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Transforming recognition into responsibility: moral obligations to informal caregivers in palliative care

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ABSTRACT

Informal caregivers are widely recognised as part of the 'unit of care' in palliative care, yet this recognition has rarely been translated into clearly specified ethical obligations. The present paper argues that informal caregivers are not merely instrumentally relevant to patient-centred care but are independent moral stakeholders whose vulnerability grounds direct obligations of support. The analysis demonstrates that ethical obligations towards caregivers cannot be justified solely by reference to patient welfare. While many such duties are best understood as prima facie obligations, some reach the level of threshold obligations where caregivers' fundamental interests—such as autonomy, integrity or protection from serious harm—are at stake. The paper argues that the provision of support to informal caregivers should not be regarded as a discretionary component of good palliative care but a threshold requirement of ethically grounded palliative practice, with implications for clinical decision-making and institutional responsibility.

INTRODUCTION

Palliative care is a specialised form of care for individuals afflicted with life-limiting illnesses, with the objective of alleviating physical, psychosocial and spiritual suffering throughout the entire course of the disease.[1]

International definitions of palliative care (as established by the WHO and the European Association for Palliative Care) consider not only patients but also their relatives to be recipients of palliative care.[2 3] In the context of palliative care, the term 'relative' is employed in a broad sense to encompass both legally or biologically related family members and socially significant others in addition to caregiving and non-caregiving family members. Collectively, these individuals are designated as informal caregivers when they provide unpaid care or support outside the confines of formal professional structures.

Care occupies a central role in palliative care by orienting clinical practice towards the needs, values and preferences of persons with serious illness, with the aim of sustaining autonomy under conditions of dependence and vulnerability. In this sense, care functions as a thick ethical concept, encompassing both caregiving practices and their normative appraisal.[4 5]

Although informal caregivers are explicitly recognised as recipients of palliative care, the ethical implications of this recognition and the normative status of obligations towards informal caregivers have not yet been systematically analysed. It remains under debate whether obligations towards caregivers are merely indirect, derived from concern for patient well-being (ie, supporting caregivers in order to enhance their capacity to care for the patient) or whether informal caregivers should be regarded as independent bearers of moral claims, such that their support constitutes an intrinsically justified moral obligation.

Aim of the article

The present article aims to clarify the normative status of informal caregivers in palliative care and to examine whether obligations towards them are merely derivative of patient-centred concerns or independently justified. The analysis of the vulnerability experienced by informal caregivers is presented as an ethically relevant condition, rather than a contingent by-product of the patient's illness. On this basis, the article seeks to distinguish between different types of moral obligations towards caregivers and to explore the conditions under which these obligations become ethically compelling within palliative care practice.

Informal caregivers in palliative care: experiences and challenges

Illness is relationally and socially constituted rather than a purely individual experience. The concept of the 'unit of care' emphasises that palliative care extends beyond the control of symptoms to the preservation of the relational architecture surrounding the dying person,[6] including shared suffering, decision-making and meaning-making within family systems. Within this framework, informal caregivers are not merely auxiliaries but co-subjects of the dying process, whose distress is ethically relevant in its own right rather than only insofar as it affects patient outcomes.

Consistent with this conceptualisation, empirical research demonstrates that informal caregivers in palliative care experience substantial multidimensional burdens, including physical exhaustion, psychological distress and social strain. They frequently assume extensive caregiving responsibilities, navigate complex emotional dynamics and face ethically challenging situations.[7] A substantial corpus of empirical evidence documents elevated levels of depression, anxiety, moral distress, poorer health outcomes and reduced quality of life among caregivers across care settings.[8–10] These burdens are exacerbated by structural inequities, such as inadequate financial support, the social invisibility of care labour and limited access to professional guidance, psychosocial support and respite services.[11] Particular attention should be paid to the specific needs of several groups, including minor children and adolescents caring for an ill parent, family

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members acting in a representative role, long-distance caregivers, caregivers with a professional background, LGBTIQ+ individuals and persons with a migration background. Grief experienced by family members constitutes a profound existential disruption that often commences prior to the patient's death and is shaped by contextual, dispositional and situational factors. Caregiver burden, lack of social resonance and insufficient narrative processing have been identified as key risk factors for complicated grief. Experiences during the final phase of life have been shown to exert a formative influence on subsequent bereavement trajectories.

