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Beyond Autonomy: Reframing Patient Empowerment through Knowledge, Agency, Partnership, and Relational Care

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Abstract

Patient empowerment is often treated as an extension of autonomy: provide information, offer choice, and allow the patient to decide. This formulation is incomplete. It underestimates the difference between receiving information and being able to use it, between possessing formal choice and experiencing effective agency, and between participating in care and having one's knowledge and priorities shape it. This article reframes empowerment as a relationally situated capacity produced through the interaction of knowledge, agency, partnership, and enabling structural conditions. Autonomy is treated as one expression of empowerment rather than its defining criterion. Patients may remain empowered while sharing or delegating decisional responsibility when those arrangements preserve meaningful influence and remain responsive to their values. Conversely, nominal independence can be disempowering when systems shift informational, coordinative, or navigational burdens onto patients without adequate support. The article distinguishes usable knowledge from information exposure, agency from decisional independence, participation from influence, and supportive dependence from paternalism. It then develops a proposed Knowledge–Agency–Partnership model in which empowerment depends on alignment among what patients can understand, what they can influence, and whether relationships and systems permit that influence to matter. The model is offered as a bounded conceptual architecture requiring empirical validation.

Keywords: Patient empowerment, Patient autonomy, Health literacy, Shared decision-making, Patient agency, Relational care

Introduction

Patient empowerment is central to patient-centered care, shared decision-making, chronic disease management, safety, and service improvement, yet it is frequently inferred from visible markers such as information provision, choice, participation, or self-management responsibility. These markers do not establish whether patients possess meaningful influence. Professional accounts of patient and family engagement show that agency can be enabled or constrained through the practices intended to involve patients [1]. Empowerment is therefore not merely something professionals "give"; it emerges within relationships marked by unequal expertise, authority, vulnerability, and dependence.

Experiential knowledge broadens this view because patients contribute knowledge derived from living with illness while professionals contribute clinical and organizational expertise [2]. Whether that knowledge becomes empowering depends on whether it is recognized as relevant to interpretation and decision. Epistemic-justice scholarship similarly argues that participation can remain superficial when patients are invited to speak but their testimony or priorities carry less credibility by default [3].

This article therefore reframes empowerment through four connected questions: what patients can understand; what they can influence; how influence is negotiated

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relationally; and whether healthcare structures make that influence consequential. It distinguishes knowledge from information, agency from independence, participation from influence, and supportive dependence from paternalism before developing a proposed Knowledge–Agency–Partnership model.

Why autonomy alone does not define empowerment

Autonomy is ethically indispensable, but empowerment becomes distorted when autonomy is equated with maximal independent control. Shared decision-making is not considered equally appropriate in every clinical situation, and some healthcare users prefer physicians to carry greater decisional responsibility [4, 5]. These findings do not legitimize paternalism; they show that the distribution of decision authority can itself be preference-sensitive. Voluntary delegation may therefore express agency rather than negate it.

A narrow autonomy standard also overlooks how decisional roles can change with urgency, illness burden, uncertainty, emotional strain, and the complexity of available options. A patient may reasonably seek extensive control over one decision while preferring a trusted clinician to lead another. The amount of final decision authority retained by the patient consequently provides an incomplete measure of empowerment.

The proposed distinction is between decisional independence and meaningful influence. Empowerment concerns whether patients can shape how knowledge, preferences, responsibility, and support are organized around care. Independent choice may instantiate that capacity in one situation; shared or delegated decision-making may instantiate it in another, provided the arrangement is voluntary, revisable, and responsive to the patient's values. This interpretation retains respect for autonomy without turning independence into a universal behavioral expectation.

Knowledge and health literacy

Information exposure is not equivalent to usable knowledge. Empowerment and mental-health literacy can form different profiles rather than one continuum [6], while health literacy and patient activation show related but distinct associations with health-seeking behavior [7]. Knowledge may support agency without guaranteeing it.

Problems arise when information is technically available but practically unusable. Patients may receive personalized materials without recognizing their relevance to their own circumstances [8]. Medication communication does not consistently adapt to differing health-literacy needs [9], and review evidence indicates that written patient information often exceeds recommended readability levels [10]. These are not simply patient deficits; they reflect the fit between information design, communication practice, and patients' interpretive resources.

