

Shared Decision-Making about Deprescribing in Advanced Illness: Patient, Family, and Nursing Perspectives

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Abstract

Deprescribing in advanced illness is often treated as a technical response to polypharmacy, treatment burden, or limited prognosis, yet continuation and discontinuation are also preference-sensitive decisions distributed across patients, families, nurses, prescribers, and care systems. This article develops a stakeholder shared-decision account that distinguishes medication appraisal from the relational work of eliciting goals, negotiating family involvement, clarifying professional responsibilities, and acting under uncertainty. Continued therapy, modification, staged withdrawal, deferral, and deprescribing can each be legitimate when clinically defensible and aligned with patient goals. The central contribution is a conditional view of shared deprescribing: good decisions depend on role-legible deliberation, explicit uncertainty, and sufficient capability and opportunity to implement the chosen course safely. Shared decision-making therefore neither requires unanimous agreement nor presumes that deprescribing is the preferred endpoint.

Keywords: Deprescribing, Advanced illness, Shared decision-making, Palliative care, Nursing advocacy, Family caregivers

Introduction

Deprescribing is more than stopping a medicine. Decisions to reduce, discontinue, continue, or revisit therapy reflect interacting patient, prescriber, and system influences [1]. In advanced illness, the problem is intensified by delayed benefits, immediate burdens, uncertain prognosis, and differing meanings attached to treatment. The relevant question is therefore not only whether a medicine remains appropriate, but who contributes what knowledge and judgment to that decision.

Nurses are important because they may observe medication burden, adherence problems, adverse effects, functional change, and family concerns before these become visible to prescribers. A recent scoping review identified medication review, education, monitoring, and multidisciplinary communication among nursing contributions, while also noting fragmentation and role barriers [2]. Palliative-care evidence further shows that shared decision-making varies across people and settings rather than occurring automatically whenever several stakeholders participate [3]. This article therefore examines how patient goals, family involvement, nursing advocacy, prescriber accountability, clinical evidence, and uncertainty can be integrated without treating consensus or medication withdrawal as obligatory.

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Conceptual approach

The unit of analysis is the stakeholder configuration surrounding a medication decision. It may include a patient with intact or changing capacity, family members with practical knowledge or surrogate responsibilities, nurses with close observational access, a prescriber with clinical authority, and an organization that can facilitate or obstruct review. Palliative-care research supports treating participation as context-dependent rather than as a fixed dyadic process [3].

Shared decision-making nevertheless contains distinguishable tasks. The Three-Talk model separates awareness of choice, discussion of options, and movement toward a preference-sensitive decision [4]. Applied to deprescribing, this distinction prevents recognition of a medication concern from being confused with a decision to stop. The present analysis extends that logic by differentiating stakeholder contributions: family knowledge is not identical to patient preference, nursing advocacy is not prescribing authority, and prescriber accountability does not substitute for knowledge of treatment burden in daily life.

Deprescribing as a preference-sensitive decision

Deprescribing becomes preference-sensitive when more than one clinically defensible option remains after appraisal of indication, benefit, burden, risk, and treatment horizon. Communication is integral because patients need to understand why a medicine was started, what continuation may achieve, what stopping may change, and how any reduction will be monitored [5]. Qualitative palliative-care evidence shows that medicines can carry different meanings for patients and families, so burden alone does not determine whether treatment should stop [6].

Older adults' trust in clinicians, beliefs about medication necessity, and desired involvement can shape openness to deprescribing [7]. Likewise, willingness to stop a medicine cannot be safely inferred from age, diagnosis, or caregiver status; studies in older people with cognitive impairment and in very old adults show variation in attitudes and stakeholder perceptions [8, 9]. Shared deprescribing therefore protects several legitimate outcomes: discontinuation, dose reduction, substitution, staged withdrawal, continuation, or defer-and-review. The quality of the decision lies in its clinical defensibility, goal concordance, transparency about uncertainty, and appropriate stakeholder participation.