Despite heterogeneity in methodological quality, these findings demonstrate a high degree of robustness across various settings and care groups. They indicate that caregiver burden constitutes a central concern across all domains of palliative care, irrespective of whether the care is provided in the home, in a hospice or in an institutional palliative care setting.

Despite a growing evidence base on the needs and burdens of informal caregivers in palliative care,[12] substantial gaps remain in structured, evidence-based interventions, including guidance on effective support measures, impact evaluation and equitable access to services.[13]

This evidence of caregiver burden, including elevated rates of depression, anxiety and moral distress,[8–10 14] reveals ethically salient forms of vulnerability, such as systematic exposure to preventable harm and structural disadvantage. These findings do not in themselves generate normative obligations; however, they identify where caregivers are systematically disadvantaged and therefore call for ethical interpretation.

Grounding obligations to informal caregivers in palliative care

Against this backdrop of empirically documented vulnerability, moral obligations towards informal caregivers can be justified from different ethical perspectives, since no single ethical framework fully captures the moral complexity of informal caregiving in palliative care. I therefore adopt a convergent approach inspired by Parfit's idea[15] that different moral theories can converge on shared normative conclusions even if they disagree more broadly. I argue that care ethics and relational autonomy accounts, deontological theories and theories of justice and solidarity all support the claim that healthcare professionals and institutions have direct obligations to informal caregivers. Rather than privileging a single comprehensive theory, I focus on this shared normative core.

More specifically, three clusters of theories help to justify these obligations. First, care ethics and relational autonomy accounts justify direct obligations to support caregivers as relational moral subjects. Second, deontological theories ground duties to respect informal caregivers as ends in themselves and to avoid exposing them to foreseeable harm. Third, theories of justice and solidarity frame caregivers as bearers of claims against unfair distributions of burdens and opportunities. In addition, phenomenological and narrative approaches complement these frameworks by illuminating the ethical relevance of caregivers' lived experiences and the disruption of shared meaning in serious illness.

In addition to these normative frameworks, vulnerability itself can be analysed as a multidimensional concept that guides the specification of obligations. Vulnerability is multidimensional, following Luna's layered model[16] adapted to palliative caregiving: fundamental (human dependence and finitude), situational (caregiving overload, anticipatory grief, end-of-life decisions) and structural (socio-economic inequities, the invisibility of care labour).[17] The normative claims developed below link primarily to situational and structural dimensions (eg, prima facie duties for overload; threshold duties for exploitation). These links indicate typical patterns rather than a rigid one-to-one mapping, and the stringency of duties still depends on the concrete context. By targeting relational and systemic exposures rather than construing caregivers as inherently deficient, this approach avoids paternalistic framing. This multidimensional account of vulnerability then guides the differentiation between prima facie duties and threshold duties without constituting a separate comprehensive theory.

These distinctions ground specific duties. Situational vulnerability, such as caregiving overload leading to increased risk of depression,[10] generates prima facie obligations to provide timely counselling and psychosocial support. Structural vulnerability, such as the substitution of unpaid labour resulting in avoidable hospitalisations,[18] demands threshold-based access to respite care, an approach reflected, for example, in the UK National Institute for Health and Care Excellence guideline on supporting adult carers.[19] Primary duty-bearers include clinical services and interdisciplinary teams responsible for systematic screening and referral, complemented by policy-level funding obligations.[17] Together, these duties constitute threshold obligations that define minimum ethically acceptable standards, applicable even under resource constraints, ensuring that no caregiver faces foreseeable serious harm through systemic neglect.

Care ethics conceives moral responsibility as emerging from relations of dependency and vulnerability. Gilligan[20] and Tronto[21] emphasise that moral attention arises in situations where vulnerability becomes salient and demands a response. In the context of palliative care, informal caregivers are profoundly entrenched in care practices, yet concurrently encounter emotional, practical and existential vulnerabilities. Care ethics establishes a direct moral responsibility towards caregivers originating from relational dynamics rather than from instrumental concern for patient outcomes alone.

The theory of relational autonomy conceptualises autonomy as a capacity that is enabled and sustained through supportive relationships.[22] In end-of-life contexts, patients' decision-making capacities are significantly influenced by the emotional and communicative stability of caregivers.[23 24] Concurrently, caregivers themselves are autonomous agents whose capacities for action may be compromised by excessive burden. Consequently, supporting caregivers should be regarded as an integral component of autonomy-promoting palliative care, rather than as a merely ancillary measure.

