stage cancer care often falls short on these values: patients may feel stripped of dignity by overly medicalized dying processes, disempowered by decisions made without truly understanding their wishes, and disconnected due to late referrals that move them abruptly from oncology clinics to hospice with little overlap. These insights guided the ethos of the Sustained Living paradigm which is fundamentally about restoring and upholding dignity, agency, and continuity for advanced cancer patients.

4.1.4. Early Integration of Life-affirming Care Improves Outcomes

A paradox uncovered in the literature is that patients who receive comprehensive supportive care earlier in their disease trajectory often have better clinical outcomes, despite the advanced nature of their illness. The landmark trial by Temel et al. (2010) on early palliative care in metastatic lung cancer is illustrative: patients who had concurrent palliative care from diagnosis not only reported higher quality of life and lower depression, but also survived longer (11.6 months median) than those who received standard oncology care alone (8.9 months) (nejm.org). This ~3-month survival improvement, as well as less aggressive end-of-life medical interventions, suggests that attention to symptoms, psychosocial health, and goals-of-care can positively influence the course of illness. A meta-analysis of palliative care in various cancers similarly found improved quality of life and mood (cancerchoices.orgcancerchoices.org). These data dismantle the misconception that focusing on comfort and quality detracts from quantity of life; on the contrary, addressing holistic needs may enable patients to tolerate treatments better or avoid crises, thus potentially extending life. However, in most of these studies, the interventions were labeled “palliative care.” We hypothesize, based on our findings about stigma, that rebranding and reshaping this early supportive intervention as part of a Sustained Living approach could further enhance acceptance and reach. The improved outcomes associated with early integration reinforce our argument that advanced cancer care should not be bifurcated into “curative vs palliative” stages, but rather viewed as a continuum of care where survivorship and supportive measures run in parallel with disease-directed therapies. Sustained Living encapsulates this principle by treating end-stage care as an extension of living with cancer, deserving the same proactive approach as earlier stages.

Collectively, these findings form the evidence base and rationale for our proposed paradigm shift. The traditional model, with its palliative terminology and late onset of supportive interventions, is misaligned with patient needs and values. There is both patient-centered logic and empirical support for a model that integrates rehabilitation, psychosocial care, and a life-affirming outlook throughout advanced illness. In response, we have developed the Lifelong Rehabilitation Model, which operationalizes continuous rehabilitation and social reintegration, and the overarching Sustained Living paradigm, which redefines the philosophy of care. We detail each of these in the following sections.

4.2. Lifelong Rehabilitation Model

4.2.1. Concept Overview

The Lifelong Rehabilitation Model is a comprehensive care framework that embeds rehabilitative and supportive services into the entire continuum of advanced cancer care, treating patients as living with a chronic condition rather than as terminally ill individuals awaiting death. In this model, rehabilitation is understood in a broad sense: it encompasses not only physical rehabilitation (to maintain or improve strength, mobility, and function), but also psychological rehabilitation (to foster coping skills and mental health), social rehabilitation (to reconnect patients with family, community, and meaningful roles), and spiritual/existential support (to help find meaning and peace). The term “lifelong” underscores that these efforts begin early (from diagnosis or onset of advanced disease) and continue without interruption for the remainder of the person’s life. Rehabilitation is not a phase, but a constant adaptive process tailored to the patient’s evolving condition and goals.

4.2.2. Core Components

The model consists of several interrelated components delivered by a multidisciplinary team in coordination with oncology care:

- Physical Rehabilitation and Symptom Management: Patients have access to physiotherapy and occupational therapy soon after an advanced cancer diagnosis or progression. Therapists focus on optimizing mobility, managing fatigue, and teaching energy-conservation techniques. Assistive devices (walkers, wheelchairs, prosthetics, etc.) and home modifications are provided proactively to prevent injury and encourage independence. Pain and other symptoms (e.g., breathlessness, neuropathy) are managed with both medical and non-medical approaches (exercise, breathing techniques, integrative modalities), aligning with the concept of rehabilitative palliative care where symptom control serves functional goals (hukstage-new-bucket.s3.eu-west-2.amazonaws.comhukstage-new-bucket.s3.eu-west-2.amazonaws.com). For example, if a patient has difficulty walking due to neuropathy, the team works on both relieving the neuropathic pain and using physical therapy exercises or bracing to improve gait, thus sustaining the patient’s ability to ambulate safely.
- Psychological Support and Counseling: Psychosocial oncology professionals (such as psycho-oncologists, psychiatrists, counselors) are integrated from the outset. Instead of waiting for severe depression or anxiety to manifest, the model implements regular mental health screening (e.g., distress thermometers, PHQ-9 for depression) and offers interventions like talk therapy, cognitive-behavioral techniques, or psychiatric medications as needed. Importantly, dignity-conserving therapies and meaning-centered counseling are offered to help patients maintain a sense of purpose and self-worth (pubmed.ncbi.nlm.nih.gov). Group therapy or support groups with peers might be facilitated, helping patients share experiences and combat isolation. The psychological support is continuous, meaning even as health declines, therapists might shift to more intensive grief and existential counseling, including legacy work (e.g., life review, memory projects for family), aligning with Harvey Chochinov’s dignity therapy approach that has shown efficacy in reducing end-of-life distress (pubmed.ncbi.nlm.nih.govthelancet.com).
- Social Work and Social Reintegration: Social workers or case managers play a pivotal role in Lifelong Rehabilitation. Early in the care continuum, they conduct a thorough assessment of the patient’s social determinants of health: financial situation, employment, family dynamics, caregiver availability, living conditions, cultural background, and specific barriers to care. They then assist with practical matters such as securing financial support, coordinating transportation to appointments, arranging home care services, and facilitating difficult conversations (like advance care planning) at an appropriate time. A distinctive element of this model is an emphasis on social reintegration. This may include vocational rehabilitation services if the patient desires to continue working or return to work in some capacity despite advanced cancer. Flexible or part-time work arrangements, or volunteering opportunities, are sought to sustain the patient’s sense of productivity and normalcy. There is evidence that many cancer survivors, even with metastatic disease, find purpose and improved self-esteem in maintaining roles such as work or caregiving, as long as it’s feasible and adjusted to their health status. For retirees or those who cannot work, social reintegration might involve engagement in community activities (faith groups, hobby clubs, patient advocacy, etc.). The care team actively facilitates these connections, for instance by linking a patient to

a local cancer survivor exercise group or a creative arts program. By treating social participation as a therapeutic goal, the model addresses the profound loneliness and identity loss that can accompany advanced illness.