Table 1. Distinguishing the conceptual operations that make deprescribing preference-sensitive in advanced illness

Analytical operation	Core question	Required information	Boundary that must remain visible	Stakeholder implication
Clinical review	Is the medicine still appropriate now?	Indication, benefit, burden, adverse effects, withdrawal risk	Review is not an instruction to stop	Prescriber judgment remains necessary
Choice recognition	Is more than one course defensible?	Continue, modify, taper, stop, or reassess	A trigger is not a decision	Patients should know when a genuine choice exists
Preference elicitation	What matters most to the patient?	Goals, fears, routines, acceptable burden, uncertainty tolerance	Preferences cannot be inferred from diagnosis or age	Patient authority is primary when capacity is intact
Family contribution	What practical or historical knowledge does family add?	Daily administration, observed burden, prior wishes	Contribution is not automatically authority	Family input must be role-bounded
Nursing advocacy	What observed concern requires escalation?	Symptoms, adherence, functional effects, goal-treatment mismatch	Advocacy is not prescribing authorization	Nurses make burdens and preferences visible
Decision closure	What happens now and when is review needed?	Chosen course, monitoring, uncertainty, review conditions	A shared decision need not be permanent	Decisions remain revisable

Shared decision-making foundations

Advanced-illness decision-making requires flexible participation. Interviews with people with advanced cancer and family caregivers show variation in desired involvement, information needs, and understanding of professional roles, including nursing contributions [10]. Home-based palliative-care research likewise shows that patients may move between direct participation and reliance on others as illness and circumstances change [11]. Shared deprescribing therefore rests on understandable options, elicitation of the patient's preferred level of involvement, negotiated family participation, and clear professional responsibilities. These conditions matter even when everyone appears to agree, because surface agreement can conceal different assumptions about prognosis, medication purpose, or what will happen after withdrawal.

Triggers for deprescribing conversations

A trigger should prompt reassessment, not dictate discontinuation. Palliative-care clinicians have described deprescribing as too often reactive and late, while favoring earlier, repeated, individualized conversations and clearer professional ownership [12]. Relevant triggers can include disease progression, treatment burden, swallowing difficulty, adverse effects, changing goals, care transitions, or concern that time-to-benefit no longer fits the patient's horizon.

Trigger recognition can still fail to produce action. Mixed-methods evidence from surgical wards shows that competing priorities, workflow, knowledge, and team processes influence whether deprescribing is considered and implemented [13]. The setting differs from palliative care, but the implementation lesson is transferable: visible clinical need may not result in review when responsibility or opportunity is weak.

Patient values and goals

Patient values influence what counts as benefit and burden. One person may prioritize fewer medicines and present comfort; another may value continuation because a treatment provides reassurance or supports a specific future goal. Palliative-care accounts demonstrate that patients and families can attach different meanings to medications [6], while evidence on deprescribing attitudes indicates that perceived necessity and trust shape openness to change [7].

Values should therefore be elicited in medication-specific terms: which outcomes matter, which burdens are unacceptable, how present comfort is weighed against uncertain future benefit, and how much uncertainty is tolerable. They should also be revisited as illness, function, caregiving circumstances, and goals change.

Family and caregiver roles

Families often contribute information that is absent from the prescribing record: whether medicines are actually taken, how difficult administration is, what burdens are visible at home, and what the patient previously expressed. Near the end of life, clinicians and family caregivers may bring different concerns to chronic-medication decisions [14]. Difference is not itself failure; its source and authority must be clarified.

Caregiver presence also should not be equated with sharedness. In advanced cancer, caregiver presence has been associated with perceived shared decision-making, but the cross-sectional design does not establish causation [15]. When the patient retains capacity, family input can enrich deliberation without displacing the patient's preference. When capacity is impaired, surrogate participation should be anchored in the patient's known values, prior wishes, and interests rather than the surrogate's independent preference [16-18].