Deontological approaches reinforce these duties. Kant's principle of humanity[25] prohibits treating caregivers as mere means. Levinas[26] grounds responsibility in encounters with vulnerability, while Jonas[27] extends it to preventing foreseeable harm. Collectively, they establish caregiver support as obligatory when fundamental interests, autonomy, integrity or protection from harm are at stake.

Phenomenological and narrative accounts further illuminate the ethical relevance of caregivers' experiences. Serious illness disrupts embodied meaning and narrative coherence not only for patients but also for those who share their existential and relational space. Supporting caregivers therefore includes addressing narrative and relational disruptions that shape both caregiving and bereavement trajectories.

Accounts of justice and solidarity emphasise the structural dimension of caregiver vulnerability. From the perspective of justice, theories such as Rawls's account of fair equality of opportunity[28] and Daniels's framework of just health under conditions of illness[29] constitute one strand among several

overlapping normative justifications for caregiver-directed obligations. These approaches help to show why caregiver-related burdens and opportunity losses are not merely unfortunate side effects of illness, but matters of fairness in the distribution of burdens and opportunities. Nussbaum's capabilities approach and Young's[30] concept of structural injustice further demonstrate that such disadvantages are not the result of individual choice but of institutional arrangements that render care labour invisible and unevenly distributed.

Prainsack and Buyx[31] conceptualise solidarity as a lived practice of sharing costs and burdens arising from shared vulnerability, which becomes normatively binding, particularly when specific groups carry structurally disproportionate loads. In the context of palliative care, this applies to informal caregivers who assume a significant proportion of care responsibilities and for whom empirical evidence has documented their substantial health-related, economic and social burdens. Foucault's concept of governmentality and biopower[32] draws attention to forms of power that govern life and health indirectly. Instead of relying on formal legal authority, such governance works through dispersed social and institutional arrangements that structure how care responsibilities are assigned and normalised. A solidarity-based approach to palliative care should therefore counteract the invisibility and uncompensated transfer of care labour to informal caregivers.

Across a range of ethical frameworks, a convergent conclusion emerges: informal caregivers are direct moral addressees in palliative care, thereby generating obligations of support. This convergence identifies a minimal shared core of negative and positive duties, at least to avoid serious harm, exploitation, coercion and neglect of caregivers' autonomy and integrity, without claiming theoretical equivalence or a comprehensive theory of caregiver support.

From empirical evidence to moral obligation

A common objection is that, particularly under conditions of scarcity, palliative care bears primary responsibility to patients and that support for informal caregivers is ethically justified only insofar as it contributes to patient well-being. This objection is predicated on a zero-sum understanding of care that fails to capture the relational structure of palliative contexts. Support for informal caregivers can be reconciled with resource-sensitive theories of justice, provided that it is not understood as an entitlement to specific individual interventions and does not require priority-setting between patients and informal caregivers. Rather, it should be regarded as a claim to the equitable integration of care labour within the healthcare system. The claim that support for informal caregivers constitutes ethically justified palliative care can also be articulated in distributive terms. Among the converging normative approaches discussed above, theories of justice help to specify when burdens and opportunity losses imposed on caregivers become unfair. Daniels' account of fair equality of opportunity is one useful illustration of this point. The practice of allocating costs to families in a systematic manner constitutes a violation of not only individual duties of care, but also the principles of structural fairness. It does so because it treats caregivers' vulnerability as normatively secondary rather than independently relevant.

Read in this light, the available empirical evidence indicates that informal caregivers in palliative care are systematically exposed to significant burdens, unmet needs and opportunity losses. These factors are compounded by their position of heightened vulnerability shaped by relational embeddedness and structural disadvantage. The preceding ethical analyses demonstrate that these features are, across diverse ethical and philosophical frameworks, normatively relevant conditions that generate positive obligations. When empirical findings are interpreted through the lenses of converging normative frameworks, the conclusion drawn is not merely that support for informal caregivers is ethically permissible or desirable, but rather that it constitutes a moral obligation.

Empirical evidence can reveal the context-sensitive conditions, relevant moral agents, conflict constellations and distributive implications of normative principles. This, in turn, helps to specify, prioritise and implement obligations that are independently justified (without itself grounding their normative validity). As Kon[33] emphasises, empirical research contributes by 'laying out the moral landscape': clarifying how ethical problems are experienced in practice, identifying morally salient consequences of action or inaction, and revealing where existing norms may be underinclusive or overinclusive. Furthermore, such evidence has the capacity to expose systematic discrepancies between normative expectations and lived realities, thereby guiding the refinement and contextual calibration of ethical obligations in complex care settings.

