

Whose Work Disappears When Medication Use Is Called Self-Management? A Critical Interpretive Synthesis of Patient Labour, Caregiver Contributions, and Assumptions of Independence

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Abstract

Medication self-management is commonly described as an individual capability, behaviour, or responsibility, yet medicines are often managed through distributed practical, cognitive, relational, and organisational work performed by patients, family caregivers, and health services. This critical interpretive synthesis examined how contemporary medication self-management literature distributes, obscures, or normalises that work and how assumptions of independence shape its representation. Searches were executed on 14 September 2026 using PubMed-indexed web retrieval, publisher and PubMed/PMC verification, and iterative citation and theoretical sampling. Forty-seven records were captured through initial phenomenon-focused searches; seven duplicates were removed, leaving 40 unique initial records. Eighteen additional unique records were identified through theoretical and citation sampling, producing 58 evidence candidates. Ten records outside the contemporary evidence boundary were set aside. Forty-eight contemporary records were assessed for relevance and contribution, of which 24 were excluded and 24 retained as included evidence units. Selection emphasised conceptual contribution to medication work, responsibility, capability, autonomy, caregiving, and visibility rather than journal prestige. Constant comparison identified six interrelated synthetic constructs: distributed medication work, conditional independence, reactive delegation, invisible coordination work, responsibility without integration, and the distinction between routinised workload and experienced burden. The synthesis indicates that medication “self-management” frequently rests on work extending beyond the nominally self-managing individual, although neither caregiver involvement nor treatment burden is universal. The evidence is concentrated in older-adult, multimorbidity, cognitive-impairment, and qualitative contexts, limiting generalisation. Medication self-management is therefore better interpreted as a variably distributed accomplishment whose apparent independence may depend on social and organisational supports that conventional terminology does not always reveal.

Keywords: Medication self-management, Patient labour, Caregiver labour, Treatment burden, Medication work, Critical interpretive synthesis

Introduction

Medication use outside formal clinical encounters is often presented as an activity that patients perform for themselves. Yet research on patient work demonstrates

that living with illness involves practical, cognitive, informational, social, and organisational tasks that frequently occur outside professional view [1]. Medication use is embedded within this broader workload. The demands associated with multimorbidity can include obtaining medicines, interpreting instructions, coordinating appointments, monitoring effects, reorganising everyday routines, and absorbing financial or emotional consequences [2]. Measures such as the Treatment Burden Questionnaire make parts of this workload visible, but no single instrument captures the

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full distribution of activity through which medicines are made usable in everyday life [3].

Medication self-management research itself points beyond narrow adherence. Qualitative synthesis of polypharmacy describes patients as making decisions, developing routines, resolving uncertainty, acquiring information, and adapting regimens within practical constraints [4]. Participatory concept mapping similarly identifies medication self-management as involving access, information, social support, ownership, communication with clinicians, and maintenance of routines rather than simply taking the correct dose at the correct time [5]. These observations create a conceptual problem. If medication management depends on activities undertaken jointly or sequentially by patients, caregivers, professionals, technologies, and services, describing the outcome as “self-management” may obscure how responsibility is actually organised.

This review therefore asks: How does medication self-management literature distribute, obscure, or normalise medication work performed by patients and caregivers, and what synthetic constructs are needed to expose assumptions of independence and structural delegation of work? The purpose is not to replace self-management with an equally totalising alternative label. It is to examine the conditions under which the term accurately denotes patient-directed activity, the circumstances in which independence depends on largely unacknowledged support, and the ways in which medication work can shift across actors without corresponding changes in authority, information, or resources.

A critical interpretive synthesis was selected because the problem is partly categorical. The relevant literature does not merely report how much work patients or caregivers perform; it constructs what counts as self-management, capability, independence, support, and responsibility. A synthesis concerned with those assumptions therefore requires interpretation across heterogeneous designs rather than aggregation of frequencies alone.

Why “self-management” requires critical re-examination

The existence of medication work does not mean that patients necessarily experience it as burdensome. Among very old adults, extensive medication-related activity could become habitual and incorporated into everyday routines, with participants not invariably describing that work as problematic [6]. This finding is important

because a critique of self-management can become distorted if every task is treated as evidence of excessive burden. Work, burden, capability, and independence are related but analytically distinct.

Other evidence shows why that distinction nevertheless requires contextual analysis. In advanced multimorbidity, practical and cognitive workload is negotiated through relational networks, and uncertainty can alter whether existing capacity is sufficient for the work required [7]. The same regimen can therefore have different implications depending on available knowledge, family assistance, professional responsiveness, health status, and competing demands. Caregiver evidence further complicates the image of an autonomous medication manager. Informal carers may obtain medicines, organise supplies, interpret instructions, monitor use, prompt administration, communicate with clinicians, detect problems, and participate in decisions [8]. Such involvement does not automatically negate patient autonomy. It does, however, mean that a description centred only on the patient can misrepresent who performs the work that makes continued medication use possible.

The critical issue is therefore not whether self-management exists, but how independence is constructed and where supporting work disappears analytically. A patient may remain the principal decision maker while another person collects medicines, fills an organiser, notices depletion, contacts a prescriber, or checks whether a new regimen has been implemented correctly. Conversely, intensive caregiver involvement may coexist with efforts to preserve patient control. The binary contrast between “independent” and “dependent” management is consequently insufficient for examining how medication responsibility is distributed.

This synthesis treats self-management terminology as an object of inquiry. It asks what kinds of work are foregrounded, which actors are recognised, what support is assumed, and what organisational responsibilities are transferred into homes or families. The aim is to preserve genuine patient agency while making visible the conditions and contributions through which that agency may be sustained.