Nursing roles in recognition and advocacy

Nurses may see treatment burden before prescribers do. Evidence across deprescribing studies identifies nursing roles in recognizing medication problems, assessing adherence and adverse effects, educating patients, monitoring after changes, and communicating concerns within the team [2]. In advanced cancer, patients and caregivers have also reported uncertainty about the nursing role in shared decision-making [10], suggesting value in making that role explicit.

Recognition and advocacy should remain distinct from prescribing authority. Nurses can initiate review by making symptoms, burdens, or goal-treatment mismatches visible. Their ability to do so depends partly on capability: shared decision-making competency among palliative-care nurses has been associated with empathy, education, and training [19]. Because this evidence is cross-sectional, it supports competency development without proving that training alone improves patient outcomes.

Prescriber responsibility

Shared decision-making does not dissolve professional accountability. Prescribers remain responsible for evaluating indication, foreseeable harms, withdrawal risks, interactions, monitoring needs, and the safety of a proposed medication change. Palliative-care clinician evidence has emphasized the importance of professional ownership [12]. Behavior-change work also indicates that organizational conditions can determine whether clinicians have sufficient opportunity to act [20].

Structured tools can assist without replacing judgment [21]. STOPPFrail version 2 provides criteria for frail older people approaching the end of life and incorporates patient-centred decision-making [22]. Such criteria can identify medicines worth reconsidering, but they cannot determine whether stopping fits an individual patient's goals, risks, or follow-up conditions.

Medication benefit, burden, and time-to-benefit

The clinical core of deprescribing compares what a medicine may still offer with what it currently costs the patient. Benefit may be immediate, delayed, preventive, or uncertain; burden may include adverse effects, swallowing difficulty, administration complexity, monitoring, interactions, and disruption of daily life. These dimensions cannot be reduced to a single score.

Time-to-benefit is particularly relevant for preventive therapy. A meta-analysis of statins for primary prevention estimated that about 2.5 years of treatment was required to prevent one major adverse cardiovascular event for every 100 adults aged 50–75 treated, while no mortality benefit was demonstrated [23]. That estimate is not a universal advanced-illness threshold; it illustrates the principle that delayed benefit should be considered against prognosis, burden, and goals.

Nor should continuation automatically be treated as safer. In a target-trial emulation among nursing-home residents, antihypertensive deprescribing was associated with less cognitive decline, especially among residents with dementia [24]. The observational design precludes a universal causal claim, but it reinforces the need for medication-specific rather than reflexive reasoning.

Table 2. Family and caregiver contributions to medication benefit–burden decisions without role substitution

Decision issue	Family/caregiver contribution	Role boundary	Nursing interface	Prescriber accountability
Everyday burden	Reports administration difficulty, refusal, swallowing problems, disrupted routines	Cannot determine clinical inappropriateness alone	Confirms observed burden and functional effects	Reassesses indication, alternatives, withdrawal risk
Patient goals	Recalls values, prior wishes, and acceptable burdens	Family preference cannot replace a capable patient's preference	Helps clarify and communicate stated goals	Tests treatment against those goals
Functional or cognitive change	Reports deterioration, confusion, or loss of self-management	Observation does not prove medication causation	Assesses timing and symptoms	Evaluates differential causes and medication contribution
Surrogate participation	Represents known values when capacity is impaired	Surrogacy is not unrestricted personal choice	Supports communication and identifies conflict	Applies clinical, ethical, and legal standards
Monitoring after change	Observes comfort, symptoms, function, and adherence	Cannot independently interpret every change as drug-related	Performs structured follow-up and escalation	Decides whether to continue, reverse, or modify the plan
Preventive benefit horizon	Contributes knowledge of future outcomes the patient values or fears	Cannot estimate treatment effect or prognosis alone	Translates lived burden and concerns	Interprets evidence, prognosis, uncertainty, and time-to-benefit

Prognostic and evidentiary uncertainty

Advanced illness rarely offers a perfectly known time horizon. Prognosis may be imprecise, trajectories may fluctuate, and long-term medication evidence may come from populations unlike the patient now being treated. Capacity can also change. Shared decision-making after severe stroke illustrates how uncertain prognosis, unknown prior preferences, and surrogate involvement complicate attempts to reconstruct what a patient would want [25]. The disease context differs, but the principle is relevant: uncertainty should be named, and the basis of any inference about preferences should be explicit.