The obligations towards informal caregivers in palliative care can be distinguished, by their normative status, into instrumental duties, prima facie duties and threshold duties specifying stringent minimum protections. Where vulnerability involves a credible risk of serious harm, coercion or structural exploitation, and where institutional actors foreseeably contribute to or sustain these conditions, a correlative duty of protection arises. The stringency of this duty increases with the severity and avoidability of harm. In such cases, support is not discretionary but required as a matter of moral obligation grounded in the protection of fundamental caregiver interests.

Instrumental duties are means-end dependent and apply in situations where structural measures aim to reduce suffering and the burden on caregivers. From a consequentialist perspective, an action is required if it effectively advances a morally endorsed goal. For example, the continuous availability of specialised ambulatory palliative care is instrumentally justified insofar as it enhances care stability and relieves informal caregivers.

Threshold duties constitute non-derogable protections activated when fundamental caregiver interests, such as credible risk of serious harm, exploitation, coercion or autonomy violations, are at stake. These function as limits that cannot be over-ridden by efficiency or indirect patient benefit. In this respect, threshold obligations function as rights-like limits that protect caregivers against serious harm and exploitation and define what may not be traded off for efficiency or indirect benefits.

These dimensions ground specific duties. Situational vulnerability, such as moral distress from end-of-life decisions leading to psychological harm,[10] generates prima facie obligations for counselling. Structural vulnerability, such as systematic underfunding of respite care services leading to caregiver breakdown,[12] demands threshold-based protections. These include mandatory respite provision, understood as a requirement for services to offer and facilitate access to appropriate respite options once structured screening reveals a credible risk of serious harm or breakdown. In this sense, respite support should no longer be treated as discretionary, but as part of the minimum ethically acceptable standard of caregiver protection, in line with international guideline recommendations on carer support,[19] while remaining subject to context-sensitive specification and shared decision-making.[34] Primary duty-bearers are clinics and interdisciplinary teams responsible for screening, complemented by policy-level funding obligations. These constitute threshold

duties specifying minimum standards that remain binding even under resource constraints, aiming to ensure that no caregiver faces foreseeable serious harm through systemic neglect.

The majority of obligations towards informal caregivers are constituted by prima facie duties.[35] While these obligations are generally binding, they may be over-ridden by stronger competing obligations in conflict situations that are characteristic of palliative care. Consequently, there is a prima facie duty to inform, accompany and support informal caregivers, which may require justified specification when a competent patient explicitly refuses information disclosure. In such cases, the provision of support for informal caregivers should not be suspended but rather adapted in ways that respect patient autonomy.

From moral obligations to clinical judgement

This section translates the foregoing moral obligations towards informal caregivers into concrete requirements for clinical decision-making in palliative care.

Obligations towards informal caregivers frequently arise in contexts characterised by value conflict and moral remainder. Recurrent conflicts in palliative care involving informal caregivers include but are not limited to the following high-impact constellations: (1) confidentiality disputes, where patient autonomy limits but does not eliminate support duties; (2) severe caregiver burden sustained by moral pressure or relational loyalty; (3) surrogate decision-making tensions when caregivers' values diverge from those of the patient or generate moral distress; (4) conflicts between caregiver well-being and institutional resource constraints; (5) discordance between patient and caregiver treatment preferences (eg, life-prolonging vs comfort-focused care)[36]; and (6) caregiver powerlessness when over-ridden by institutional no-decision scenarios.[7]

Such reasoning can be operationalised through formal reconstruction of the relevant descriptive and normative premises. In confidentiality disputes, patient autonomy limits direct disclosure but does not eliminate prima facie support duties. Non-disclosing counselling (eg, via general psychosocial resources) or safeguarding interventions remain obligatory if credible risk of serious harm (threshold duty) is foreseeable. This respects patient wishes while preserving threshold protections for caregivers, with formal reconstruction ensuring transparency in balancing competing claims. Non-disclosing support may include general psychosocial counselling, referral to independent caregiver services, safeguarding assessment where serious harm is foreseeable and structured monitoring of caregiver burden.

