Towards a shared and supported decision-making model: fostering relational autonomy in end-of-life care

Published in ***Medicine, Health Care and Philosophy*** 2025

https://doi.org/10.1007/s11019-025-10307-1

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Funding

This work was funded by a Trinity Research Doctorate Award for Group-based Research Projects at Trinity College Dublin.

Declarations

Conflict of interest: The authors report no conflict of interest.

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Introduction

Respecting patient autonomy is a fundamental ethical principle in end-of-life care (Farsides 1998). However, autonomy in this context cannot be reduced to an isolated act of self-governance, nor can its respect be confined to passive non-interference or the formal recording of consent. Faced with progressive illness, cognitive decline, emotional distress, and the existential weight of end-of-life decisions, many patients may struggle to articulate or sustain their preferences without appropriate forms of support (Elsner and Rampton 2022). To be meaningfully respected, autonomy must therefore be supported through relationships and institutional conditions that enable patients to reflect, deliberate, and make decisions aligned with their values and preferences (Bélanger et al. 2011). The question, then, is not solely how to respect patients' autonomy in end-of-life care, but how autonomy, understood in relational terms, can be genuinely fostered. At the heart of this question lies a key philosophical debate: whether relational autonomy should be understood in procedural or in substantive terms (Mackenzie and Stoljar 2000), a distinction that fundamentally shapes what fostering autonomy means in practice, particularly in contexts marked by vulnerability and interdependence.

This paper addresses that debate by advancing a normative and practice-oriented model of decision-making specifically adapted to the clinical and existential complexity of end-of-life contexts. Our contribution lies in showing how two approaches typically treated in isolation, shared decision-making and supported decision-making, can be integrated into a richer, context-sensitive framework. This integration advances current ethical discussions on respecting and supporting autonomy by making them more responsive to patients' relational embeddedness, the ethical demands of vulnerability, and the institutional realities of end-of-life decision-making.

The article unfolds in three sections. Section 1 examines the different ways in which autonomy in end-of-life care is conceptualised in relational terms and introduces differing perspectives on how it can be fostered, highlighting the relevance of the distinction between procedural and substantive accounts. Section 2 presents and analyses a composite clinical case to explore how relational autonomy is enacted and challenged in practice. Section 3 introduces the articulation between shared and supported decision-making as a practical model for fostering relational autonomy in end-of-life care, and examines its broader philosophical foundations as well as potential barriers to its integration in the current healthcare context.

The reflections offered in this paper are grounded in a combination of clinical, therapeutic, and philosophical perspectives. The authors bring together extensive clinical experience in specialist palliative care, expertise in end-of-life decision-making, and scholarship in social and political ethics. Our composite case at the heart of this essay does not depict a single patient but draws on multiple real clinical encounters, reconfigured to highlight recurring ethical and relational challenges in end-of-life care. This approach reflects a shared commitment to bridging clinical sensitivity and philosophical inquiry, and to developing conceptual tools that remain attentive to the lived realities and uncertainties of practice.

Fostering relational autonomy in end-of-life care

Mapping relational autonomy in end-of-life care

The principle of respect for autonomy has acquired particular prominence in end-of-life care, where decisions often involve profound questions of value, identity, and meaning (Billings and Krakauer 2011). Since the development of specialised palliative care in the late twentieth century, attention to patient autonomy has been central to ethical reflections on how to support individuals facing the end of life (Houska and Loucka 2019). This focus has only intensified in recent decades, as debates around the wish to hasten death, euthanasia, and assisted suicide have highlighted the ethical and legal stakes of enabling individuals to exercise control over the timing and manner of their dying (Sjöstrand et al. 2013). In these discussions, the capacity to make informed and independent decisions is often framed as a marker of dignity, self-respect, and moral agency (Rodríguez-Prat et al. 2016).

While this emphasis on autonomy has played an essential role in shifting end-of-life care away from paternalistic models and toward more person-centred approaches, it also raises important ethical questions. In particular, conceptions of autonomy that rely primarily on individual rational agency risk marginalising the lived realities of patients who may experience physical decline, cognitive impairment, emotional distress, or existential crisis (Tonelli and Misak 2010). In such circumstances, decision-making often unfolds not as a solitary act of will, but as a relational and dynamic process involving family caregivers and healthcare professionals (Foley et al. 2025). Over the past two decades, a growing body of philosophical and empirical work has argued that autonomy in end-of-life care must be understood not as the exercise of unencumbered choice, but as a capacity shaped and sustained by interpersonal and institutional contexts (Jennings 2016). The shift in thinking reorients the ethical focus from respecting autonomy as a static right to fostering it as an evolving capacity embedded in vulnerability, dependence, and care.

This relational turn has been explored by Gomez-Virseda et al. (2019), whose systematic review of 50 argument-based ethics publications shows that the notion of relational autonomy takes several forms in the context of end-of-life care. Informed by this work, we propose a typology of the main meanings relational autonomy takes today in this field, identifying three approaches to understanding autonomy in relational terms in end-of-life care, each expressing a particular type of relationality: toward oneself, toward others, and toward a common good.

The first type recognises that, in the face of serious illness and approaching death, identity is rarely stable or fully transparent. Values and wishes must often be clarified, revisited, and rearticulated over time. Autonomy, in this view, involves the ongoing and often uncertain task of relating to oneself, a task marked by ambivalence, self-doubt, and difficulty in articulating what truly matters (van Wijngaarden 2024). Because this relationship to the self is rarely fully transparent or settled, it requires the presence and support of others, such as family caregivers and healthcare professionals (Foley 2018), but also external conditions of freedom and opportunity that enable individuals not only to make meaningful choices but to enact them in ways that feel coherent and self-authored (Lolich and Lynch 2017).