Uncertainty need not always delay action. A defer-and-review pathway may be reasonable when immediate burden is low and important information is missing; monitored reduction may be preferable when burden is substantial and reversal is feasible. What matters is how uncertainty changes the confidence, timing, and reversibility appropriate to the decision.

Communication and trust

Communication makes clinical evidence, patient goals, family knowledge, and professional responsibility mutually intelligible. In serious illness, communication priming substantially increased goals-of-care conversations and documentation, while overall goal-concordant care was not significantly improved [26]. Thus, more conversation is not equivalent to a better aligned decision.

The same boundary appears in the Serious Illness Care Program trial: structured communication improved some secondary outcomes but not the co-primary outcomes of goal-concordant care and peacefulness at the end of life [27]. A pragmatic ICU trial likewise found that clinician nudges changed some end-of-life care processes without improving the primary length-of-stay outcome [28]. These findings resist a linear assumption that communication alone resolves uncertainty, conflict, or implementation barriers.

Trust shapes whether communication can do its work. Patients may consider deprescribing more openly when recommendations are understood as attention to their goals rather than withdrawal of care. Families may tolerate uncertainty better when clinicians explain why continuation or discontinuation remains reasonable. Nurses need confidence that concerns they identify will reach decision-makers, and prescribers need to treat nursing and family

observations as clinically relevant without confusing them with prescribing authority. Trust therefore does not replace evidence; it affects whether evidence, preferences, and concerns can move through the stakeholder configuration without distortion.

Disagreement may remain after good communication. That should not automatically be interpreted as failure. The next task is to determine whether stakeholders have the capability, opportunity, and motivation to act on the available options, and whether apparent agreement represents true concordance or unresolved conflict.

Capability, opportunity, and motivation for deprescribing

A clinically justified and preference-concordant decision still may not be implemented. Deprescribing behavior depends on whether stakeholders possess the capability to understand and execute a medication change, the opportunity to coordinate it within the care environment, and sufficient motivation to initiate or sustain it. Hospital-based research using behavioral frameworks has identified determinants across all three domains, including knowledge, professional roles, patient concerns, workflow, and follow-up arrangements [29, 30]. These findings caution against treating reluctance to deprescribe as a simple information deficit.

Capability includes knowledge of the medicine, withdrawal risks, alternatives, and monitoring requirements. For patients and families, it also includes comprehension of the proposed change and confidence in managing the resulting plan. Opportunity includes prescriber access, nursing continuity, pharmacy support, records, time for discussion, and a mechanism for reassessment. Motivation includes beliefs about medication necessity, fear of deterioration, professional norms, and confidence that another stakeholder will respond if problems emerge.

These conditions interact. A patient may prefer fewer medicines but decline a change when follow-up is uncertain. A nurse may identify a persistent treatment burden yet lack timely access to the responsible prescriber. A prescriber may agree that treatment is no longer useful but hesitate when responsibility for monitoring is unclear. Shared decision-making therefore extends beyond reaching a stated preference: the chosen pathway must be executable within the actual care environment.

Concordance and decision conflict

Concordance refers here to alignment between the chosen medication plan and the patient's informed goals, not to identical beliefs among all participants. Family members, nurses, and prescribers may support the same immediate action for different reasons. Conversely, apparent agreement may hide uncertainty, reluctance, or misunderstanding.

Advanced-cancer evidence demonstrates variation in desired participation and the perceived contribution of different professionals [10]. Caregiver presence may be associated with higher perceived shared decision-making, but it cannot establish that the patient's goals and the caregiver's preferences are identical [15]. Serious-illness communication trials also show that increasing discussion does not guarantee measured goal concordance [26]. Structured communication can improve some processes while leaving principal outcomes unchanged [27].