In contexts of limited resources, these conflicts do not require case-by-case prioritisation of caregivers over patients, but rather the transparent specification of ethically justified minimum standards of caregiver support that can be upheld alongside patient-centred obligations. Minimum standards include routine screening and counselling for prima facie duties, as well as harm protection measures (eg, mandatory respite care) for threshold duties. Implementation can build on established structures (eg, Carer Support Needs Assessment Tool (CSNAT), the short multidimensional screening tool for caregivers (CAREPAL) [37 38] or National Institute for Health and Care Excellence structured carer support[19]), distributing responsibility across clinical teams (for screening) and institutions (for pathways) while translating ethical duties into measurable forms of accountability.

Addressing these situations in an ethically defensible manner requires structured and transparent ethical reasoning. Under conditions of uncertainty, preliminary practical judgements can be reconstructed by explicitly setting out the relevant descriptive and normative premises and their logical relations. In this process, distinctions between forms of kinship, relational proximity and actual caregiving responsibility are ethically salient, as the scope and stringency of obligations vary accordingly. The method of formal reconstruction, understood as explicitly structuring premises and conclusions, provides a means to justify context-specific obligations, to balance competing claims and to communicate resulting judgements intelligibly within interprofessional teams and towards patients and informal caregivers. This approach is consistent with accounts of empirical bioethics[33] that emphasise the explicit articulation of normative assumptions, the clarification of competing obligations and the transparent communication of ethical judgements. Accordingly, obligations towards informal caregivers require context-sensitive specification as a condition of ethically justified clinical judgement.

From moral obligation to epistemic and institutional responsibility

The obligations identified in this article are not confined to individual clinicians but extend to healthcare institutions and system-level governance.

At the clinical level, interdisciplinary teams bear responsibility for systematic identification, initial support and referral. At the organisational level, healthcare institutions are responsible for ensuring accessible support pathways and for implementing minimum standards at a structural level. At the policy level, governments and health authorities bear responsibility for fair burden distribution through funding, regulation and governance frameworks.

Insufficient caregiver support drives avoidable emergency admissions, prolonged hospital stays and societal costs including reduced labour participation and health risks. Structured support ensures both ethical adequacy and responsible stewardship of palliative resources.[13]

The systematic externalisation of care responsibilities to families also reinforces social inequalities. It disproportionately affects socio-economically disadvantaged households, individuals with migration histories and those with limited access to institutional support.[39]

Reliance on unpaid caregiving without systematic assessment constitutes institutionalised irresponsibility.[31 32] Clinics must therefore implement routine screening,[37] and policymakers must fund respite services in accordance with established guidelines,[19] thereby countering exploitation and ensuring fair burden-sharing.

These considerations entail not only institutional accountability but also epistemic responsibility. As Kon[33] argues, ethical responsibility extends beyond normative justification to the empirical clarification of the conditions, effects and unintended consequences of ethically required practices. Where such knowledge is lacking, care risks remaining inconsistently implemented and epistemically underdetermined. This obligation is particularly salient where caregivers themselves become research participants, given their heightened vulnerability and dependence on care structures.

The learning health system framework[40] provides a normative basis for translating these responsibilities into governance and policy, conceptualising research and clinical practice as mutually obligating activities. This position is reinforced by the Declaration of Helsinki, which affirms a positive responsibility to study health-related conditions associated with significant burden or unmet need. Consequently, recognising caregivers as moral addressees in palliative care requires policy frameworks that support caregiver-focused research, integrate caregiver-related

outcomes into quality assurance and prioritise caregiver support within national research agendas. Where ethically required practices are insufficiently specified, inconsistently implemented or foreseeably harmful, a secondary obligation arises to generate the knowledge necessary for their responsible realisation.

CONCLUSION

This article has argued that informal caregivers in palliative care are independent moral addressees whose vulnerability grounds direct obligations of support. Although international frameworks recognise informal caregivers as part of the 'unit of care', this recognition remains ethically incomplete unless translated into specified and enforceable obligations. While many duties towards caregivers are appropriately understood as prima facie obligations, some acquire heightened normative force where caregivers' fundamental interests, such as autonomy, integrity or protection from serious harm, are at stake. In these circumstances, support for informal caregivers is not merely discretionary or instrumental to patient benefit but constitutes a threshold obligation of ethically justified palliative care. Accordingly, ethically adequate palliative care must systematically incorporate caregiver assessment, structured support pathways and institutional accountability. Failure to meet ethically justified minimum standards of caregiver support should be understood not merely as a deficit in quality, but as an ethically relevant form of neglect, with corresponding institutional and epistemic responsibilities.

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