The second type emphasises that autonomy is grounded in the relational constitution of identity itself (van Nistelrooij et al. 2017). In end-of-life contexts, decisions are not made solely for oneself, nor are they expressions of an isolated will. Patients are often aware that their choices will affect the lives, memories, and values of those close to them. Their identities are intertwined with those of their loved ones, and the decisions they make reflect not only personal values but also a concern for how these choices will shape the futures of others (Fagan et al. 2024). Autonomy, here, implies not only self-determination but also a capacity to reflect on the responsibilities one holds toward those with whom one's life is bound (Hasdenteufel and Quintard 2022).

The third approach understands autonomy as something achieved with others, through cooperation and ethically attuned effort (Jacobsen et al. 2021). Autonomy, then, is shaped and enhanced by participation in the common project of making care good, meaningful, and bearable for all involved. This process includes practices of negotiation, deliberation, and discussion through which possible courses of action are defined (St Ledger et al. 2021). In this view, respecting autonomy does not mean that close relatives and healthcare professionals must refrain from expressing what they believe to be in the patient’s best interest; rather, it calls for a form of engaged responsiveness that nourishes deliberation and supports the patient’s capacity to decide (De Panfilis et al. 2019).

These different approaches show that autonomy in end-of-life care emerges through relationships. Yet this very relationality is ethically ambivalent: it enables autonomy but may also compromise it. For instance, rigid institutional policies (Wright 2018) or pressure from loved ones may constrain what options are presented, supported, or even considered (Blackler 2016). In each case, relationality can either foster or diminish autonomy depending on the quality of the relationships, the distribution of power, and the institutional conditions in which decisions are made. The practical question that emerges, then, is how to orient the relationality of autonomy in a way that genuinely supports patients in making decisions that reflect who they are and what matters to them. One response to this challenge is offered by Gomez-Virseda et al. (2020), who propose a procedural application of relational autonomy in end-of-life care. Their model outlines a structured, three-step process involving multidisciplinary deliberation, alignment with patients' goals of care, and reassessment of the decision's authenticity, coherence, and moral weight over time. While this approach acknowledges the ethical complexity of end-of-life decision-making, it remains limited by its procedural structure. If the actors involved do not possess the moral sensitivity, relational skills, and interpretive capacities necessary to engage with patients in an attuned and supportive manner, no procedural framework can secure the conditions for relational autonomy. In other words, the solution does not lie in the refinement of procedures alone, but in a deeper ethical understanding of how autonomy can be supported in practice. This requires attending not only to what is done, but to how it is done, by whom, and under what relational and institutional conditions.

The procedural-substantive debate

To explore this further, we turn to the recent work by Foo et al. (2024) which offers a clinically grounded ethical proposal for fostering relational autonomy in end-of-life care. Its importance for our inquiry lies in how it brings to the clinical arena the ongoing philosophical debate between procedural and substantive conceptions of relational autonomy, exemplified respectively by John Christman (2014) and by Catriona Mackenzie (2008). While both of these perspectives agree that, in contexts of vulnerability, respecting autonomy requires actively promoting it, they diverge on the theoretical grounds and practical means of doing so. In what follows, we outline the main elements of this controversy before introducing how our position differs from both Foo et al.'s procedural interpretation of Christman's model and Mackenzie's substantivist account.

Foo et al. (2024) present the case of a 63-year-old patient with terminal bone cancer who, following a below-knee amputation, asks for life-sustaining treatment to be withdrawn so as not to burden her daughter, a single mother of two. Her stance is ambivalent: at times she wishes to live longer to spend more time with family; at others she feels her life has been “enough” and prefers not to impose further care responsibilities on others. Although deemed fully competent, she wishes clinicians to address her daughter directly and let her decide on her behalf. Conversations with the daughter reveal the patient’s long history of hardship, habitual self-sacrifice, prioritising family needs over her own, and avoiding dependence. The daughter, however, takes a different view, wanting all possible treatments to prolong her mother’s life. This combination of fluctuating preferences, delegated authority, ingrained self-abnegation, and diverging views makes shared decision-making exceptionally challenging.

What should the healthcare team do in such a situation? For Foo et al. (2024), the answer lies not in resolving the immediate decision but in developing a richer and collective understanding of the patient’s autobiography, values, aspirations, and commitments. Their approach aligns with Christman’s procedural and content-neutral conception of autonomy, which assesses agency through the coherence of decisions with the agent’s diachronic practical identity (Christman 2022). What matters is enhancing the patient’s ability to articulate what is important to her, sustain critical reflection, and ensure the absence of alienation from the values guiding her choices. In the case they present, such deliberative and interpretive work could deepen the patient’s awareness of her own identity and of how her interdependence with her daughter forms part of it, thereby supporting a more autonomous decision.

By contrast, substantive accounts of relational autonomy are content non-neutral: when self-effacement has been internalised as a core value, critical reflection alone is not enough to secure autonomy (Oshana 2006). In such cases, the team’s role would include helping the patient consider alternative ways of living and reshaping her practical identity. Yet, as Foo et al. argue, such transformation lies well beyond the responsibilities of healthcare professionals in the time-constrained context of end-of-life care, and strong substantive criteria risk sliding into normative paternalism by defining autonomy according to standards external to the agent (Christman 2004). Mackenzie’s weaker substantivist view addresses this concern by adding to Christman’s procedural conditions a substantive one: self-authorisation, the capacity to see oneself as a legitimate source of authority (Mackenzie 2014). In Mackenzie’s account, self-authorisation involves self-respect, self-trust, and self-esteem, as well as the ability to take responsibility for one’s actions and decisions. In Foo et al.’s case, these conditions seem unmet, as the patient’s wish to withdraw life-sustaining treatment appears shaped by a lack of self-referring attitudes and a diminished sense of authority to decide for herself.