Decision conflict should therefore be diagnosed rather than merely eliminated. Conflict may concern the patient's goals, interpretation of treatment benefit, willingness to accept uncertainty, family burden, professional responsibility, or the meaning of stopping therapy. Some disagreement is compatible with a sound decision when the patient's authority is respected and the chosen plan remains clinically defensible. A unanimous decision produced through deference, coercion, or unrecognized misunderstanding may be less genuinely shared than a transparent decision reached despite continuing disagreement.

Proposed shared deprescribing decision framework

The evidence supports a stakeholder configuration in which medication appraisal and relational deliberation proceed together. Clinical reassessment identifies whether more than one defensible course exists. Patient goals give those options personal meaning. Families contribute practical observations, historical knowledge, and—where appropriate—surrogate representation. Nurses make treatment burden, functional change, adherence difficulty, and stated preferences visible. Prescribers retain responsibility for medication-specific clinical judgment and safe implementation. Communication connects these contributions, while capability, opportunity, and motivation determine whether the selected course can actually be enacted.

A realist synthesis of antithrombotic continuation and discontinuation near the end of life similarly indicates that decisions arise through context-sensitive mechanisms involving clinicians, patients, families, organizational conditions, and prevailing treatment norms [31]. That therapy-specific evidence does not establish a universal deprescribing mechanism, but it supports treating medication decisions as conditional configurations rather than isolated acts [32-36].

The synthesis proposed here adds a distinction among preference authority, relational contribution, professional observation and advocacy, prescribing accountability, and implementation capacity. These functions may be distributed across different people. Their alignment can facilitate a clear decision, while mismatch can produce delay, conflict, or an apparently agreed plan that is difficult to implement. Uncertainty modifies the configuration by changing how strongly any option can be recommended and how readily the decision should be revisited.

Figure 1 depicts these relationships as a conditional field rather than a linear sequence. It preserves continuation as a legitimate outcome and separates supported relationships from the integrative relationships proposed by this article.