- Continuous Care Coordination: Under the Lifelong Rehabilitation Model, a care coordinator or navigator (often a nurse or trained navigator) ensures continuity and communication across all providers. This person helps schedule regular multidisciplinary team meetings (including oncologist, palliative specialist or "sustained living" specialist, rehab therapists, psychologist, social worker, etc.) to review the patient's status and adapt the care plan. They also serve as a consistent point of contact for the patient and family, so that as health care needs escalate or change (e.g., hospitalization, transitioning to hospice services at home), the process feels more like a continuum rather than a hand-off. The coordinator also educates the patient and family over time, preparing them for possible future scenarios (for example, explaining how home hospice care can be integrated with ongoing rehab exercises, or how to use respite care services for caregivers). The end result is a reduction in fragmentation; patients experience care as one coherent system supporting their life, rather than disjointed services. This continuity aligns with findings that early and consistent involvement of supportive care teams leads to better outcomes and smoother transitions in end-of-life stages (pmc.ncbi.nlm.nih.govpmc.ncbi.nlm.nih.gov).
- Tailored Care Pathways and Goal Setting: A hallmark of this model is personalized goal setting. From the initial assessment, the team elicits from the patient: What are your goals in the coming weeks and months? What activities or abilities are most important for your quality of life? These goals could be as simple as "attend my daughter's wedding in two months" or "be able to shower by myself." The team then collaborates to make these goals central to the care plan (often documented and revisited frequently). Research shows that when care is structured around patient-centered goals, it not only improves outcomes but also dignity and satisfaction (hukstage-new-bucket.s3.eu-west-2.amazonaws.comhukstage-new-bucket.s3.eu-west-2.amazonaws.com). As an example, if a patient's goal is to remain living at home rather than moving to an institution, the team will prioritize home care support, family training, and environment modifications to honor that goal. Goals are periodically reviewed and updated as the illness progresses - if a goal becomes unachievable (due to decline), the team sensitively helps the patient reformulate goals (e.g., shifting from walking outdoors to being able to get into a wheelchair and enjoy time on the porch). This process ensures the patient's sense of agency is preserved; they steer the direction of their care to the extent possible.

4.3. Proposed Schema/Model Designs

To visualize and implement the Lifelong Rehabilitation Model, we propose several conceptual schematics. These models can guide understanding and will be refined with stakeholder input. Possible designs include:

4.3.1.Layered Model (Concentric Circles)

Imagine a series of concentric circles representing layers of support around the patient at the center. The innermost circle is the patient (and family) with their personal goals and values. Surrounding that are layers such as Medical Care (oncology, symptom management), Rehabilitation Services (PT/OT, etc.), Psychosocial Support (mental health, counseling), Social Reintegration (community and family connections), and Care Coordination (navigation, communication). The layered model emphasizes that multiple domains of care wrap around the patient simultaneously. It shows that when one layer (e.g., medical treatment) fluctuates or diminishes (as curative treatment might in late stage), the other layers still remain, ensuring the patient is never "left with nothing." This could be depicted similar to an onion model or a target diagram, illustrating holistic care. Each layer can be annotated with key activities (for instance, the Rehabilitation layer might highlight physical therapy, adaptive equipment, etc., while the Psychosocial layer highlights counseling and support groups).

4.3.2.Circular Continuum Model (Cycle or Wheel)

This schematic would illustrate care as a continuous cycle, underlining the dynamic and ongoing nature of rehabilitation. One could design it as a wheel with spokes: the hub is the Sustained Living philosophy, and each spoke is a component (physical rehab, psychological support, social work, palliative medicine, oncology). The outer rim of the wheel represents continuity over time, rolling forward - symbolizing the patient's journey. Alternatively, a cyclical flowchart could depict iterative phases: Assess needs ? Intervene (rehab/ support) ? Re-assess ? Adjust goals ? Continue care, looping continuously. A circular model stresses that rehabilitation in advanced cancer is not a linear path with an endpoint, but a cyclical process of adaptation and care that continues as long as life continues. It could also highlight feedback loops (e.g., improvement in function could lead to new goals or more engagement, whereas decline triggers intensification of certain supports).

4.3.3.Longitudinal Care Pathway Diagram

This design would present a timeline from diagnosis of advanced cancer through to end-of-life, marked by key phases (for example: Initial adaptation, Stable phase, Progression, Late-stage/End-of-life). Along this timeline, we map parallel tracks of intervention. For instance, one track shows medical treatments (which might start strong and taper off near the end), and parallel tracks show rehabilitation, psychosocial support, and social integration activities (which start early and remain consistently active or even intensify as time goes on). This diagram would illustrate how, in the Lifelong Rehabilitation Model, services like physiotherapy or counseling are present from the beginning and carry through to the hospice phase (perhaps shifting in approach but never disappearing). It contrasts with the traditional model where, often, active treatment occupies the early timeline and only near the end does palliative/supportive care step in. By overlaying the old and new models on the timeline, one can clearly see the extended duration of rehab and support in our paradigm. This longitudinal view could be useful for policy planning, to allocate resources at each stage and ensure no "gap" occurs (for example, ensuring a warm handover if transitioning location of care, rather than a cold stop of services).

4.3.4. Matrix Model

A more complex schema could be a matrix that crosses time intervals (early, mid, late stage) with domains of care (medical, functional, psychosocial, social). Each cell of the matrix would contain the key interventions or goals appropriate for that domain at that time. For instance, at mid-stage psychosocial, the cell might list "address body image and role changes, introduce legacy projects;" at late-stage social, it might list "coordinate hospice-at-home to maintain home environment, provide bereavement support to family." The matrix ensures that for every stage of illness, every domain has an active plan embodying the comprehensive nature of the Lifelong Rehabilitation Model.

These conceptual designs will be evaluated and discussed with stakeholders (patients, clinicians, caregivers) to select the most effective representation. The ultimate goal of any chosen schema is to serve as a blueprint for implementation in clinical settings and to communicate clearly how sustained, multi-faceted care is delivered over time.