Health literacy itself is multidimensional. Different literacy dimensions show different relationships with physicians' efforts to achieve shared decision-making [11]. A patient may understand a diagnosis yet struggle with probabilistic comparisons, or understand risks while lacking confidence to question a recommendation. This article therefore treats empowering knowledge as information that becomes interpretable, relevant, and actionable through appropriate communication and recognition of experiential knowledge.

Agency and perceived control

Agency concerns what patients can influence, resist, revise, or authorize, not merely how much they speak or decide independently. Readiness for participation includes self-efficacy, emotional state, communication capacity, understanding, and situational constraints [12]. Formal permission to participate is of limited value when patients feel unable to disagree, request time, disclose uncertainty, or seek support.

Consultation research shows that agency is interactional: patients may propose, challenge, negotiate, or withhold agreement, while clinicians can open or close those possibilities [13]. Stated willingness to participate is therefore different from realized influence [14], and involvement depends on relational and contextual conditions as well as individual characteristics [15].

The article proposes that effective agency requires an intelligible field of options, a credible possibility of affecting what happens next, and relational permission to exercise that influence. Without these conditions, apparent choice may overstate empowerment. Perceived control is therefore important but insufficient: patients must also possess practical opportunities to convert intention into influence.

Participation and shared decision-making

Participation is visible and measurable, but it is better treated as a channel through which empowerment may be enacted. Patient-reported evidence identifies explanation, listening, trust, assertiveness, and social

support as recurring conditions of participation [16]. Participation therefore cannot be located solely within patient motivation.

Outcome evidence also requires caution. In a large outpatient study, communication and trust related positively to patient experience, whereas greater perceived involvement did not map uniformly onto satisfaction [17]. An umbrella review found generally neutral-to-positive effects of shared decision-making across several outcomes, but with substantial uncertainty and heterogeneity [18]. More participation cannot therefore be assumed to yield better experience, adherence, or clinical outcomes in every setting.

What enters the decision matters as much as whether a patient participates. Psychosocial concerns and personal perspectives are often incompletely elicited or integrated [19], while care planning appears more meaningful when the resulting plan makes sense within the patient's circumstances [20]. Participation may therefore be procedural without being influential.

The distinctions are condensed below because similar-looking participation states can imply very different degrees of empowerment **(Table 1)**.

Table 1. Distinguishing participation states that can appear similar while carrying different implications for empowerment

Participation state	Visible feature	Agency signal	Relational condition	Interpretive risk	Empowerment implication
Informed but non-influential	Information received; questions invited	Ability to alter plan unclear	Professional control dominates	Equating information with influence	Knowledge without demonstrated agency
Preference expressed but not integrated	Goals or concerns stated	Voice present	Perspective heard but not used	Treating elicitation as deliberation	Procedural participation
Negotiated participation	Patient questions, resists, or revises	Influence observable	Reciprocal adjustment permitted	Requiring equal control as proof	Stronger enacted agency
Voluntary low-intensity participation	Patient prefers limited direct involvement	Delegation is chosen	Delegation remains revisable	Labeling preference-sensitive delegation as passivity	Can remain empowering
High-workload participation	Patient coordinates information or follow-up	Activity is high	System support is weak	Equating workload with empowerment	May conceal responsibilisation

The relevant indicator is therefore not participation volume but whether participation changes the informational or decisional trajectory in a way aligned with the patient's preferences and circumstances.

Partnership and relational power

Partnership concerns whose knowledge is recognized, whose interpretation carries authority, and whose preferences can alter care. This is especially visible where stigma or hierarchy is pronounced. Patient-reported barriers to participation overlap with mental-health evidence showing that power imbalance and stigma can constrain shared decision-making [16, 21].

Partnership should not therefore be defined by friendliness or the symbolic presence of patient voice. It requires reciprocal responsiveness. In diabetes care, autonomy support and shared decision-making showed different associations with satisfaction and adherence rather than behaving as interchangeable empowerment variables [22]. The finding is associative and context-specific, but it illustrates that adjacent relational processes need not produce identical outcomes.