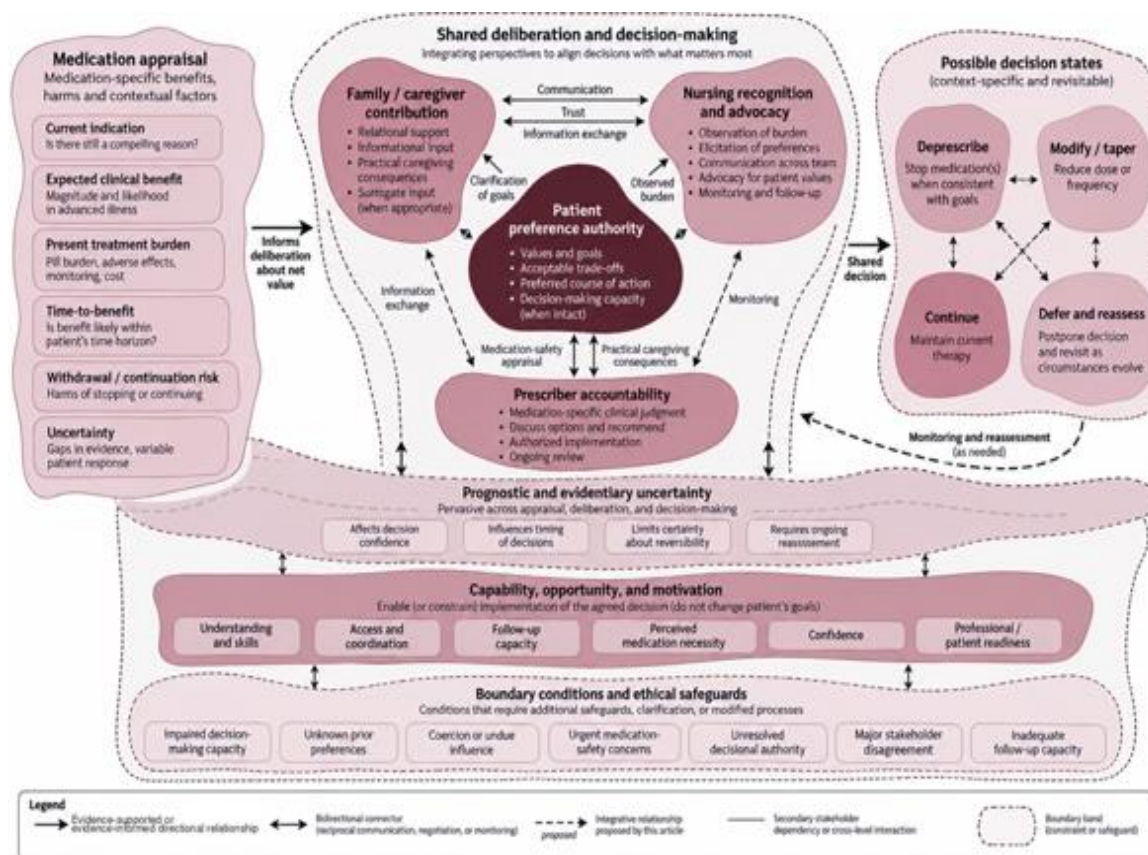


Figure 1. Conditional stakeholder configuration for shared deprescribing decisions in advanced illness

Decision pathways

The framework does not terminate in a binary stop-or-continue choice. One pathway is deprescribing when expected benefit has diminished, burden or risk is meaningful, the patient accepts withdrawal, and monitoring is feasible. Another involves modification or tapering where abrupt cessation is undesirable or the goal is burden reduction rather than complete withdrawal. Continuation remains defensible when treatment supports a valued goal, offers near-term benefit, or when uncertainty makes withdrawal less acceptable to the informed patient.

A further pathway is deliberate deferral. Clinicians may retain a medicine temporarily while obtaining information, clarifying prognosis, resolving conflict, or establishing monitoring capacity. Such deferral differs from inertia in that the reason and review conditions are explicit. Decisions should also remain revisable. Palliative-care clinicians have emphasized repeated individualized reassessment [12], while time-to-benefit reasoning demonstrates why the balance can change as the patient's clinical horizon changes [23].

Situations of stakeholder disagreement

Stakeholder disagreement may arise even when communication is respectful and information is adequate. Patients and families may assign different meanings to treatment [6]. A patient may accept risk to preserve a valued preventive strategy while family members prioritize reducing daily burden. Nurses may perceive treatment-related harm that has not yet changed the patient's preference. Prescribers may judge a requested medication unsafe or may be unwilling to stop treatment without adequate monitoring.

Capacity adds another layer. When a patient cannot participate fully, disagreement may concern how prior preferences should be reconstructed, how much weight to give present behavior, or which surrogate has authority [25]. These disputes should be separated from disagreement about clinical evidence. The appropriate response depends on what is contested: goals, facts, authority, uncertainty, or implementation.

Boundary conditions and ethical safeguards

The framework weakens when apparently shared decisions occur without meaningful choice, adequate information, or legitimate authority. Impaired capacity may require supported decision-making or surrogate

involvement. Unknown prior wishes require explicit acknowledgment of inference. Coercive family dynamics, urgent medication toxicity, or substantial withdrawal risk may justify safeguards beyond ordinary deliberation. Structured deprescribing criteria can support review but cannot substitute for individual judgment [22]. Communication interventions likewise demonstrate bounded effects: improving discussion processes does not ensure concordance or better clinical outcomes [27]. Shared decision-making should therefore be understood as a disciplined process for integrating authority, evidence, values, and uncertainty—not as a procedural guarantee that all parties will agree.

Nursing practice implications

Nursing practice has leverage at several points. First, nurses can identify signals that should trigger medication review: declining function, swallowing difficulty, adverse effects, medication refusal, increasing administration burden, or inconsistency between treatment and stated goals. Second, they can elicit how patients understand medicines and what outcomes they value. Third, they can surface discrepancies between patient, family, and professional assumptions.