Against even this weaker substantive conception, Foo et al. (2024) argue that, in the complex and time-pressured context of end-of-life care, it is impractical to expect healthcare professionals to attempt to transform a patient's attitudes toward herself. In their view, self-authorisation cannot be a necessary condition for autonomy in this setting because it imposes a perfectionist ethical ideal that would exclude many patients from being considered autonomous agents. While we agree that promoting self-referring attitudes cannot be a task that must precede decision-making, we contend that it is also insufficient to limit the decision-making process to the single criterion of authenticity with the patient's diachronic practical identity.

The reason is as follows: ethical discussions about respecting and promoting patients' autonomy often assume that only the patient's autonomy is at risk. Yet end-of-life care remains ethically challenging regardless of experience, exposing professionals to ethical suffering, the distress of acting against one's values or moral sense (Rolo 2017). Such suffering, while sometimes a source of moral growth, can also erode professionals' self-esteem, self-trust, practical identity, and autonomy (Pujol 2023). Respecting a patient's authentic choice may itself cause ethical suffering when it conflicts with one's own conception of good care, a conception shaped by accumulated experience and the ethical norms that define "doing the job well" and taking pride in it.

Unlike Foo et al., who prioritise the co-construction of an authentic patient autobiography, we place the attuned and shared nature of decision-making at the heart of the process. Our view remains liberal - patients retain final authority - but rejects the idea that respecting autonomy means insulating them from external normativity. In this perspective, promoting an authentic autobiography or self-referring attitudes is not a standalone task; it emerges from the collective and deliberative search for shared decisions, encompassing both everyday matters and existential ones. Relating this to the three approaches to relational autonomy set out earlier (towards oneself, towards others, and towards a common good), Foo et al.'s proceduralism aligns with the first two: autonomy's dependence on others and its entwinement with significant relationships. Our view also incorporates the third, by creating conditions for moral agents to work together toward a common good, one that emerges from the encounter itself and the cooperative work that follows. Before setting out the practical and philosophical foundations of our model, we present a composite case to ground the conceptual discussion in the real complexity of clinical practice.

Fostering relational autonomy in practice: a composite case study and ethical reflection

Clinical case

Mrs Mia is a 75-year-old patient hospitalised in the ward of her referring oncologist following several episodes of confusion. She has an advanced digestive cancer. Given the patient's clinical status, no further lines of chemotherapy were considered appropriate. A brain scan showed no signs of a cerebrovascular accident (i.e. stroke) and her confusion significantly improved after the introduction of hydration. Mrs Mia has been under the care of the referring oncologist since she was diagnosed with cancer. She is described by the day hospital staff as an autonomous woman, capable of clearly expressing her preferences with genuine independence of mind. She lives alone at home and has a son living abroad, whom she has not seen for several months.

Despite the significant improvement in her confusion, Mrs Mia remains profoundly asthenic, cachectic, in pain, and nauseous. The attending physician is concerned and takes the initiative to call her son to share this concern. The son made urgent arrangements to be at his mother's bedside. He requests an extra bed to stay by her side day and night. He shows great attentiveness, providing numerous forms of care such as feeding her, massaging her, and helping her mobilise and walk as often as possible. Mrs Mia's referring oncologist occasionally visits the ward. During one such visit, her son asks if a third line of chemotherapy remains a possibility. The oncologist replies that in his mother's current condition, it would be unreasonable, but he is willing to consider it if her clinical state improves. Mrs Mia's health continues to deteriorate. Her pain increases, requiring the introduction of morphine, a decision made by the ward physician in agreement with the patient. The treatment effectively alleviates her pain but exacerbates her confusion. Her son is deeply distressed by his mother's altered state of consciousness and asks the weekend on-call physician if the baseline morphine dose could be stopped. He explains his mother's poor tolerance of opioids and notes that his mother does not wish to be drowsy and confused. The on-call physician does not believe that prioritising treatment of drowsiness or confusion over pain would be in the patient's best interest. However, to reach a compromise, the physician agrees to discontinue the baseline dose of morphine, maintaining the morphine pump solely in bolus mode. Mrs Mia's consciousness rapidly improves, but her pain remains insufficiently relieved.

Mrs Mia's son remains constantly present in his mother's room. He actively tries to alleviate her pain through massages and by finding a comfortable position in bed. He frequently requests assistance from the healthcare team, asking for an alternative mattress, additional cushions to improve his mother's positioning, and for a physiotherapist to help his mother to mobilise. The healthcare team begins to find him irritating and complains about his behaviour. The staff do not understand his numerous requests and perceive him as overly involved, even intrusive, in her mother's care. More importantly, they strongly disapprove of how he interjects himself between them and the patient. Some report being the target of his hostility when administering morphine boluses, as if their intent was to increase his mother's drowsiness and confusion. They feel distressed seeing Mrs Mia in pain but are exhausted by the constant need to negotiate pain relief measures with her son. However, all the healthcare team acknowledge that Mrs Mia never expresses disagreement with her son and appears to accept the situation willingly.

One nurse on the ward shares that she feels a form of affection for Mrs Mia's son, which she perceives shields her from the irritation reported by her colleagues. She is the only member of the healthcare team whom the patient's son allows to be alone in the room with his mother. The nurse also recounts that during one-on-one care sessions, such as administering a morphine bolus, she and Mrs Mia would sometimes exchange a conspiratorial smile and agree not to inform her son. The nurse describes one-on-one moments with the patient's son during which the latter allowed himself to cry and share his grief at the thought of losing his mother.