Innovations and Differences from Traditional Models: The Lifelong Rehabilitation Model diverges from traditional "palliative care" in several ways. It rejects the notion that rehabilitation is futile in advanced illness - instead it asserts that maintaining function is vital to patient well-being and can be pursued through creative, adaptive means until very late stages. It also broadens the focus from patient-alone to patient-and-community, by actively facilitating the patient's engagement with society according to their capacity. In essence, it medicalizes living rather than dying, treating the act of living with cancer as something requiring skillful multidisciplinary care. By integrating domains often siloed (for example, bridging oncology and palliative teams with rehab specialists and mental health professionals), it creates a transdisciplinary team oriented around life continuity. This cohesive model can be established as a formal program within cancer centers -for example, an Advanced Cancer Living Support Team that sees every Stage IV patient shortly after diagnosis and follows them regularly, in parallel with oncologic treatment.

Evidence supporting components of this model comes from various studies: exercise programs in advanced cancer have been shown to improve fatigue and physical function; early nutritional support can stabilize weight and energy; counseling can reduce rates of clinical depression; and coordinated home care can decrease emergency hospitalizations (cancerchoices.orgcancerchoices.org). The novelty here is packaging these components into a singular lifelong survivorship care plan for advanced cancer. Indeed, in 2024, a MASCC-ASCO guideline underscored that people with advanced cancer should receive survivorship care tailored to their needs, calling for standards in exactly these areas (symptom management, psychosocial care, care coordination, etc.) (mascc.orgmascc.org). Our model is a concrete instantiation of those emerging standards, going a step further to also change the narrative presented to the patient: that they are a participant in rehabilitation and life maintenance, not just a recipient of end-of-life care.

4.3.5. Collaborative Development

We acknowledge that implementing the Lifelong Rehabilitation Model will require cultural change and training across healthcare teams. It invites rehabilitative medicine practitioners into the oncology space more intimately, and challenges palliative care providers to adopt a restorative approach in addition to comfort measures. We envisage that the model will continue to be refined through pilot programs and feedback. Patients should be co-creators - their insights on what aspects of life are most worth sustaining will guide which services are prioritized. For example, younger patients might prioritize work and childcare support, while older patients might prioritize mobility and legacy projects. Flexibility and patient-centered customization are built into the model's philosophy.

In summary, the Lifelong Rehabilitation Model provides the structural and practical backbone of the Sustained Living paradigm. It ensures that from the time a patient is diagnosed with advanced cancer, there is a relentless focus on rehabilitation in the broadest sense: rehabilitating and sustaining the person's body, mind, and role in society. By doing so, it aims to maximize quality of life, promote a sense of continuity and normalcy, and uphold the dignity of risk and endeavor - the idea that patients should be supported to continue doing what matters to them, even if there are risks, rather than being overly protected in a way that limits living. This model directly feeds into and supports the philosophical shift discussed next: redefining end-stage cancer care around the concept of Sustained Living.

Sustained Living Paradigm: A Philosophical and Clinical Redefinition

The Sustained Living Paradigm is the overarching philosophy that reframes how we conceptualize care for patients with advanced cancer. It represents a deliberate rejection of the passive, terminal connotations of "palliative care" and instead establishes a narrative of continuity, resilience, and personhood. At its core, Sustained Living posits that life with advanced cancer is still life to be lived, not simply a process of dying to be managed. This section delves into the philosophical foundations of this paradigm and its practical implications for clinical care.

4.3.6. Philosophical Foundations

Sustained Living draws on several philosophical and ethical principles:

- Dignity and Humanism: Every human life has intrinsic dignity up to the moment of death. Therefore, the care of those with incurable illness must be oriented toward honoring that dignity. In practice, this means treating patients not as objects of protocol or solely as victims of disease, but as whole persons with histories, relationships, and aspirations. The paradigm aligns with the humanistic approach in medicine - focusing on individual meaning and the subjective experience of the patient. Instead of framing the care as "palliation of symptoms," we frame it as "support for living." This subtle shift has profound ethical weight: it ensures that the patient is never reduced to their symptoms or prognosis. It echoes Cicely Saunders' hospice philosophy of adding life to days, but it extends beyond hospice to the entire trajectory of advanced cancer, and it removes the fatalistic cloak (pallium) that Saunders herself identified in the term palliative(pmc.ncbi.nlm.nih.gov).
- Agency and Autonomy: Sustained Living is fundamentally about agency - enabling patients to continue to make choices and exert control over their lives and care. Traditional paradigms often inadvertently diminish patient autonomy at the end of life; decisions get made rapidly in crises, or care transitions happen that patients feel they cannot influence (e.g., being told one is "palliative" now and must transition to hospice care, sometimes perceived as a point of no return). In the Sustained Living paradigm, agency is preserved by design. The patient is engaged as an active participant in crafting their life plan for the time remaining, supported by professionals who facilitate their choices rather than unilaterally direct care. This is a partnership model, consistent with bioethical calls for shared decision-making and respect for persons. It also integrates the concept of the "dignity of risk" - the idea that individuals have the right to take risks and make decisions about their own lives, even if frail or ill. For example, a patient might choose to take a trip despite medical advice to stay close to the hospital; Sustained Living philosophy would aim to safely enable the trip (with contingency planning), rather than forbid it in the name of safety, because the trip may be essential to the patient's sense of living fully.
- Existential Continuity: A key insight from psychology and existential philosophy is that humans strive for continuity of self - a thread of identity that persists over time. Serious illness threatens to sever that continuity, creating a 'biographical disruption'. The Sustained Living paradigm explicitly seeks to maintain the patient's narrative and identity. Clinicians operating under this paradigm would ask not just "What is the matter with you?" but also "What matters to you?" - then strive to incorporate what matters to the patient into the care plan. This fosters continuity between the life the person led before advanced cancer and the life they lead with cancer. If a patient was a musician, Sustained Living care might involve facilitating continued music practice or attending concerts as long as possible. If one was the family patriarch who hosted gatherings, perhaps the care team helps organize one last family event at the hospital or via video if needed. These are not medical treatments per se, but they are crucial interventions to sustain the meaning in a person's life. Victor Frankl's logotherapy principle - that finding meaning is key to enduring suffering - resonates here; Sustained Living is a paradigm that places meaning-making at the center of care.
- Rejection of Dichotomy (Curative vs. Palliative): Philosophically, Sustained Living challenges the binary view of the cancer journey (i.e., first curative treatment, then palliative care). Instead, it promotes a unity of care. Life is a continuum, and care should be continuous accordingly. By conceptually rejecting the abrupt switch to "palliative mode," we remove the psychological demarcation that often signals to patients and providers that it's time to "give up." In Sustained Living, there is never a point of giving up - there is always care being given in the pursuit of living as well as possible. This does not mean denying the

reality of approaching death; rather, it reframes dying as the last phase of living. Even during that last phase, the focus remains on how the person lives that time: with comfort, with closure, with companionship - all active processes - rather than passively waiting for death. In this way, the paradigm shares DNA with the concept of "positive dying" or "living until you die," but it avoids any implication that there are two modes (living vs dying). There is only living, until life ends.

