

COUNTERING SOCIAL DEATH: A CONCEPTUAL FRAMEWORK FOR RADICAL, COMMUNITY-SUPPORTED PALLIATIVE CARE IN WHOLE PERSON MEDICINE

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Introduction

Modern biomedicine has earned its reputation for technical precision. The same precision, however, has steadily narrowed the clinical gaze to the physical body and its measurable dysfunctions, leaving the biographical, relational, and existential dimensions of illness at the margins of professional attention.[1,2] For those approaching the end of life, in particular, the cost of this narrowing is high. Care that could be woven into family, neighbourhood, and religious community is instead transferred to specialist environments where monitoring equipment, protocols, and shift handovers structure the day. The dying trajectory becomes, in this setting, an episode to be managed rather than a life passage to be accompanied.[3]

Whole person care (WPC) arose precisely to challenge this drift. Anchored in the work of Balfour Mount and elaborated by Tom Hutchinson and colleagues at McGill, WPC does not deny the value of biomedical intervention; it insists that cure and healing are distinct projects, and that the latter remains both possible and necessary when the former is exhausted.[2,3] Healing, in this tradition, is not a synonym for recovery. It names the movement of a person toward coherence, meaning, and wholeness even as the body fails. The clinical encounter, reoriented in this way, becomes a site where a suffering person is met as a subject rather than processed as an object.[3]

Yet WPC has always carried an unresolved tension. Its practice can be isolating. The whole person care movement is maturing, and its leading voices now argue that the field can no longer treat community as a backdrop to clinical work, but must recognise it as a therapeutic vector in its own right. The direction is clear: WPC must turn outward.

The most developed framework for that outward turn is 'public health palliative care' (PHPC), the project Allan Kellehear began advancing in the late 1990s.[4] PHPC begins from a simple inversion: dying is, first, a social event with a medical component, not a medical event with social trimmings. The inversion is not rhetorical. It follows from an observable fact—namely, that people living at home with life-limiting illness spend only a small fraction of their remaining days in direct contact with formal healthcare professionals, and the overwhelming majority of their experience is shaped by neighbours, kin, local institutions, and the physical environment in which they live.[5,6] Kellehear's Compassionate Cities programme translates this observation into civic practice, asking municipalities to treat end-of-life care as a public health responsibility comparable to sanitation or road safety.[5]

When the civic infrastructure that PHPC presupposes is absent, fractured, or bypassed by clinical systems that concentrate care inside institutions, a specific harm follows. Borgstrom names it 'social death': the process by which a person still biologically alive comes to be treated as though they were already gone.[7] These three strands—whole person care's commitment to relational healing, public health palliative care's socio-ecological orientation, and critical thanatology's analysis of social exclusion—converge to open a path toward reimagining end-of-life care. This review synthesises these strands to propose a comprehensive framework for countering social death through radical, community-supported palliative care. The argument unfolds in four movements: a deconstruction of social death's mechanics; an account of phenomenological accompaniment and mindful congruence at the bedside; an engagement with decolonial praxis and mutual aid; and a consideration of how the ninety-five percent of lived experience outside the clinic can be reclaimed through compassionate communities and death doulas. Strategic recommendations for clinical practice, professional education, and health policy follow.

Deconstructing Social Death: Sociological and Psychological Mechanics

The concept's empirical foundation is Sudnow's 1967 ethnography of dying in American hospitals, *Passing On*, which documented how ward staff rationed attention according to a tacit calculus of social viability, conversed about patients in their presence as if absent, and occasionally initiated autopsy paperwork before biological death had occurred.[8] Sudnow's central finding was structural rather than incidental: in institutional settings, social death is not an aberration but a routine by-product of how acute care organises its work. The patient's personhood is gradually bracketed; the body becomes the sole object of custodial management. Froggatt's later study of English nursing homes extended this analysis to long-term settings, showing how the sequestration of residents from the outside social world produces a slow, institutional form of social dying that precedes biological death by months or years.[9]