Mrs Mia's overall condition continues to worsen, prompting the ward physician to suggest transferring her to a palliative care unit. Mrs Mia agrees, as does her son. However, the latter continues encouraging his mother to eat and get up as often as possible despite her significant pain, and he again questions the possibility of a third line of chemotherapy. Mrs Mia's condition deteriorates further and she becomes increasingly anxious, fatigued, and uncomfortable. The ward physician suggests introducing a benzodiazepine at night to help manage her anxiety. Mrs Mia agrees, as she has with all medical recommendations since her hospitalisation began.

The weekend on-call physician proposes reintroducing the baseline morphine dose and extending benzodiazepine use throughout the day to optimise the patient's comfort. Mrs Mia's son does not oppose this but, a few hours later, requests that the benzodiazepine dose be reduced. During a discussion with the on-call physician, he is listened to patiently. Mrs Mia's son allows himself to cry and expresses feelings of guilt. He regrets that the transfer to the palliative care unit was not anticipated earlier, blaming the referring oncologist, whom he accuses of fostering false hope. In the days that follow, Mrs Mia sleeps and appears comfortable. Her son continues to request additional hydration and expresses residual hope that recovery remains possible.

Ethical reflection

This clinical case is structured around a central ethical motif: Mrs Mia's oscillation between her son's and the healthcare professionals' positions regarding the dilemma of pain relief versus maintaining consciousness. This oscillation creates an impression of inconsistency, leading to a situation of unshared decision-making and potential conflict. In this case, the healthcare professionals and Mrs Mia's son hold divergent conceptions of what constitutes good care, differences that remain unresolved in part because deliberation lacks Mrs Mia's sustained participation. Two primary obstacles hinder her involvement. First, her physical deterioration, marked by severe pain, nausea, and extreme fatigue, greatly reduces her ability to participate in deliberation. These symptoms not only limit her capacity to articulate preferences but also lead to episodes of disengagement, making it difficult for her to take an active role in negotiating her care. Addressing this requires careful and timely symptom management to restore a minimal level of bodily unity, enabling her to participate more meaningfully in discussions. Second, a relationship of mutual distrust between her son and the healthcare team further obstructs meaningful deliberation. This distrust is fuelled by the son's perception that the team is not fully attentive to his mother's needs, particularly with respect to pain management. Without a shared space where all three parties, patient, relatives, and professionals, can openly negotiate and compromise on their respective visions of good care, the process risks collapsing into parallel monologues rather than becoming the cooperative work required to foster relational autonomy.

Interestingly, in this case, the support required to overcome the first obstacle, Mrs Mia's physical deterioration, is significantly provided by her son. He takes an active role in alleviating his mother's pain while avoiding opioid-induced confusion, employing non-pharmacological interventions such as massages, adjustments in positioning to improve comfort, and other methods aimed at restoring a sense of bodily unity. However, these efforts would likely be more effective if complemented by the healthcare team's expertise in pain management and palliative care strategies. Yet, such collaboration remains obstructed by the absence of a trusting relationship. Without a foundation of trust, the son may continue to view the medical team's interventions with scepticism, while healthcare professionals may struggle to engage constructively with their shared concerns.

One noteworthy aspect of this case is that a member of the healthcare team succeeded in establishing a trusting relationship with Mrs Mia's son, thereby gaining better access to the patient and her subjective experience. This success prompts an important question: how did she manage to foster trust where others encountered resistance? One possible explanation lies in her ability to recognise and respond to the psychological defence mechanisms at play in this context. In end-of-life care, it is not uncommon for informal caregivers to express themselves in ways that may appear aggressive or hostile towards the healthcare team (Timmermann et al. 2018). Such expressions often function as defence mechanisms, allowing close relatives to cope with the profound moral and emotional strain of the situation. In Mrs Mia's son's case, outward expressions of anger may have shielded him from confronting more difficult inner states, such as guilt, doubt, and ethical suffering, arising from the awareness that, despite his desire to do what is best for his mother, she continued to experience significant pain. These feelings could lead him to question his own handling of the situation and his capacity to protect her from further suffering. In turn, healthcare professionals, when faced with such emotionally charged reactions, may interpret them as ingratitude or hostility, particularly when already under significant workload pressures. This perception can lead to pejorative judgements about the family, further reinforcing a cycle of mistrust. These judgements can also function as defence mechanisms, shielding professionals from confronting the deeper ethical dimension of their own suffering. In this case, the team was grappling with the ethical burden of witnessing Mrs Mia's unrelieved pain despite their best efforts.

These intersecting defence mechanisms, aggressiveness on the family's side and judgemental attitudes on the healthcare team's side, can create what might be termed a *pathology of communication* (Dejours 2016). In such a dynamic, communication ceases to serve as a vehicle for mutual understanding and instead becomes a battleground for unacknowledged suffering. The nurse who succeeded in building trust likely did so by adopting a different stance, one characterised by emotional attunement. Rather than reacting defensively to his hostile attitude, the nurse may have recognised it as an expression of pain and responded with validation and support.