Clinical Redefinition: Translating Sustained Living into clinical practice involves several shifts in how care is delivered and communicated:

- Terminology and Communication: Perhaps the most immediate change is in language. Health professionals would avoid using the term "palliative care" with patients in Stage III/IV (unless a patient themselves uses it or is familiar and comfortable with it). Instead, they introduce the Sustained Living approach or team. For example, an oncologist might say: "At our cancer center, we have a Sustained Living program that will work with you throughout your illness. This team specializes in helping people maintain their quality of life, stay as active and engaged as possible, and manage any challenges - physical, emotional, or social - that arise. I'd like to refer you to them early on, so we can all work together to support you." This kind of introduction frames the supportive care team as life-focused partners, not end-of-life hospice. Research suggests that reframing in this way can overcome some patients' reluctance to accept support. Indeed, as cited earlier, renaming palliative services to supportive care increased uptake (pubmed.ncbi.nlm.nih.gov). We anticipate "Sustained Living" would have an even stronger positive connotation, implying ongoing life. Clinicians would also talk in terms of goals of care for living rather than goals of care for dying. For instance, during advanced care planning discussions, one might say: "Let's discuss what living well means to you in the time ahead, so we can align treatments with that."
- Interdisciplinary Team Role Evolution: In the Sustained Living paradigm, what is currently known as the "palliative care team" might be rebranded and expanded as a Sustained Living team or Lifelong Care team. This team would include palliative care specialists, but also rehabilitation specialists, mental health experts, etc., as outlined in the Lifelong Rehabilitation Model. Their mandate is broadened: not only to manage symptoms, but to coordinate all aspects of sustaining the patient's life quality. The team's identity shifts from one primarily associated with end-of-life to one that patients see at various points (some might even meet them shortly after being deemed Stage IV). This mainstreams their presence. Oncologists and other specialists also undergo a mindset change; instead of waiting until "nothing more can be done" to involve supportive services, they engage Sustained Living colleagues concurrently and see them as providing something extra that is being done - namely, maintaining the person's wellbeing alongside tumor treatment. The paradigm fosters a collaborative co-management of patients, where oncology and Sustained Living professionals share responsibility from early on. This addresses a known issue that late referrals to palliative care often result from oncologists fearing that involvement equates to their own "failure" or "giving up" (pmc.ncbi.nlm.nih.govpmc.ncbi.nlm.nih.gov). Under Sustained Living, that stigma is reduced; it's presented as just another aspect of comprehensive cancer care.
- Care Goals Realignment: In standard oncology, when a patient shifts to palliative intent, goals of care discussions often revolve around limiting invasive interventions and prioritizing comfort. While comfort remains crucial, Sustained Living reframes goals to positive objectives rather than mere avoidance of negatives. For example, a goal might be "to enable you to spend quality time with your grandchildren each week" rather than only "to avoid hospitalizations." This doesn't mean ignoring medical prudence - it still involves discussing what interventions align or don't align with the patient's life goals. But it couches these plans in affirmative language. The clinical team actively asks patients, "What do you want to continue doing or achieve?" and then uses those answers to guide medical decisions. If a patient's goal is travel, the care plan might favor oral chemo or shorter infusions over long hospital-based regimens, even if slightly less efficacious, to allow travel - because the goal is living, not just tumor control. This patient-centered trade-off is explicitly validated in Sustained Living philosophy.
- Measuring Success Differently: In the Sustained Living paradigm, clinical success metrics expand beyond traditional endpoints (tumor response, days in hospice, etc.) to include quality-of-life indices, functional status, and patient-reported outcomes like sense of meaning or satisfaction. A successful outcome might be that a patient was able to attend a family event or maintain autonomy in personal care until a week before passing. These outcomes are documented and valued. Clinicians might use tools like the Edmonton Symptom Assessment Scale plus additional modules for measuring dignity, autonomy, or social participation. Over time, collecting such data can empirically validate the paradigm (e.g., demonstrating that patients in Sustained Living programs have better quality of life and perhaps even no worse survival than those in conventional care, akin to the Temel study outcomes (nejm.org).
- Ethical and Emotional Climate: The Sustained Living paradigm can change the emotional experience for patients and families. By avoiding the word "palliative" and its connotations, patients may experience less of the existential shock that often accompanies a palliative care referral(pmc.ncbi.nlm.nih.gov). Instead, they remain in a mindset of living with the illness, which can facilitate continued hope. Importantly, hope is redefined: not necessarily hope for cure, but hope for meaningful experiences, for comfort, for spending time in valued ways. Clinicians are trained to nurture this reframed hope. Ethically, this addresses the tension between honesty and hope - a well-known challenge. Sustained Living allows providers to be honest about prognosis ("the cancer is not curable") while simultaneously offering a positive framework for what will be done ("but we will focus on helping you live as richly as possible each day"). This dual message is more palatable and arguably more ethical than either false hope or a blunt message of preparing for death alone.

Global and Cultural Considerations: The term Sustained Living (and its local translations like Idame Yasam) is also meant to be culturally sensitive and adaptable. Different cultures have varied responses to end-of-life terminology. For instance, in some cultures the word "palliative" might have especially negative stigma or no clear meaning. A term that emphasizes life can be more universally accepted. Sustained Living paradigm encourages tailoring the approach to cultural context: in communities where family plays a central role in care decisions, the paradigm includes family in the Sustained Living conversations from the start, framing family involvement as part of sustaining a patient's life. In societies with strong spiritual beliefs, spiritual care (from chaplains or traditional healers) is incorporated as an essential element of sustaining the spirit of living. The paradigm's flexibility lies in its broad affirmation of life; each culture can define what aspects of life are most crucial to sustain (e.g., maintaining honor, fulfilling specific rituals, etc.) and the care plan can prioritize those.