Organizational evidence reaches a similar conclusion. Patient and family partners in improvement collaboratives emphasize mutual respect, shared ownership, explicit expectations, and equitable participation processes [23]. In value-based healthcare, hierarchy, representativeness, strategy, and weak feedback can constrain participation [24]. Patients and caregivers discussing safety likewise describe partnership as integral to how safe care is experienced [25].

The proposed implication is that partnership is the relational medium through which knowledge and agency acquire practical force. Patients may possess relevant knowledge and desire influence yet remain

disempowered when relationships discount that knowledge or prevent disagreement from affecting decisions. Partnership therefore concerns consequential responsiveness rather than the appearance of collaboration.

Supportive dependence versus paternalism

Dependence is unavoidable in healthcare: patients rely on clinicians, family members, interpreters, caregivers, technologies, and institutions. The central distinction is not independence versus dependence but whether support expands or displaces the patient's effective influence.

Triadic consultation research shows that companions may clarify information, reinforce concerns, challenge proposals, or alter the course of discussion [26]. This can extend agency when the companion supports expression of the patient's priorities; it can constrain agency when the companion's position replaces the patient's. Supported decision-making in mental healthcare is likewise shaped by organizational, process, and relational implementation conditions [27]. Cultural context matters, but systematic review evidence on minority patients shows heterogeneous preferences and barriers, cautioning against inferring a preferred decision style from group membership [28].

The decision register below distinguishes supportive reliance from substitution of another person's control **(Table 2)**.

Table 2. Decision register for distinguishing supportive dependence from paternalistic substitution

Care-context state	Immediate decision load	Evidence of retained influence	Legitimating condition	Warning sign	Interpretation
Voluntary clinician delegation	Clinician	Patient chooses and can revisit delegation	Recommendation remains value-responsive	Delegation is presumed	Dependence can coexist with empowerment
Companion-assisted deliberation	Patient and companion	Companion amplifies patient priorities	Patient remains reference point	Companion preferences replace patient's	Support is enabling only while patient-anchored
Temporary reliance during distress	Clinician, team, or trusted other	Later review or correction remains possible	Transfer is proportionate and reversible	Temporary limitation becomes exclusion	May preserve agency across fluctuating capacity
Structured supported decision-making	Patient with assistance	Support improves comprehension or expression	Assistance increases effective participation	Process is nominal while others decide	Quality of implementation is decisive
Urgent clinician-led restriction	Clinician	Input may be temporarily limited	Restriction is bounded and later explained	Exceptional authority becomes routine	Can be necessary without defining empowerment generally

Paternalism therefore cannot be inferred solely from who makes the final decision. Clinician-led decisions may remain compatible with empowerment when requested, bounded, and revisable, while nominally patient-led processes may be disempowering when information is inaccessible or responsibility is transferred without support.

Structural conditions of empowerment

A relational account remains incomplete without the systems in which relationships occur. Time, continuity, language access, information architecture, digital access, referral pathways, and follow-up opportunities affect whether knowledge and agency become consequential.

This is clearest when healthcare systems transfer work to patients. Qualitative research involving women with multiple long-term conditions during pregnancy shows how fragmented care can shift coordination and navigation burdens onto patients, producing responsibilisation rather than empowerment [29]. More patient work is therefore not necessarily more patient power. Responsibility may be formally transferred while the resources needed to exercise meaningful control remain absent.

Structural redesign can also expand opportunity. Codesign work in cardiac services shows that patients and communities can identify accessibility and health-literacy barriers that routine service design may overlook [30]. This does not establish downstream clinical

effectiveness, but it demonstrates that empowerment-relevant conditions can be altered at service level rather than addressed only through patient education.

Structural conditions also interact with relational power. Hierarchy may determine whether patient participation affects organizational decisions [24]; implementation constraints may weaken supported decision-making [27]; stigma may narrow participation despite formal rights [21]. The article therefore proposes an opportunity-structure component of empowerment: knowledge and motivation are insufficient when systems make questions difficult to ask, alternatives difficult to access, or preferences difficult to enact.