Sweeting and Gilhooly sharpened the analytical picture by mapping which populations are most exposed to premature social termination. Their review identified three groups at extreme risk in late-modern societies: the very old, those in the advanced stages of terminal physical illness, and those whose cognitive decline—through dementia or persistent vegetative states—strips them of the capacities on which modern cultures predicate full personhood.[10] In a complementary empirical study they showed how dementia, in particular, accelerates social death: relatives and carers begin to withdraw emotionally before biological death, and the person living with dementia is progressively excised from the relational register of the living.[11] The mechanism, they argued, is cultural rather than individual. High modernity rewards future-oriented productivity, cognitive rationality, and autonomous self-governance; those who visibly fail on these dimensions are reclassified out of full social membership.

Broader scholarship extends this analysis by identifying additional vectors of exclusion. People living with highly stigmatised conditions experience a premature withdrawal of relational contact long before the active dying phase begins.[12] Further, neurodivergent individuals confront distinctive systemic barriers to social connection within conventional clinical environments that compound the risk of relational abandonment when physical vulnerability is superimposed on cognitive difference.[13] These findings confirm that social death is not a uniform endpoint but a differentially distributed risk, shaped by stigma, neurotype, and the politics of recognition.

At the micro-relational scale, two converging bodies of work explain how social death is enacted in everyday encounters. Kitwood's formulation of "Malignant Social Psychology," developed in the context of dementia care, challenged the assumption that the cognitive and functional decline observed in institutionalised residents is driven by neuropathology alone. Kitwood argued that a substantial portion of that decline is produced by depersonalising social environments—by the infantilisation, objectification, ignoring, banishment, and invalidation that residents routinely experience at the hands of well-meaning but undertrained carers.[14] Sabat extended this analysis through the companion concept of 'Malignant Positioning'. When caregivers position a person as "as good as dead" or cognitively empty, Sabat showed, they strip that person of the social personae through which agency

is exercised, and the positioning becomes self-fulfilling: the predicted decline is produced by the very interaction that predicted it.[15,16] Social death, on this account, is not something that merely happens to a person; it is something that is done to them, interaction by interaction, by the social world around them.[7]

Phenomenological Accompaniment and Mindful Congruence

If social death is enacted interaction by interaction, then the counter-practice must also be enacted interaction by interaction. Whole person care provides the conceptual frame for this counter-practice by re-distinguishing cure from healing. Cure targets the disease; healing targets the person, restoring a sense of coherence and meaning even when biological recovery is out of reach.[2,3] The clinical question becomes not only “what can be done for this body?” but also “how can this person be accompanied?” The latter question, once asked, redirects professional attention from intervention to presence.

Arman and Rehnsfeldt's phenomenological study of suffering and nursing care gives empirical substance to that redirection. They describe what patients call “the little extra”—not a separate procedure but a quality of attending that transforms the experience of care. Presence, on their account, is a three-dimensional practice: being present to the patient, being present to oneself, and being anchored in the present moment, with the act of presence itself received as a kind of gift.[17] This is not a soft adjunct to “real” medicine. It is the medium through which suffering becomes endurable and through which the threatened dissolution of personhood is held at bay.

Hutchinson's model of mindful clinical congruence operationalises this phenomenological insight for everyday practice.[2] Drawing on the ‘family-systems communication’ theory of Virginia Satir, Hutchinson asks the clinician to remain simultaneously aware of three intersecting dimensions of every encounter: the Self (the clinician's own interior life, vulnerabilities, and unfinished grieving), the Other (the patient as a biographical subject, not a diagnostic instance), and the Context (the institutional pressures, time constraints, and bureaucratic demands that shape what is clinically possible).[2,18] Congruence, in this framework, is the disciplined maintenance of awareness across all three dimensions at once. When the discipline lapses, the clinician tends to default to one of Satir's defensive survival stances—the super-reasonable retreat into pure technical rationality, the placating deflection of emotional demand, or the blaming projection of interior discomfort onto the patient.[18] These defaults are not character flaws. They are predictable responses to the emotional load of clinical work, and they are also the micro-mechanism through which social death is reproduced at the bedside: the patient is positioned, interaction by interaction, as an object to be managed rather than a person to be met.