Two main insights can be drawn from this case. First, the task of fostering a patient's autonomy cannot be separated from the cooperative task of building, each time a collective decision must be made, a shared understanding of what constitutes good care for that specific patient. This is not a one-off clarification but an ongoing process of negotiation and moral alignment between patient, relatives, and professionals. Second, this cooperative task rests on two essential conditions. The first, as proceduralist accounts of relational autonomy rightly emphasise, is to support the patient in recovering a minimal sense of self, both bodily and psychological, necessary to access, formulate, and express their wishes. The second is to sustain a process of constant deliberation, through which the different moral perspectives involved can work towards consensus or construct compromises that are responsive to the evolving clinical and relational context. Importantly, the deliberative process also strengthens the patient's capacity for self-reflection, self-affirmation, and the consolidation of their practical identity.

One additional insight can be drawn from this composite clinical case. Over the three weeks of hospitalisation, Mrs Mia's son interacted with multiple doctors and numerous other professionals, reinforcing his sense of distrust and giving him the impression of having to restart the attuning process again and again. The lack of continuity in care may have disrupted the relational work necessary to build trust and support autonomous engagement. Ongoing deliberation can help counterbalance this discontinuity by providing a shared space in which professionals regularly exchange information, reflect on relational dynamics, and collectively adjust their approach to patient care. This form of deliberation fosters greater consistency in decision-making, helping to mitigate the disorienting effects of staff turnover and fragmented care. However, it requires protected time and institutional support for interdisciplinary dialogue, a resource often lacking in busy clinical environments (Safaei 2015).

Building on the clinical insights drawn from Mrs Mia's case, the next section of this paper seeks to further formalise the ethical and relational work required to foster relational autonomy in end-of-life care. The model we are aiming to operationalise is one that articulates the interdependence *between* supporting patients' capacities for autonomy and creating the relational conditions necessary for meaningful deliberation. In this regard, we operationalise and integrate two approaches for decision-making increasingly mobilised in clinical ethics, shared decision-making and supported decision-making. We do so because they correspond closely to the dual task at hand: fostering autonomous agency while enabling patients to engage in complex, value-laden decisions through sustained dialogue and relational support. They also offer an existing set of practices, institutional norms, and policy commitments through which autonomy is enacted in clinical settings.

A shared and supported decision-making model for relational autonomy in end-of-life care

Here, we propose a model that integrates shared and supported decision-making to promote relational autonomy in end-of-life care. We outline the key tenets of each approach and examine the strengths of their interrelation. We then explain and operationalise the basis for their integration, before turning to the philosophical orientation that underpins it.

Shared decision-making

Shared decision-making emerged in the 1990s as a response to two contrasting models of medical decision-making, each reflecting different conceptions of patient autonomy and professional authority (Charles et al. 1997). The paternalistic model prioritises the physician's clinical expertise in determining what is in the patient's best interests, sometimes at the expense of fully engaging with the patient's own values and preferences. In contrast, the consumerist model positions the patient as an autonomous decision-maker with full authority over their care, while physicians primarily serve as providers of information and facilitators of therapeutic choices. Rather than simply navigating a middle ground between these approaches, shared decision-making is grounded in a relational understanding of personhood, recognising that medical decisions are shaped through deliberation between patients, healthcare professionals, and informal caregivers (Stigglebout et al. 2015). While there is no universally accepted definition of shared decision-making in the scientific literature, we adopt the understanding of it as a deliberative process in which medical decisions are co-constructed through the interaction of all participants, integrating the clinical expertise and ethical commitments of healthcare professionals with the values, preferences, and lived experiences of patients, as well as the perspectives of informal caregivers regarding the patient's wishes and best interests (Elwyn 2021).

Two core criteria are consistently identified as central to the practice of shared decision-making. The first criterion is uncertainty. Shared decision-making is considered particularly relevant in situations where multiple options appear equally reasonable, a state often referred to as equipoise (Gwyn and Elwyn 1999). Such situations involve uncertainty regarding the expected benefits, risks, and outcomes of available options, or about which therapeutic path best aligns with the patient's goals and values. The second criterion is the pursuit of consensus. Shared decision-making requires the joint articulation of perspectives that integrate both values and arguments informed by varying degrees of technical knowledge and lived experience (Légaré and Thompson-Leduc 2014). While patients and close relatives may not possess the same clinical-based grounding as healthcare professionals, their insights nonetheless include experiential expertise that is crucial to the decision-making process. Misunderstanding shared decision-making as a process in which only patients contribute values and preferences, while healthcare professionals provide technical knowledge, risks overlooking the fact that all participants engage in a deliberative process shaped by their own ethical, professional, and personal commitments (Epstein and Gramling 2013). The objective is not necessarily to reach consensus but to engage in a process of collaborative inquiry, in which participants seek to understand each other's viewpoints and co-construct a shared understanding of the decision at hand. In practice, this process often takes the form of attunement, an ongoing relational dynamic characterised by mutual respect, trust, and openness to new insights (Epstein and Street 2011). The significance of shared decision-making, therefore, lies not in the final decision itself but in the interactive process through which it is reached (Elwyn and Miro-Shatz 2010).