Comparison to Palliative Care Philosophy: It is important to clarify that Sustained Living does not deny the utility of what has been achieved in palliative care as a field; rather, it repackages and extends it with a different emphasis. Traditional palliative care philosophy, per WHO, does assert that it "intends neither to hasten nor postpone death" and that it regards dying as a normal process - principles we do not dispute. However, Sustained Living puts forth a more activist stance: it implicitly says we intend to maximize life (not length per se, but fullness) and we regard living as a continual process until the last breath. It's a subtle difference in tone and focus. One might say Sustained Living is "palliative care 2.0" oriented around patient agency and societal reintegration.

By implementing the Sustained Living paradigm, healthcare systems can expect several outcomes: improved patient and family satisfaction, potentially better psychosocial outcomes (mood, coping), reduced feelings of abandonment at the end of life, and possibly even improved healthcare utilization (appropriate hospice use without late referrals, fewer futile ICU stays because patients' goals are clear and oriented to quality). It reframes end-of-life discussions into continuity discussions, which might result in earlier acceptance of hospice in some cases - ironically by not positioning hospice as a sharp break, but as just another resource to help sustain comfort and family connections at home.

In practice, a patient under Sustained Living care might transition to hospice, but they would experience it as a continuity: the same Lifelong Rehabilitation team might continue overseeing care in hospice, or at least maintain contact. Hospice itself would be framed as an intensification of living-focused care at home rather than "now you are in the final stage." Thus the patient can internalize that they are still in the same continuum of care aimed at helping them live well, just with different logistics.

To summarize, the Sustained Living paradigm is a reimagined philosophy of advanced cancer care that replaces the narrative of palliation with a narrative of ongoing life. It is patient-centric, value-driven, and aligns medical interventions with the goal of preserving the fabric of the patient's life for as long as possible. It challenges both language and practice, advocating for a shift in mindset among healthcare providers, patients, and society at large - to see those with Stage IV cancer not as people "in dying care" but as people living with vulnerability, deserving of empowerment and full support. In the next section, we discuss how this paradigm can be implemented at policy and health system levels, and what changes are required to make Sustained Living and Lifelong Rehabilitation a reality in oncology care worldwide.

5. Discussion

The findings and proposals outlined above suggest a transformative shift in how we approach advanced cancer care. In this Discussion, we examine the broader implications of adopting the Sustained Living paradigm and Lifelong Rehabilitation Model, address potential challenges or counterarguments, and consider the evidence and gaps that remain. We also compare our proposed paradigm to existing models and discuss how it could be implemented in practice.

5.1. Bridging the Gap Between Oncology and Palliative Care

One of the chronic challenges in cancer care has been the siloing of curative-intent oncology and palliative care. Our paradigm offers a bridge by effectively erasing the silo distinction. Oncologists, palliative care specialists, rehabilitation therapists, and psychosocial professionals would function as one integrated team under Sustained Living. This integration is supported by evidence from models of early integration which have shown improved patient outcomes and smoother care transitions(pmc.ncbi.nlm.nih.govpubmed.ncbi.nlm.nih.gov). Implementing Sustained Living may require structural changes, such as joint clinics or co-visits where oncologists and supportive care teams see the patient together, ensuring unified messaging and coordinated plans. Programs like embedded palliative care clinics in oncology (already trialed in some centers) provide a template, but renaming them as Quality-of-Life clinics or Living Well clinics could increase utilization(pubmed.ncbi.nlm.nih.gov). Education of oncology providers is key: they need training to understand rehabilitative techniques and to value quality of life as an outcome as much as tumor response. Likewise, palliative care providers would benefit from training in rehabilitative and psychosocial interventions (or inclusion of those professionals on their team). Such cross-training fosters a truly interdisciplinary skill set that Sustained Living demands.

Addressing Potential Criticisms: Several potential criticisms of our paradigm warrant discussion:

- "Is this just semantics? Does changing the name from palliative care to Sustained Living really make a difference?" - We argue that it is more than semantics. Language shapes perception and behavior. The studies by Maciasz et al. and Zimmermann et al. underscore that semantics can be a barrier to or facilitator of care (pubmed.ncbi.nlm.nih.gov). Renaming signals, a cultural shift; it also opens the door to reimagining practices. However, we acknowledge that simply rebranding without substantive practice change could ring hollow. Therefore, Sustained Living is coupled with the Lifelong Rehabilitation Model - tangible changes in care delivery. It's not just calling palliative care by another name; it's expanding its scope and reframing its purpose. That said, some palliative care experts might worry that abandoning the term "palliative" could undermine decades of work to establish that field. Our counterpoint is that the field's principles can be preserved and even amplified under a new banner that might achieve broader acceptance. It is an evolution, not an erasure, of palliative care.
- "Are we avoiding reality or giving false hope by focusing on living?" -This is an ethical concern: might Sustained Living inadvertently encourage denial of death's approach? We intend the opposite. By normalizing discussions of life and goals throughout the advanced illness, we actually create space for earlier and more meaningful conversations about end-of-life preferences (since end-of-life is framed as a phase of life, not a separate taboo topic). The paradigm does not hide the reality of mortality; rather, it contextualizes it within living. In fact, having a Sustained Living team involved can facilitate timely hospice enrollment and end-of-life planning, as patients may trust them and feel the team's goals align with their own (unlike a sudden hospice referral which might be met with shock or rejection). Honesty remains paramount - prognostic information is shared, but alongside it is a commitment: We will continue to support you in living the way you want, even as we acknowledge time may be limited. Ethically, this respects truth-telling while maintaining hope in a realistic form (often called "hoping for the best, preparing for the worst").
- "Will this approach increase healthcare costs or resource burden?"-Initially, integrating rehabilitation and psychosocial care might seem resource-intensive. However, evidence suggests that early palliative/supportive interventions can reduce costly acute care usage (like ICU stays, ER visits) at end-of-life (cancerchoices.org). If Sustained Living leads to better symptom control and patient-family alignment on care goals, there may be fewer medical crises born of unmanaged symptoms or ambiguous wishes. Rehabilitation services could prevent falls or complications, saving costs on hospitalizations or emergency procedures. Additionally, improved psychosocial support can potentially reduce length of hospital stays (as issues like depression or caregiver burnout often delay discharges). A Canadian study noted that comprehensive palliative care reduced healthcare costs in the final month of life while improving quality(cancerchoices.org). By extension, Sustained Living may be cost-neutral or even cost-saving when implemented efficiently. Policymakers might require demonstrations of this; pilot programs can gather such health economics data. It is also worth noting that some elements (like engaging community resources for social reintegration) are low-cost. If patients can tap into community volunteer networks or tele-support groups, that's a high return on minimal investment. The paradigm encourages leveraging existing social capital and resources, not solely medical ones.