Decolonizing Death Work: Decolonial Praxis and the Ethics of Mutual Aid

Bedside presence, however congruent, cannot by itself dismantle the structural conditions under which social death flourishes. A second line of critique is needed, one that interrogates the socioeconomic and historical architectures in which dying occurs. The decolonial strand of death studies has been particularly forceful here, demonstrating that what counts as a “good death” has always been culturally and historically contingent.[6]

Powell and colleagues' account of palliative care development in Africa makes the structural point concrete. Across many African settings, they show, the professionalised hospice model imported from high-income contexts collides with realities of extreme resource constraint, geographic dispersion, fragile health-system infrastructure, and linguistic-cultural plurality. Where the model is imposed without adaptation, it either fails to reach the majority of those who need it or actively displaces indigenous and community-led deathways that had previously sustained the dying and the bereaved.[20] The lesson is not that professional palliative care is unwelcome in low-resource settings; the lesson is that its introduction must be negotiated with the communities it purports to serve, not delivered to them as a finished product.

Rotolo and colleagues' description of the Peer Medical Foundation demonstrates how this works in practice: their grassroots, peer-led model redistributes both material resources and relational recognition to populations whom professionalised services have historically failed to reach,[22] showing that mutual aid is not merely a supplement to professional care but a core mechanism of whole person care for structurally marginalised communities.

Reclaiming the Ninety-Five Percent: Socio-Ecological Palliative Dynamics

The integration of bedside congruence with decolonial mutual aid requires a structural reorientation of how society allocates responsibility for dying. For several decades the professionalisation of palliative medicine has encouraged a quiet civic delegation: death has been handed over to specialist clinicians, and community confidence in accompanying the dying—what Kellehear calls death literacy—has eroded in parallel.[5,6] Reclaiming the overwhelming majority of the dying experience that takes place outside formal clinical contact requires the deliberate cultivation of community assets and the rebuilding of local confidence. The Compassionate Communities and Compassionate Cities movements, which Kellehear built on the Ottawa Charter for health promotion, translate this reclaiming into civic practice: municipalities are invited to treat end-of-life care as a public health responsibility, designing schools,

workplaces, faith institutions, and public spaces that explicitly recognise and support dying, caregiving, and bereavement.[5]

A growing workforce of non-clinical end-of-life companions has emerged to occupy the relational space that Compassionate Communities names. Death doulas, sometimes called end-of-life doulas, work as non-clinical care partners who provide continuous emotional, practical, and spiritual accompaniment across the dying trajectory and into early bereavement. Yoong and colleagues' scoping review of the death doula role synthesised the international literature and identified doula functions ranging from advance care planning conversations and non-pharmacological symptom support to vigil presence in the final days and post-mortem ritual facilitation.[23] Because doulas are not constrained by shift rotas or institutional protocols, they can offer a continuity of presence that is structurally unavailable to clinical staff, and in doing so they bridge the ninety-five percent of lived experience that formal services cannot reach. This observation, foregrounded by Kellehear, reflects the evidence that individuals with life-limiting illness spend only a small fraction of their remaining time in direct contact with formal healthcare professionals, while the overwhelming majority of their experience is shaped by family, neighbours, and community.[5,6] Stein's earlier analysis of mutual aid in bereavement groups complements this picture: when the bereaved support the newly bereaved, the therapeutic benefit flows in both directions, and the isolation that often follows loss is structurally interrupted.[24]