Despite its relevance for end-of-life care, shared decision-making also presents significant limitations. These limitations can be broadly classified into two main categories. The first category concerns the overestimation of patients' capacity for autonomous decision-making. Even in the absence of a diagnosed dementia or significant neurocognitive impairment, emotional and existential challenges often impair decision-making abilities during the terminal phase of illness (Kolva et al. 2014). The second category lies in the inherent power asymmetry within the care relationship. While shared decision-making is often framed as an equal partnership between patients and healthcare professionals, this idealised vision can obscure the structural and relational imbalances that shape medical encounters. In practice, differences in clinical expertise, institutional authority, and access to information create asymmetries that cannot be eliminated entirely (Joseph-William et al. 2014). At the end of life, these imbalances are further amplified by patients' heightened vulnerabilities, making them more susceptible to external influences. Even when healthcare professionals uphold the principle of patient autonomy, they may still attempt to steer patients toward what they perceive as the best course of action (Featherstone et al. 2024). Minimising the significance of these asymmetries risks disguising paternalistic practices as shared decision-making, leading to decisions that may be labelled as shared but are in reality, shaped by the implicit dominance of medical authority (Kowalski et al. 2024). However, rather than viewing these power asymmetries as fundamentally incompatible with shared decision-making, an ideal model of equal partnership should acknowledge their role in shaping the distribution of responsibility (Gerwing and Gulbrandsen 2019). While both patients and healthcare professionals contribute to decision-making, their responsibilities are not identical. The ethical duty to initiate, facilitate, and uphold the shared nature of decision-making ultimately rests with healthcare professionals (Rabben et al. 2024). Hence, to meet the intertwined task of fostering relational autonomy through both shared and supported decision-making, the deliberative emphasis of the former must be complemented by the relational and affective scaffolding provided by the latter, thus bypassing the limitations of shared decision-making in contexts of vulnerability.

Supported decision-making

The concept of supported decision-making emerged in the context of the United Nations Convention on the Rights of Persons with Disabilities, which formally introduced the term and gave it a specific legal meaning in 2006 (Ní Shé et al. 2020). Supported decision-making is founded on the principle that all individuals, regardless of disability, should be presumed autonomous and placed at the centre of decision-making (Arstein-Kerslake et al. 2017). The Convention and subsequent legal frameworks led numerous countries to enact legislation aimed at promoting, protecting, and safeguarding the equality, freedom, and dignity of individuals with disabilities (Ordinaire 2017). Legally, supported decision-making refers to a voluntary agreement in which an adult with impaired capacity (the "beneficiary") enters freely into an arrangement with one or more trusted individuals (the "supporters"), who assist in the decision-making process while respecting the beneficiary's will and preferences (Davidson et al. 2015). Decision-making capacity is understood as the task-specific ability to comprehend and evaluate relevant information, reason about available options, and communicate a choice. In practice, supported decision-making encompasses a network of relationships and structured interventions designed to enhance self-governance, enabling individuals with disabilities to make and express their own decisions effectively (Glen 2025).

Although legal frameworks often present supported decision-making as a cognitive, procedural, and synchronic process, conceptual and empirical studies have shown that supported decision-making must extend beyond cognitive support, even in the context of neurocognitive diseases by highlighting its pre-cognitive and embodied dimensions (Jaworska and Chiong 2021; Muramoto 2011; Sutherland et al. 2022). They emphasise that autonomy is not merely a function of processing information rationally but also emerges through relationships, bodily expressions, and the socio-cultural environment in which a person is embedded. For individuals with progressive cognitive impairments, decision-making capacities can be supported through trusted relationships that help recall past preferences, interpret bodily cues, and facilitate meaningful engagement. When informal caregivers and healthcare professionals foster recognition and attunement to non-verbal communication, they enable individuals to exercise autonomy even in the absence of full cognitive or linguistic capacities.

The above understanding aligns with phenomenological perspectives on embodied cognition and identity, which highlight that decision-making is not only dependent on cognitive reasoning but is also deeply shaped by bodily experiences, affective states, and relational contexts. Decision-making involves identifying, articulating, and defending preferences, an introspective and self-reflective process shaped by the complexity of identity opacity. From a phenomenological perspective, this opacity arises from the primacy of bodily and affective experiences over abstract cognition (Lewis and Holm 2023). While logical reasoning and cognitive abilities contribute to decision-making, much of the process is rooted in pre-cognitive, bodily, and affective dimensions. Rather than a rigid boundary between cognitive and pre-cognitive aspects of autonomy, decision-making entails bringing emotions, intuitions, and embodied sensations into conscious awareness and language (Lewis and Holm 2022). Thus, supporting decision-making requires the development of both technical and relational skills, not only to facilitate cognitive reasoning but also to alleviate physical discomfort, restore a sense of bodily unity, and reinforce the patient's sense of identity (Entwistle et al. 2010).

Just as academic work highlights the need to move beyond solely cognitive conceptions of supported decision-making, it also raises critical questions of accountability, particularly in relation to power asymmetries within healthcare and legal systems. Supported decision-making is not only a legal and procedural framework but also an ethical stance that seeks to resist ableism and challenge entrenched power imbalances in healthcare (O’Donnell et al. 2023). In care settings, decision-making often operates within an implicit culture that privileges verbal fluency and decisiveness. Patients who struggle with articulation, whether due to cognitive conditions, communication barriers, or emotional distress, risk being sidelined in critical discussions about their own care. The structural privileging of verbal articulacy can lead to implicit exclusion, reinforcing the idea that decision-making capacity is synonymous with the ability to express choices in a conventional manner. Moreover, power asymmetries within medical and legal decision-making structures can further marginalise individuals with impaired capacity. When decisions are made on behalf of individuals through guardianship or substitute decision-making arrangements, the person directly affected may be overlooked in practice. Healthcare professionals and legal authorities may engage primarily with guardians or legal representatives, inadvertently treating the individual as a passive subject rather than an active participant (Jackson 2023). This dynamic not only reinforces paternalistic assumptions but also exacerbates social invisibility, as individuals are effectively positioned outside the deliberative process.