Nursing advocacy is most effective when accompanied by routes for escalation and follow-up. Evidence describing nursing roles and behavioral barriers suggests that competence without opportunity may have limited effect [2, 30]. Services should therefore support structured communication with prescribers, documentation of patient goals, clear monitoring responsibilities after medication changes, and opportunities for nurses to participate in interdisciplinary review without obscuring prescribing accountability [37].

Research propositions

The framework generates several testable propositions.

Proposition 1. Greater clarity about patient, family, nursing, and prescriber roles will be associated with higher-quality deprescribing deliberation even when stakeholders do not reach unanimous agreement.

Proposition 2. The effect of nursing recognition and advocacy on medication change will be stronger where prescriber access and follow-up capacity are high than where organizational opportunity is restricted.

Proposition 3. Repeated reassessment will contribute more to goal-concordant medication decisions when prognosis, decisional capacity, or patient priorities are changing than when these conditions are stable.

Proposition 4. Communication interventions will have limited effects on enacted deprescribing when capability or opportunity constraints remain unresolved.

Proposition 5. Explicit differentiation of patient preference from family contribution will reduce hidden decisional conflict, particularly where caregivers carry substantial medication-management burden.

These propositions require longitudinal and intervention research capable of separating decision quality, medication change, implementation fidelity, and patient-valued outcomes.

Results and Discussion

This synthesis shifts the central question from whether advanced illness should trigger deprescribing to how a defensible medication decision is constructed among stakeholders. Existing deprescribing frameworks establish the importance of patient, prescriber, and system factors [1]; palliative-care research shows that shared decision-making is context-sensitive [3]; communication work demonstrates that better processes do not automatically produce concordant outcomes [26]; and behavioral studies show that implementation depends on more than knowledge [29]. The proposed stakeholder framework links these observations without collapsing them into a single causal sequence.

Its distinctive implication is that role clarity and decision quality can be evaluated separately from the eventual medication outcome. A continued medicine may represent high-quality shared decision-making if benefit, burden, uncertainty, and goals have been considered [38-41]. Conversely, medication discontinuation may be poorly shared if it results from organizational pressure, unexamined assumptions about prognosis, or marginalization of patient preferences. Observational evidence suggesting favorable outcomes after selected deprescribing [24] and realist evidence demonstrating context-dependent mechanisms [31] reinforce the need to resist universal directional claims.

The framework also gives nursing a defined but bounded position. Nurses contribute clinical observation, longitudinal knowledge, preference elicitation, advocacy, and monitoring, while the prescriber retains responsibility for medication-specific judgment and safe authorization. Family participation is similarly differentiated from patient authority. These distinctions make disagreement interpretable rather than treating every difference among stakeholders as evidence that shared decision-making has failed [32, 42-44].

Limitations

The evidence base is heterogeneous in disease, medication class, setting, stakeholder population, and methodology. Several important studies concern older adults or serious illness more broadly rather than

deprescribing in advanced palliative illness specifically. Communication trials address goals-of-care processes and therefore support relational mechanisms more strongly than medication-specific outcomes. Nursing evidence contains substantial qualitative and cross-sectional work, limiting causal inference about the effects of nursing participation.

The framework is also a conceptual synthesis rather than a validated predictive model. Its proposed relationships require empirical testing across jurisdictions with different nursing scopes of practice, family roles, prescribing structures, and access to follow-up. Medication-specific safety considerations may legitimately override some general features of the framework.

Conclusion

Deprescribing in advanced illness is best understood as a preference-sensitive medication decision embedded in a multistakeholder clinical environment. Patient goals, family knowledge, nursing observation and advocacy, prescriber responsibility, medication benefit and burden, uncertainty, communication, and implementation conditions contribute different forms of information and authority. Their integration does not require unanimous agreement, and it does not make stopping medication the default measure of success.

A strong shared decision is one in which the available courses are clinically defensible, the patient's goals and decisional authority are respected, stakeholder roles are explicit, uncertainty is acknowledged, and the selected course can be implemented and revisited safely. Under those conditions, deprescribing, modification, continuation, or deliberate reassessment may each represent appropriate care.

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