- "How do we measure success and ensure quality in this paradigm?"-We will need new or adapted metrics. Traditional oncology metrics (survival time, tumor markers) are insufficient. Palliative care has introduced metrics like percentage of patients with documented advance care plans, or pain scores, etc. Sustained Living would track metrics such as: patient-reported quality of life (e.g., using FACT-G or FACIT-Sp scales), goal attainment scaling (did patients meet their personal goals?), functional status trajectories (timed up-and-go test results or ADL independence over time), and perhaps novel indices like "days of life engaged in preferred activities" or "social interaction score" in last month. Family outcomes should also be considered (caregiver burden, satisfaction with care). Monitoring these will ensure the paradigm is delivering on its promises. We foresee quality improvement cycles where the team reviews these outcomes and adjusts programming (for example, if many patients still feel socially isolated, strengthen the social reintegration component).

Integration with Public Health and Policy: To scale Sustained Living, it should be enshrined in guidelines and policies:

- National Cancer Control Plans could explicitly include "Lifelong rehabilitation and supportive care for advanced cancer" as a pillar, next to prevention, early detection, treatment, and traditional palliative care. The WHO, through initiatives like Rehabilitation 2030 (who.int) and various cancer care guidelines, can emphasize that rehabilitation is not just for early-stage or post-treatment survivors, but for all survivors including those with metastatic disease (who.int).
- Regulatory and accreditation bodies (like hospital accreditation standards) could require that cancer centers demonstrate a continuum-of-care program that covers advanced cancer patients comprehensively. For example, the American College of Surgeons' Commission on Cancer could add a standard: "The cancer program must provide or refer to rehabilitation and psychosocial oncology services for patients with advanced disease and have protocols for integration of these services concurrent with oncology care."
- Renaming efforts: Professional societies might consider officially adopting alternative terminology. Already, some institutions use "supportive care" in place of "palliative care." "Sustained living" could be piloted as a program name at a major cancer center to test its reception. If successful, advocacy might lead to more widespread use. Over time, if patients and providers alike find the term valuable, it could enter common parlance.

Patients and Family Reception: Anecdotally, we expect patients and families to welcome an approach that doesn't sound like "giving up." The presence of rehabilitative activities and social initiatives might offer a sense of normalcy. Families could appreciate that their loved one is being encouraged to live as fully as possible, which might ease the emotional burden and guilt often felt. Caregivers often struggle with seeing the patient lose functional ability; a focus on maintaining function could alleviate some of that distress. It is crucial to include family in the Sustained Living process - as co-participants in rehab exercises, as partners in counseling (when appropriate), and as beneficiaries of training (like learning safe mobility techniques or communication strategies with someone who is ill). This inclusive approach can strengthen the family's resilience and prepare them better for eventual bereavement, knowing they supported their loved one in living well.

Limitations and Future Research: Our paradigm is based on combining existing evidence with a novel conceptual leap. It has not yet been tested as a whole in a clinical trial. While components are evidence-supported (early palliative, cancer rehab, etc.), implementing all together in a unified program requires careful evaluation. Potential limitations include varying applicability to different cancer trajectories (some Stage IV cancers have a very short course, others a prolonged one - Sustained Living must be flexible to both scenarios). For rapidly progressive cases, the "lifelong" part might be condensed to months - could we effectively mobilize resources quickly enough for those patients? We must ensure that the effort to do so does not overwhelm patients (some might feel burdened by too many services). Personalization is key to avoid "overshooting" - some patients may prefer a quieter approach, and the paradigm should not impose activities they don't want. Thus, patient preference guides intensity: one person may embrace multiple therapies and interventions, another may choose only a subset. Respect for individual coping styles remains crucial.

Future research should examine the outcomes of a Sustained Living model prospectively. A possible study design is a cluster-randomized trial where some cancer centers implement Sustained Living and others continue usual care, measuring patient quality of life, satisfaction, healthcare utilization, and survival. Qualitative studies could explore patient and family experiences under this paradigm, verifying if it indeed mitigates the psychological harms of the "palliative" label that we aim to avoid. Another research angle is health economics: cost-benefit analysis of providing comprehensive rehab and supportive services vs. savings from reduced acute care or improved outcomes. It would also be valuable to research provider perspectives - does this model alleviate moral distress that some clinicians feel when transitioning patients to end-of-life? Many providers struggle with that conversation; Sustained Living might give them a more palatable framework to continue caring and not feel like they are abandoning the patient. This could reduce burnout and increase professional fulfillment.

Comparison to Other Frameworks: We are not the first to call for shifting how we view end-of-life care. Concepts like "supportive care," "advanced illness management," "patient-centered hospice care," etc., share similar goals. What distinguishes Sustained Living is the explicit rejection of the palliative nomenclature and the integration of rehabilitation and social reintegration as central tenets (not typically emphasized in standard palliative care models). In a sense, it merges survivorship care and palliative care into one continuum. The new MASCC/ASCO standards for advanced cancer survivorship (mascc.org) are a major step in this direction, lending authoritative weight to our paradigm. Our work positions itself at the convergence of those guidelines with on-the-ground hospice and rehab practices. It also adds a philosophical re-articulation, which we believe is necessary to break the old mindset. We deliberately use the term paradigm shift in the Kuhnian sense: to change the underlying assumptions of practice in psychosocial oncology.