The doula workforce, however, remains unregulated and unaccredited in most jurisdictions, and the resulting ambiguities are not trivial. Role boundaries with clinical teams are often unclear, ethical oversight is inconsistent, and the fee-for-service model that predominates in many settings threatens to reproduce, rather than disrupt, the socioeconomic exclusions that the decolonial critique identifies. Collins and colleagues' practice-oriented review of what palliative care clinicians should know about end-of-life doulas offers a constructive path forward: clinical services should move from professional territorialism toward collaborative integration, treating doulas as essential partners in the holistic care team while working to establish the ethical and structural safeguards the role requires.[25]

Synthesis and Strategic Recommendations for Whole Person Care

The threads of the argument can now be drawn together. To counter social death and reclaim the ninety-five percent of lived experience at the end of life, whole person medicine must integrate three interdependent layers: the relational depth of mindful clinical congruence at the bedside; the socio-ecological orientation of compassionate communities in civic life; and the structural solidarity of mutual aid networks that centre those whom professionalised services have historically failed. The evidence reviewed demonstrates that social death is not an inevitable consequence of biological mortality. It is an active, socially constructed process of exclusion that can be dismantled through intentional clinical, educational, and community interventions. Four strategic recommendations follow.

First, healthcare systems should transition from a centralised, professionalised service-delivery model toward an asset-based community development approach.[5] Palliative care organisations should actively partner with local mutual aid networks, community centres, and neighbourhood associations, treating them as essential collaborators rather than as referral destinations.[21] The stance the clinician adopts in these partnerships matters as much as the partnership itself: professional services should bring technical medical support while deferring to the community's expertise in relational accompaniment and practical resource redistribution, rather than colonising community spaces with clinical protocols.

Second, clinical intake procedures should be redesigned to systematically map the patient's socio-ecological network.[1] Palliative care assessments that limit themselves to physical symptom scores miss the social determinants of dying that the ninety-five percent rule identifies. Evaluations should therefore identify local community connectors, neighbour support systems, and non-medical advocates such as death doulas, and should integrate these external actors into formal care-planning discussions.[23,25] Aligning clinical interventions with the patient's daily social reality and cultural preferences is the structural precondition for preventing institutional isolation and relational abandonment.

Third, medical and professional healthcare curricula should be restructured to integrate critical thanatology, decolonial death studies, and relational communication training.[2] Future clinicians must learn to recognise the historical and structural inequalities that shape end-of-life trajectories for marginalised and racialised populations, and to decenter Euro-American assumptions about "the good death" that travel as universal when they are in fact particular.[6,20] This critical training should be combined with Hutchinson's model of mindful clinical congruence, equipping students with the psychological disciplines required to remain emotionally available to patients without defaulting to the defensive stances that produce both burnout and social death.[2,18]

Fourth, healthcare administrators should establish structural stewardship programmes that sustain the emotional and moral resources of the clinical team. Recognising that the clinician's self is the primary instrument of healing, organisations must reject individualistic wellness models and implement collective, team-based reflective practice and mutual supervision instead.[19] By sharing the moral weight of complex clinical decisions and validating the emotional labour of care, institutions can cultivate a sustainable clinical culture that prevents professional depletion and ensures the continuous, compassionate accompaniment of the dying person.

Conclusion

The evidence demonstrates that social death is not an inevitable consequence of biological mortality but an active, socially constructed process of exclusion that can be dismantled. Integrated strategies

that transition healthcare systems from professionalised service delivery to asset-based community development, redesign clinical intake to assess socio-ecological networks, restructure medical curricula to incorporate critical thanatology and relational communication training, and establish institutional stewardship programmes that sustain clinicians' emotional resources can move whole person medicine closer to the ground. In doing so, they transform the end-of-life trajectory from an experience of medicalised isolation into a shared, relational practice of collective accompaniment—and, in the best cases, into a profound recognition of the shared humanity that survives even the body's failure.

Declarations

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