By addressing the power imbalances that arise in clinical and legal settings, supported decision-making becomes not just a procedural safeguard but an active commitment to inclusivity, agency, and resistance against systemic disempowerment. Supporters may play an essential role in enhancing decision-making capacity by helping individuals articulate their values, weigh options, and navigate uncertainty (Peterson et al. 2021). However, this same interdependence can also create opportunities for unintentional coercion or undue influence, making it essential to establish ethical safeguards that distinguish justified interventions from subtle domination. Unlike cognitive prostheses, such as memory aids or assistive technologies, human supporters are not neutral extensions of a person's cognitive processes. They have their own beliefs, values, and interests, which may consciously or unconsciously shape the decision-making process. Supporters therefore face a dual responsibility: on one hand, they must respect and uphold the person's autonomy, ensuring that they remain an active participant in decisions about their own life. On the other hand, they must also act as a safeguard against harmful decisions, particularly when the individual's vulnerability increases the risk of self-endangerment or exploitation (Bigby et al. 2017). This ethical tension is particularly pronounced in family caregiving relationships, where supporters may have justified concerns about well-being yet must resist the temptation to impose their own preferences. To ensure ethical accountability, supporters must engage in self-reflective ethical reasoning, critically assessing the extent to which their own interests, emotions, or assumptions may be shaping the process.

After examining the main features of supported decision-making, it can be understood as especially relevant to addressing the two central limitations of shared decision-making presented earlier in the paper. Supported decision-making enables a form of care that actively fosters patients' capacity to engage meaningfully in end-of-life decision-making, both by restoring a sense of coherence between body, self, and agency, and by rebalancing clinical relationships through ethical dialogue, trust-building, and accountability. How, then, can shared and supported decision-making be theoretically and institutionally integrated to enhance patient autonomy at the end of life? More broadly, what can this detour through the clinical realities of end-of-life care, and their operationalisation into a shared and supported decision-making model, contribute to the philosophical and institutional understanding of how to foster relational autonomy in times of vulnerability?

Transformative deliberation, democratic habits, and institutional constraints for shared and supported decision-making

To clarify, from a philosophical perspective, how shared and supported decision-making contribute to fostering relational autonomy, this section examines the ethical orientation that underpins their interrelation. As previously highlighted, the ethical purpose of supported decision-making in our model is to open up the possibility for patients to enter a deliberative process, one that can be destabilising for all participants, insofar as fostering accountability implies to go as far as reconsidering what is held to be right or wrong. In this sense, what unites these two approaches is a specific ethics of deliberation, one that is transformative in nature (Bobbio 2010).

From a classical deliberative perspective, deliberation is fundamentally a rational discourse aimed at achieving mutual understanding. It assumes that participants enter the deliberative space with differing perspectives but engage in reasoned argumentation to reach a decision that is justifiable to all. Habermas's theory of communicative action (Habermas 1984) envisions an ideal speech situation in which participants are free from external coercion, the best argument prevails, and all voices are heard on equal footing. In this view, deliberation is a process through which participants refine their preferences, test their reasons against others, and collectively arrive at rational and legitimate decisions.

While the Habermasian model of deliberation provides an important foundation, it does not fully account for the complexities of decision-making in emotionally and existentially charged contexts such as end-of-life care. A transformative ethics of deliberation goes beyond classical ideals by recognising that participants engage in deliberation not only through rational argument, but through emotionally and bodily grounded experiences (Machin 2015). Furthermore, unlike deliberative models that prioritise persuasion or negotiation, a transformative ethics of deliberation do not merely exchange viewpoints but engage in a process that reshapes how participants understand autonomy and their ethical commitments to one another (Healy 2011). From this perspective, deliberation is not simply a mechanism for affirming individual choice, but a dynamic process through which patients, families, and healthcare professionals co-create an ethical space marked by mutual recognition, openness, and shared moral responsibility (Gulbrandsen et al. 2016). A transformative ethics of deliberation thus affirms patients not only as autonomous individuals but as integral members of a relational and moral community, capable of shaping and being shaped by the presence and responsiveness of others.

This resonates strongly with John Dewey's conception of democracy, not simply as a political arrangement or decision-making procedure, but as a way of living (Dewey 1916). For Dewey, democracy is a form of associated life grounded in habits of shared inquiry and mutual concern. It flourishes when individuals develop the dispositions and capacities required to live together reflectively, responsibly, and responsively. In this light, the task of fostering relational autonomy in end-of-life care should be understood not only as a clinical or ethical obligation but also as a democratic one. It calls upon the everyday democratic capacities of all involved, patients, caregivers, and professionals alike, to engage in relationships shaped by listening, responding, and mutual transformation.

Importantly, Dewey did not view these capacities as innate or guaranteed. They must be cultivated over time through experience and participation. What he called democratic habits, such as openness to the perspective of others, willingness to revise one's beliefs, and the ability to co-create meaning in uncertain or conflictual situations, are not simply moral virtues. They are social and emotional skills forged through ongoing, situated practices (Honneth 1998). In the emotionally charged context of end-of-life care, these habits become especially salient: the capacity to deliberate together in the face of vulnerability, fear, and suffering cannot be taken for granted. From this perspective, the clinic becomes a testing ground for democracy, not because it mimics institutional procedures, but because it demands the cultivation of precisely those habits and sensibilities that sustain democratic life more broadly. To deliberate well in end-of-life situations is not only to affirm individual choice but to engage in a form of democratic practice: one that upholds the dignity of all involved by making space for their voices, their uncertainties, and their capacity for change.