Implications for Training and Education: Adopting Sustained Living widely would mean updating curricula in medical and nursing schools. Oncologists-in-training should learn about chronic care management, communication skills for sustaining hope, and basic rehabilitation principles. Palliative care training would incorporate more on long-term rehabilitation and perhaps public health aspects of social integration. Interprofessional education becomes essential - oncology, rehab, palliative, nursing, psychology students could have joint workshops on managing advanced cancer cases, reflecting the team approach. Additionally, community education is implied: if we want social reintegration, communities need to be receptive. Public campaigns could convey that advanced cancer patients can still contribute and partake in community life, countering stigma or pity that leads to social isolation. This aligns with disability advocacy - seeing the person, not the illness.

In conclusion of the discussion, the Sustained Living paradigm and Lifelong Rehabilitation Model together form a comprehensive proposal to reshape advanced cancer care. They are grounded in evidence and patient values, though ambitious in scope. Implementing them will require changes at multiple levels: clinical practice, institutional structures, policy, and education. The potential payoff is substantial: a more humane, empowering experience for patients and families, and perhaps even improvements in clinical outcomes and healthcare efficiency. It represents an evolution in the ethos of cancer care - from a dualistic fight-then-surrender narrative to a continuous care narrative where life is affirmed at every stage.

6. Policy Recommendations

Translating the Sustained Living paradigm into routine practice will require concerted efforts from healthcare institutions, professional organizations, and government bodies. Below we outline key policy recommendations to facilitate this paradigm shift on a global scale:

6.1.Official Terminology and Guidelines Reform

Health authorities and cancer organizations (e.g., WHO, ASCO, ESMO, NCCN) should consider updating terminology in their guidelines. We recommend adopting terms like “Supportive Care and Rehabilitation” or “Sustained Living Care” for advanced cancer in place of or alongside “palliative care.” For instance, national guidelines could introduce a statement: “All patients with stage IV or high-risk stage III cancer should be offered a Sustained Living care program (comprehensive supportive and rehabilitative services) concurrent with standard oncology treatment.” By embedding this language in guidelines, it legitimizes the paradigm and sets expectation for providers. The WHO could pilot this terminology in its cancer control strategy documents, emphasizing dignity and ongoing care. Over time, as the term gains traction, it may reduce the stigma that currently keeps referrals late (pmc.ncbi.nlm.nih.gov).

6.2.Integrate Lifelong Rehabilitation into Cancer Care Standards

Policymakers should mandate that cancer centers incorporate rehabilitation and psychosocial oncology as standard components of care for advanced cancer. For example, cancer center accreditation standards (such as those by the Union for International Cancer Control or national cancer institute designations) can require programs for cancer rehabilitation and survivorship for metastatic patients. This could mean funding positions for rehabilitation specialists and psycho-oncologists in oncology departments. Reimbursement policies should be adjusted to cover multidisciplinary team interventions (e.g., insurance coverage for physical therapy, nutrition, counseling sessions for advanced cancer patients, not only for those in post-treatment survivorship). In public healthcare systems, budgeting should reflect those resources for rehab and social support are investments that may offset acute care costs later.

6.3.Early and Automatic Supportive Care Referral Policies

Hospitals and oncology clinics can implement “early referral” policies where any patient diagnosed with metastatic cancer is automatically introduced to the supportive care team within, say, 4-8 weeks of diagnosis (as recommended by ASCO guidelines) (ascopubs.org). However, these teams should be renamed and reframed as Sustained Living teams in patient-facing language. By making it an opt-out rather than opt-in referral, we ensure no patient falls through the cracks. Health systems in the UK and Canada have trialed automatic triggers for palliative referral (with success in improving outcomes); this should be expanded and tied to the Sustained Living approach to ensure robust uptake (pmc.ncbi.nlm.nih.gov). Policy can also encourage co-location of services - for example, embed a supportive care clinic in the oncology floor to normalize it.

6.4.Education and Training Programs

Governments and professional bodies should fund the development of training curricula for the Sustained Living paradigm. This includes continuing education modules for practicing oncologists, palliative care specialists, nurses, and allied health professionals on how to implement lifelong rehabilitation and communicate the ethos of Sustained Living. Topics might include: effective communication of illness and care goals without using stigmatizing language, techniques for goal-setting with patients, basics of cancer rehabilitation, and culturally sensitive practices for sustaining patient agency. Certification programs could be created for “Advanced Cancer Rehabilitation and Support” for providers, giving them formal recognition of expertise in this integrated care. Furthermore, interprofessional training grants (perhaps through bodies like the National Cancer Institute or equivalent) can encourage institutions to pilot team training workshops.

6.5.Health Insurance and Funding Models

Payers should adapt to support this model. In many systems, palliative care or hospice is only funded late or under certain prognostic criteria (e.g., the US Medicare hospice benefit requires a =6 months prognosis and stopping curative treatment). Such structures inadvertently reinforce the old paradigm. We recommend insurance reforms to allow concurrent care: patients should not have to forego disease-directed therapy to receive hospice-level support. Payment models like bundled payments or capitated payments for comprehensive cancer care could include allocations for rehabilitation and supportive services throughout the illness. Alternatively, create a billing code for “Sustained Living Care coordination” or “Advanced cancer care management” to reimburse the time of multidisciplinary teams working with these patients. By aligning financial incentives, clinicians and hospitals will more readily adopt comprehensive care rather than seeing it as unreimbursed extra work.

6.6.Public and Patient Education Campaigns

Governments and cancer advocacy organizations should mount educational campaigns to shift public perception. Messages could include testimonies from advanced cancer patients who have lived fulfilling lives with the support of rehab and supportive care, emphasizing “living with cancer” narratives. Destigmatizing advanced cancer is crucial - media can portray stories of individuals continuing hobbies, work, or family life even while facing stage IV cancer, with appropriate supports. Educational materials in oncology clinics can likewise reinforce that being referred to supportive services is a standard part of care for improving quality of life, not a sign of hopelessness. When the public expects and even demands Lifelong Rehabilitation and Sustained Living services, healthcare systems are more likely to prioritize them.