Structurally enabling care reduces avoidable informational and coordinative burdens, preserves routes for clarification and challenge, accommodates differing communication needs, and creates credible mechanisms through which patient input can alter care. These conditions establish the context within which the proposed Knowledge–Agency–Partnership model is developed.

The knowledge–agency–partnership model

The preceding sections suggest that empowerment is best understood not as a single patient attribute but as a relationally situated capacity that depends on several conditions being aligned. On this basis, this article proposes the Knowledge–Agency–Partnership (KAP) model. The model distinguishes three analytically separate but interacting domains: usable knowledge, exercisable agency, and consequential partnership. Structural conditions surround rather than replace these domains because they shape whether each can be developed, expressed, and sustained.

Knowledge refers to more than exposure to information. It includes the patient's ability to interpret clinical information, connect it with experiential knowledge, understand uncertainty, and recognize what is relevant to the decision at hand. Evidence that health literacy and empowerment form distinguishable profiles [6], that literacy dimensions show different relationships with shared decision-making [11], and that apparently personalized information may not be experienced as usable [8] supports keeping knowledge analytically separate from empowerment itself.

Agency refers to the practical capacity to influence what happens. Readiness for shared decision-making includes understanding, self-efficacy, communication capacities, emotional state, and situational conditions [12], while naturally occurring consultations show that agency is enacted through proposing, resisting, negotiating, and accepting [13]. Agency therefore cannot be inferred from an invitation to choose. It becomes visible when patients can alter the informational, deliberative, or decisional trajectory in ways that remain responsive to their priorities.

Partnership refers to the relational conditions that determine whether knowledge and agency carry weight. Patient participation is shaped by trust, listening, explanation, social support, and interactional opportunity [16]. Power imbalance and stigma can narrow that opportunity [21], whereas partnership-oriented improvement work highlights mutual respect, ownership, and explicit expectations [23]. Partnership therefore functions as the relational pathway through which patient knowledge and agency become consequential.

The proposed model is reciprocal rather than sequential. Greater knowledge may increase the range of questions a patient can ask, but a dismissive relationship can suppress their use. Agency may stimulate further information seeking, but structural barriers can make options inaccessible. Partnership may enable a patient to express uncertainty and thereby identify new informational needs. These relationships should therefore be treated as conditional and potentially bidirectional rather than as a validated causal chain.

Structural conditions modify all three domains. Health-literacy-sensitive communication, time, continuity, accessible services, digital access, language support, navigation requirements, and organizational authority affect whether patients can convert understanding into influence. Codesign can help expose otherwise hidden accessibility barriers [30], while fragmented services can transfer responsibility without transferring corresponding power [29]. The model therefore predicts that apparent deficits in empowerment may arise from mismatches between domains rather than from patient motivation alone.

The crosswalk below is necessary to separate premises supported by the reviewed evidence from relationships newly synthesized within the proposed KAP architecture **(Table 3)**.

Table 3. Evidence–interpretation crosswalk for the Knowledge–Agency–Partnership model

Model element	Evidence-supported premise	Context that modifies expression	Interpretation boundary	Proposed model implication
Usable knowledge	Information, literacy, and activation are related but non-equivalent	Readability, communication quality, language, digital access, relevance	Information exposure does not establish understanding or influence	Knowledge contributes to empowerment when it becomes interpretable and actionable
Exercisable agency	Readiness, willingness, and enacted involvement are distinguishable	Emotional state, decision complexity, time, clinician behavior	Formal choice does not prove effective control	Agency exists when patients can meaningfully alter the care trajectory
Consequential partnership	Trust, listening, recognition, and power shape participation	Professional hierarchy, stigma, family roles, organizational design	Participation can remain symbolic	Partnership determines whether patient knowledge and agency acquire practical force
Structural opportunity	Service organization can enable or obstruct participation	Access, continuity, navigation load, workforce, policy, technology	Responsibility transfer may increase burden rather than power	Structural conditions can amplify or suppress all three KAP domains
Cross-domain alignment	The three domains show overlapping but non-identical relationships with experience and behavior	Illness stage, preference, culture, care setting	No approved study validates the complete KAP architecture	Stronger empowerment is proposed to occur when knowledge, agency, and partnership become mutually reinforcing
Domain mismatch	One domain can be present while another is constrained	Power asymmetry, inaccessible information, unwanted decisional load	Low empowerment should not automatically be attributed to low motivation	Mismatch patterns may explain divergent experiences within nominally patient-centered care