The above reference to democratic practices extends proceduralist and substantivist accounts of relational autonomy by adding that fostering such autonomy is inseparable from the cultivation of democratic life itself. Supporting patients' decision-making capacities is not merely a matter of recognising their rights or responding to their needs; it is the precondition for entering a shared process of deliberation. Yet deliberation, understood as a transformative ethical practice, is not simply procedural: it depends on the lived enactment of democracy as a form of associated life. This involves the ongoing development of democratic habits and skills, including the capacity to listen, to respond, to revise one's position, and to co-construct meaning with others. Our model thus bypasses the distinction between procedural and substantive conceptions of relational autonomy. The question is not how to restore an authentic sense of self (procedural) or how to aim for self-transformation and self-authorisation dispositions (substantive), but how to create and sustain the conditions in which all parties involved, patients, relatives, and professionals, can participate as moral agents in a cooperative process of defining and pursuing the patient's good, understood as a common good emerging from the encounter itself. In this sense, our account can be described as a *pragmatic* conception of relational autonomy.

While a model of shared and supported decision-making grounded in a transformative ethics of deliberation might offer a meaningful framework, its implementation in everyday clinical practice faces substantial and well-documented obstacles. These are not simply logistical or circumstantial but touch the very conditions that make deliberation possible. Power imbalances between patients, relatives, and healthcare professionals decisively shape the possibility of genuine engagement. Defence mechanisms may help individuals manage the reality of ethical suffering, but they can also diminish their capacity to perceive and respond to the suffering of others, thus undermining the very reciprocity that deliberation requires. At an institutional level, degraded working conditions marked by high staff turnover, mounting economic pressure, increasing bureaucratic demands, and chronic lack of time weaken the capacity of healthcare professionals to engage in a deliberative process. In palliative care settings, these challenges are further intensified by the emotional turbulence of end-of-life situations, including anguish, anticipatory grief, and profound ethical uncertainty. These elements do not merely complicate deliberation; they challenge its feasibility at its core.

Fostering relational autonomy in end-of-life care cannot rest solely on the shoulders of individuals. It also depends on the organisational conditions that either support or undermine the possibility of sustained deliberation. As illustrated in the clinical case of Mrs Mia, the absence of continuity in care and of deliberation, exacerbated by staff turnover and fragmented communication, can erode trust and compromise the relational groundwork required for meaningful engagement in a shared process of decision-making. However, this kind of interdisciplinary deliberation requires protected time, institutional support, and recognition of its value, conditions increasingly squeezed out of healthcare systems governed by economic logics of productivity, efficiency, and standardisation (Pavolini 2015). Within such systems, ethical and relational practices are often subordinated to bureaucratic imperatives, leaving little room for the moral labour that deliberation entails.

A further challenge often raised concerns the presence of seemingly insurmountable conflicts between patient preferences and the ethical limits of the healthcare team (Prentice 2018). From the perspective of Dewey's democratic theory, however, such conflicts are not signs of failure to be avoided or suppressed, but rather constitutive elements of democratic inquiry. Democracy, in this view, is not defined by the absence of disagreement and power issues but by the capacity to engage with it collectively, through reflective problem-solving and situated experimentation (Caspary 2008). Accordingly, a transformative ethics of deliberation does not aim to resolve all tensions or eliminate ethical suffering, nor does it presume that consensus will always be possible. It is instead an invitation to remain present to one another in the midst of conflict, and to engage in a shared search for workable compromises that respect the autonomy and ethical integrity of all involved. This vision may appear to set the bar too high, especially in emotionally charged, time-pressured contexts such as end-of-life care. Yet it is precisely this level of exigence that confers meaning on the task. Supporting patients at the end of life cannot rest on a pre-established definition of what constitutes a "good death"; rather, it must be grounded in a joint effort to invent, together, a path through suffering, uncertainty, and relational complexity. The common good, in this context, is not given in advance, it is the contingent and always provisional result of a democratic process of deliberation.

Conclusion

This article occupies a singular position at the intersection of clinical experience and philosophical inquiry, aiming to contribute to the understanding of how relational autonomy can be meaningfully fostered in the specific context of end-of-life care. Its originality lies in the proposal of a decision-making model that binds together two frameworks often treated separately: shared and supported decision-making. In our view, supported decision-making is not an adjunct to shared decision-making but its condition of possibility in palliative care contexts marked by vulnerability, emotional complexity, and existential uncertainty. Conversely, shared decision-making, once made possible, further strengthens patients' decision-making capacities by engaging them in a deliberative process of recognition, clarification, and moral responsibility. At the heart of this model lies a transformative ethics of deliberation that articulates relational autonomy with democratic habits and skills. We believe this articulation captures the ethical ambition of the palliative care movement itself: to create the conditions of togetherness through the cultivation of democratic spaces in which individuals feel recognised in their singularity while participating in a collective endeavour oriented towards a common good (Saunders 1967).

Our explicit linking of relational and democratic theories of autonomy opens up new philosophical and institutional questions about both shared and supported decision-making. In particular, it invites further inquiry into how democratic habits and skills might be fostered within institutional settings increasingly shaped by economic rationalities, performance imperatives, and standardisation. Unlike

Mackenzie, who locates the development of democratic dispositions in media culture and education (Mackenzie and Sorial 2022), we argue that such dispositions arise more fundamentally through the practice of democracy itself, that is, through collective deliberation and the experience of cooperation (Dejours and Deranty 2010). As we have argued, this practice depends in large part on the organisation of work. The pressing question, then, is to what extent patients, relatives, and healthcare professionals can participate in shaping such work organisations (Skillington 2012). This, we contend, is one of the necessary conditions for ensuring that patients' autonomy is genuinely respected. Far from undermining autonomy, a relational understanding raises its ethical demands: it acknowledges how difficult it is to uphold autonomy meaningfully in the emotionally charged and institutionally constrained context of shared and supported decision-making in end-of-life care today.

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