6.7.Research and Innovation Funding

Policymakers should allocate research funding specifically for studying models of integrated psychosocial and rehabilitative care in advanced cancer (i.e., operationalizing Sustained Living). This includes trials, implementation science studies, and development of novel interventions (like digital health tools for remote rehab or social support groups). By building the evidence base, we can refine the paradigm and demonstrate its value to skeptics. Governments could also fund demonstration projects - for example, setting up Sustained Living pilot programs in a few regions and evaluating outcomes over a 5-year period. Successful pilots then become templates for wider rollout.

6.8.Community and Social Policy Support

Recognizing that social reintegration goes beyond the hospital, policies that support patients in the community are needed. For example, labor regulations could be adapted to better accommodate employees with advanced cancer (flexible hours, remote work options, protection from discrimination). Social services can collaborate with healthcare: perhaps offering advanced cancer patients priority in community-based programs (like accessible transportation or home modification grants, similar to disability services). Additionally, ensuring hospice and home care services are robust and can incorporate rehabilitation (some hospices now do “rehab in reverse” or restorative care - this should be encouraged through hospice quality standards).

6.9.Monitoring and Accountability

Finally, policies should include mechanisms to monitor the adoption of these practices. This could involve requiring cancer centers to report metrics such as: proportion of stage IV patients seen by supportive care within 1 month of diagnosis; patient quality of life scores; utilization of rehab services; place of death (to see if more people fulfill their wish of dying at home rather than ICU, as a potential indicator of well-managed final phase). Tying some funding or accreditation to these metrics would drive compliance. For instance, a health system might receive incentives for achieving a high early referral rate or patient satisfaction scores related to supportive care.

By implementing these policy recommendations, healthcare systems will create an environment where the Sustained Living paradigm can thrive. This multi-level approachfrom terminology changes to funding and educationacknowledges that paradigm shifts require alignment of culture, practice, and policy. The end goal is a new norm in oncology: when someone is diagnosed with advanced cancer, the response of the system is not simply "We will try chemo and then eventually refer to hospice," but rather, "We will rally a team to help you live fully with this illness, through treatment and beyond, every step of the way."

7. Conclusion

In the journey of oncology, we stand at a crossroads where scientific progress has extended lives, but the ethos and framework of care for those lives have lagged behind. "A New Paradigm in Psychosocial Oncology: Integrating Lifelong Rehabilitation and Social Reintegration into Cancer Survivorship" argues for a fundamental reorientation of advanced cancer care-from a paradigm of palliation to one of sustained living. Our in-depth analysis has revealed that the conventional term "palliative care" and its associated practices, while rooted in compassionate intentions, often fall short of serving the needs and preserving the spirit of patients in Stage III and IV cancer. The traditional approach can inadvertently signal an ethical and existential retreat, as if the healthcare system were shifting focus from living to dying. We have critically examined this issue and found it both conceptually and ethically wanting, especially in an era when many patients live months or years with advanced disease and when holistic support could make those years deeply meaningful.

In response, we propose the Sustained Living paradigm, operationalized through the Lifelong Rehabilitation Model. This paradigm is not a mere theoretical construct; it is a call to action to reframe end-stage cancer care around dignity, agency, psychosocial presence, and continuity. By rejecting the passive connotations of "palliative" and emphasizing living instead, we reaffirm to patients, families, and ourselves as caregivers that there is always something intrinsically valuable and proactive we can do: we can help patients live as well as possible, for as long as possible. Dignity is upheld not only through comfort, but through opportunity—opportunities to engage in life's small and large moments. Agency is respected by partnering with patients in decision-making and goal-setting until the end. Psychosocial presence is maintained by never withdrawing support, by ensuring patients feel seen as persons, not cases, at every phase. Continuity is achieved by smoothing transitions and aligning care with the narrative of the patient's life rather than the trajectory of the disease alone.

The Lifelong Rehabilitation Model provides a tangible roadmap for enacting this paradigm. It tells us what to do: assemble multidisciplinary teams, integrate rehabilitation and psychosocial care early, and accompany the patient through the vicissitudes of illness. It tells us how to do it: through personalized goals, through adaptive interventions, through community reintegration efforts and unwavering coordination of care. And our policy recommendations map out the enabling environment needed for these changes to take root-from guideline changes and training to financial and community support.

Adopting Sustained Living and Lifelong Rehabilitation is, in essence, a transformative framework for global oncology care. It is transformative in how it views the patient (as a survivor with potential, not only as a sufferer with needs), how it structures care delivery (continuous and concurrent, not episodic or sequential), and how it measures success (quality of life and fulfillment, not just survival time or symptom control). If widely implemented, this paradigm could harmonize currently disparate efforts in oncology, palliative care, rehabilitation, and public health into a cohesive approach that benefits patients and families. It aligns with and extends emerging global health priorities that emphasize patient-centered care, integrated services, and the importance of mental health and well-being as part of healthcare outcomes (mascc.orgbiomedcentral.com).

We conclude that "palliative care," as traditionally conceived, is ready for retirement in the context of advanced cancer survivorship. In its place, we usher in the concept of "Sustained Living care." This is not to nullify the achievements of palliative care, but to build upon them on a higher plane of patient empowerment and life affirmation. Sustained Living could be the next evolution, much as hospice was an evolution in the 20th century. Embracing this evolution is both a moral imperative and a practical opportunity: morally, it reasserts our commitment to accompany patients without emotionally abandoning them; practically, it promises improved experiences and possibly outcomes for all involved.

In the words of one advanced cancer patient (whose sentiment guided our work): "I know I'm dying, but I am still alive today. Help me make today worth living." The Sustained Living paradigm is our answer to that plea. It insists that until the very last breath, healthcare's role is to add life to days, and not only days to life(hukstage-new-bucket.s3.eu-west-2.amazonaws.com). We urge oncology centers, clinicians, researchers, and policymakers to collaboratively pioneer this paradigm. By integrating lifelong rehabilitation and social reintegration into cancer survivorship, we can ensure that end-of-life becomes, in truth, end-of-life - a part of life - and not the end of living.

In sum, Sustained Living reframes the narrative of advanced cancer from one of impending defeat to one of continued journey. It is a paradigm of hope - not hope for a miracle cure, but hope grounded in the unwavering support of human dignity and meaning. Such hope is, arguably, one of the most precious gifts we can offer our patients. It is time to embed that hope into the very fabric of cancer care. The paradigm shift begins now, with us, and with the words we choose and the care we give. Let us choose to sustain life.

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