Because the model concerns reciprocal enablement, constraint, and mismatch rather than a sequence of stages, its central logic requires a visual field in which the three domains remain separate while their cross-domain dependencies and structural boundaries remain visible.

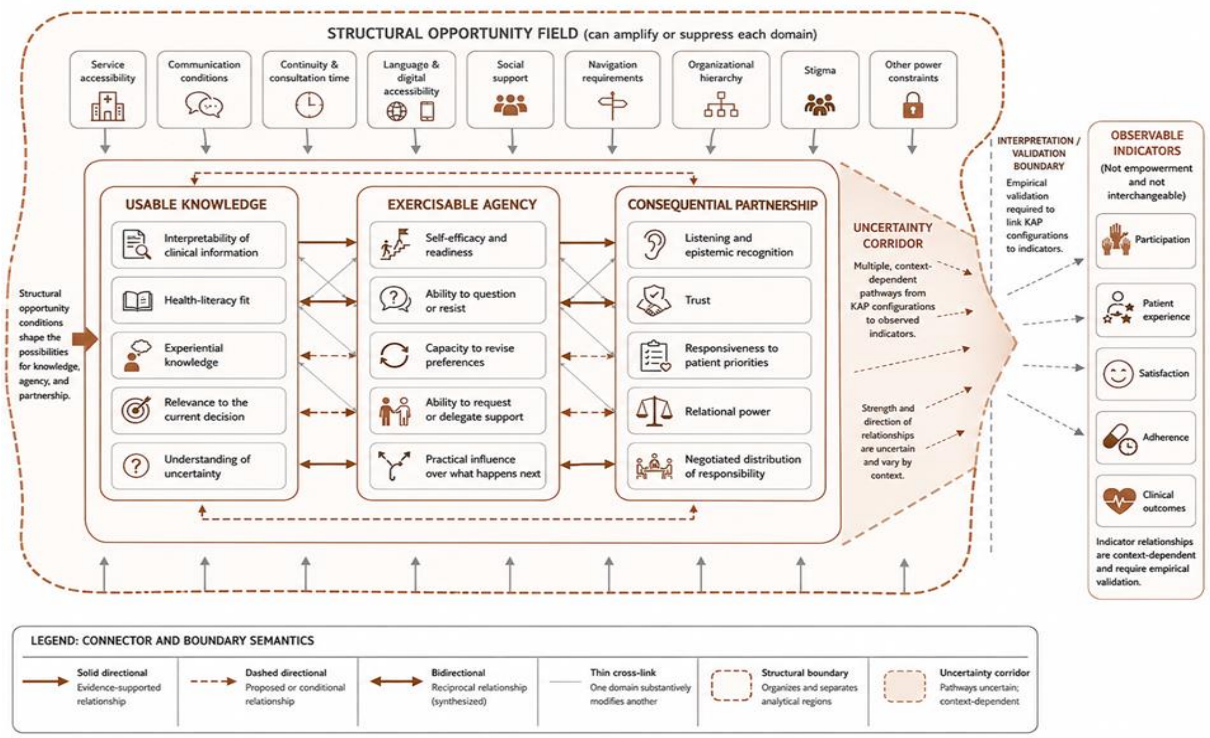

Figure 1. Reciprocal conditions through which knowledge, agency, and partnership become consequential in patient empowerment

Indicators and outcomes of empowerment

The model requires careful measurement because commonly used indicators occupy different analytical levels. Willingness to participate, readiness, patient activation, observed involvement, trust, satisfaction, adherence, patient-reported experience, and clinical outcomes are not interchangeable. Readiness measures can capture whether a patient feels prepared to participate [12], while willingness measures capture preferred engagement [14]. Neither demonstrates that a healthcare relationship provides the opportunity to exercise agency or that expressed preferences influence subsequent care.

Participation and experience can also diverge. Greater perceived involvement does not uniformly correspond to greater satisfaction [17], and umbrella-review evidence does not support assuming that shared decision-making improves every outcome in every setting [18]. This matters conceptually because an empowerment measure becomes misleading if it imports an assumed outcome relationship into its definition.

Patient-reported experience measures illustrate the same measurement problem. Construct-specific instruments can demonstrate acceptable measurement properties within their intended contexts, as shown in the development and validation of a hearing-care patient-reported experience measure [31]. Yet validity for patient experience does not transform experience into a generic measure of empowerment. A patient can report respectful care while exercising little influence, or experience substantial agency during a difficult decision without reporting high satisfaction with the outcome.

The proposed KAP model therefore implies multidomain measurement. Knowledge should be assessed for usability rather than information receipt alone. Agency measurement should distinguish willingness, readiness, perceived control, and enacted influence. Partnership should assess recognition, responsiveness, trust, and relational power rather than merely consultation satisfaction. Structural opportunity should be measured separately so that restricted participation is not automatically interpreted as a patient-level deficiency.

This approach also requires temporal precision. Readiness before a consultation, influence during deliberation, perceived partnership after the encounter, adherence over subsequent weeks, and longer-term clinical outcomes are temporally different observations. Treating them as interchangeable obscures both directionality and alternative explanations. Prospective

research should therefore test whether particular configurations of knowledge, agency, partnership, and structural opportunity predict later experiences or behaviors more effectively than single empowerment proxies.

Implications for clinical practice and measurement

Clinical practice should move beyond asking whether patients were informed or offered a choice. A more useful set of questions is whether patients could understand the relevant information, exercise the amount and type of influence they wanted, and obtain support without losing ownership of their priorities. This requires communication adapted to actual interpretive needs rather than uniform information provision. Persistent readability problems [10], health-literacy-sensitive communication gaps [9], and failures of intended personalization [8] show why nominal provision is an inadequate endpoint.

Clinicians should also treat preferred decisional roles as dynamic rather than as fixed personal characteristics. The same patient may seek substantial direct control in one circumstance and greater clinician or family support in another. This variation should not automatically be interpreted as inconsistency, passivity, or reduced empowerment. Instead, the relevant question is whether the chosen distribution of responsibility remains voluntary, comprehensible, proportionate to the context, and open to revision.

Supported decision-making requires similar discipline. Assistance is empowering when it improves the patient's capacity to understand, communicate, deliberate, or enact preferences; implementation problems arise when support becomes procedural while decision authority effectively shifts elsewhere [27]. Clinicians should therefore attend not only to who speaks but also to whose priorities organize the decision.

At organizational level, inviting participation is insufficient unless structures provide feedback, representation, continuity, and credible routes through which patient contributions can influence decisions [24]. Codesign can reveal accessibility problems that routine service development overlooks [30], but the presence of codesign should not itself be treated as proof of empowerment or improved outcomes.

Measurement systems should correspondingly resist a single composite empowerment score unless its dimensional structure is demonstrated empirically. Separate assessment of usable knowledge, exercisable agency, consequential partnership, and structural opportunity would make it possible to identify different failure modes. A knowledge problem may call for communication redesign; an agency problem may require more time or explicit permission to question; a partnership problem may reflect distrust or hierarchy; a structural problem may require organizational rather than educational intervention.

Results and Discussion

Reframing empowerment beyond autonomy resolves several tensions within patient-centered healthcare. It explains how patients can be highly informed yet weakly empowered, how shared decision-making can occur without meaningful influence, and how reliance on clinicians, companions, or other supporters can sometimes increase rather than diminish agency. It also explains why apparently patient-centered processes do not produce uniform downstream effects. Evidence across shared decision-making and autonomy-support research shows heterogeneous outcome patterns rather than one consistent pathway to adherence or other benefits [18, 22].

The proposed KAP model consequently shifts the central question from "Did the patient decide?" to "Could the patient understand, influence, and shape care within a relationship and system responsive to that influence?" This distinction prevents decisional independence from becoming the behavioral benchmark against which all patients are judged. It also prevents transferred responsibility from being misclassified as empowerment when healthcare systems externalize navigation, interpretation, or coordination work without transferring corresponding resources or authority.

A principal contribution of the model is its treatment of mismatch. Usable knowledge can coexist with restricted agency when disagreement is discouraged. Agency can coexist with weak knowledge when decisions are offered without accessible explanation. Partnership can appear strong at an interpersonal level while organizational systems make preferred options inaccessible. These configurations imply different causes and therefore different corrective strategies. The model does not propose that every domain must be maximized; rather, it proposes that empowerment depends on whether the configuration permits the patient's preferred and contextually feasible level of influence.

The model has important boundaries. Preferences for involvement vary by decision and circumstance. Acute urgency may legitimately narrow deliberation. Illness burden, uncertainty, distress, and fluctuating capacity may change how much responsibility a patient wants to carry. Companions can amplify or suppress patient voice. Cultural and social context matter, but group membership cannot determine an individual's preferred role. Structural disadvantage, inaccessible communication, fragmented services, stigma, and organizational hierarchy may constrain empowerment even when clinicians explicitly endorse patient-centered values.

These boundaries also show why supportive dependence and paternalism cannot be differentiated solely by observing who makes the final decision. The analytical distinction concerns authorization, responsiveness, reversibility, and retained influence. A clinician-led decision can be compatible with empowerment when leadership is requested and remains responsive to the patient's goals. Conversely, a formally patient-led decision may be disempowering when choices are incomprehensible, inaccessible, or presented without meaningful support.

The evidence base limits the strength of inference. The reviewed literature combines qualitative studies, cross-sectional analyses, naturalistic observational work, measurement studies, systematic reviews, implementation research, and conceptual scholarship. These designs are useful for construct discrimination, mechanism hypotheses, and boundary identification, but they do not validate the complete KAP model as a causal mechanism. The reciprocal and conditional relationships displayed in **Figure 1** are therefore theoretical propositions grounded in convergent evidence, not estimates of direction, magnitude, or intervention effect.

Future validation should first establish whether knowledge, agency, partnership, and structural opportunity can be measured as discriminable domains. Longitudinal research could then examine whether changes in usable knowledge precede changes in agency, whether partnership modifies those relationships, and whether structural conditions alter their expression. Comparative studies should test domain configurations across illness trajectories, cultural contexts, levels of clinical urgency, digital environments, and healthcare systems. Research should also examine mismatch states directly rather than assuming that a low global empowerment score identifies a single deficit.

The model should ultimately be judged not by conceptual elegance but by discriminant validity, explanatory usefulness, and its ability to generate testable predictions without reproducing the very simplification it seeks to correct. Its purpose is to provide a more precise vocabulary for asking when patient involvement represents meaningful influence, when dependence supports agency, and when healthcare structures place the appearance of autonomy over the conditions necessary for empowerment.

Conclusion

Patient empowerment is inadequately captured by autonomy, information provision, participation, or self-management responsibility considered separately. A patient may exercise empowerment through independent choice, shared deliberation, or voluntary reliance on trusted others, provided that knowledge is usable, agency is exercisable, and relationships remain responsive to the patient's priorities. Conversely, formally autonomous care may be disempowering when information is inaccessible, influence is symbolic, or responsibility is transferred without adequate support.

The proposed Knowledge–Agency–Partnership model reframes empowerment as a context-dependent capacity produced through alignment among usable knowledge, exercisable agency, consequential partnership, and enabling structural conditions. It distinguishes supportive dependence from paternalism and patient participation from genuine influence while preserving uncertainty about downstream outcomes. The model is a conceptual architecture rather than a validated causal theory. Its value therefore depends on whether future research can discriminate its domains, test their reciprocal and conditional relationships, identify meaningful mismatch states, and determine whether this reframing improves measurement and understanding of patient-centered care.

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