Materials and Methods

Critical interpretive synthesis was used to integrate heterogeneous evidence while interrogating the categories through which that evidence is organised.

Contemporary examinations of CIS reporting show substantial variation in how searching, sampling, critique, and synthesis are documented, making explicit methodological transparency especially important [9]. More recent methodological mapping similarly characterises CIS as an iterative approach in which searching, interpretation, and theory development may proceed recursively rather than as strictly separated stages [10].

Accordingly, the review was not organised as a conventional effectiveness review seeking a pooled estimate. Evidence was sampled for its ability to illuminate the meanings and boundaries of medication self-management, patient work, caregiver participation, independence, capability, and delegation. The analysis moved repeatedly between individual reports and emerging interpretive questions, with direct findings kept distinguishable from review-level constructs.

Initial question and sampling logic

The initial compass question asked how medication self-management literature allocates and represents work among patients, caregivers, and services. Sampling was guided by relevance and conceptual contribution rather than by a requirement that all studies share one intervention, outcome measure, or clinical condition.

Theoretical sampling was permitted to evolve as gaps became visible, consistent with CIS applications in which subsequent searching is directed by developing explanatory questions [11]. For example, evidence describing medication tasks prompted additional attention to caregiver coordination; evidence concerning autonomy prompted attention to responsibility transitions; and treatment-burden literature was sampled to determine whether workload and experienced burden could legitimately be treated as equivalent.

Journal quartile was not an eligibility criterion for review evidence. The final manuscript bibliography was subject to a separate Q1 reference policy, but evidence units were selected according to their contribution to the review question.

Searching

Searches were executed on 14 September 2026. Initial phenomenon-focused routes covered medication self-management and patient work; treatment burden and medication work; caregiver medication management; medication autonomy, independence, and responsibility; and older-adult medication self-management across

transitions. The principal concepts were combined in variants of “medication self-management,” “patient work,” “treatment burden,” “medication labour,” “caregiver medication management,” “independence,” “autonomy,” “responsibility,” “dementia,” “older adults,” and “transition.”

Purposeful searching is compatible with CIS when the search is used to develop and challenge an explanatory account rather than to simulate exhaustive homogeneity across conceptually diverse evidence [12]. Treatment-burden search formulations were also examined because they provide adjacent terminology for identifying workload, capacity, and self-care evidence [13]. Reporting logic was documented with reference to contemporary systematic-review transparency principles, while avoiding conversion of the review into an effectiveness-style PRISMA synthesis for which its interpretive design was not intended [14].

The initial phenomenon-focused routes captured 47 records. Seven repeated records were removed, leaving 40 unique initial records. Iterative citation and theoretical sampling subsequently contributed 18 additional unique candidates, yielding 58 evidence candidates. These numbers represent the records actually captured and screened during the executed search process; they are not presented as database-wide hit totals.

Iterative/theoretical sampling

Theoretical sampling proceeded alongside early comparison of the retrieved material. Four questions drove additional searching. First, when reports treated medication-taking as the principal form of self-management, further sampling sought studies describing information work, coordination, monitoring, and decision work. Second, when caregivers appeared mainly as sources of “support,” additional studies were sought that described their concrete medication activities. Third, evidence concerning cognitive decline and transitions was sampled to clarify when responsibility shifts and whether such shifts are planned or reactive. Fourth, treatment-burden evidence was examined specifically to test whether performing work necessarily implied experiencing burden.

Citation chaining and author/topic searching were used to pursue these conceptual gaps. Sampling stopped when the principal distinctions required to answer the review question could be examined across multiple evidence types and further retrieval was no longer changing the

central interpretive categories sufficiently to justify continued expansion.

Selection based on relevance and contribution

Evidence was eligible when it contributed directly to at least one of the following: medication work performed by patients; medication work performed by unpaid caregivers; how independence, autonomy, or capability was represented; how medication responsibility moved across actors; how health-service arrangements shaped that work; or how terminology and measurement made such activity visible or invisible.

The contemporary evidence boundary was 2017–2026. Of 58 unique evidence candidates, 10 records outside that period were set aside. Forty-eight contemporary records were assessed for relevance and contribution. Twenty-four were excluded because their principal contribution concerned adherence or intervention effectiveness without meaningful analysis of work or responsibility, psychometric measurement without sufficient interpretive contribution, a different actor or work domain, broad autonomy or ethics without medication-management evidence, or intervention processes that did not materially answer the synthesis question. Twenty-four evidence units were retained.

Selection was therefore purposive but auditable. Inclusion meant that an evidence unit contributed to the developing explanation; it did not mean that every included study addressed every construct or that the final synthesis treated heterogeneous findings as interchangeable.

Critical appraisal

Critical appraisal was used to calibrate interpretive weight rather than to create a numerical quality threshold. Confidence-oriented approaches to qualitative synthesis emphasise methodological limitations, coherence, adequacy, and relevance when judging how strongly a finding should inform interpretation [15]. Those domains were adapted to the present heterogeneous corpus.

Qualitative studies were examined for sampling adequacy, transparency of data generation, analytic grounding, coherence between data and interpretation, and relevance to medication work. Observational studies were additionally considered in relation to construct validity, temporal design, and confounding. Reviews were examined for search transparency, selection logic, and fit between included evidence and synthesis claims.

Weakness in one domain could restrict the use made of an evidence unit without automatically eliminating it. No appraisal score was converted into an exclusion rule. This was important because conceptually useful studies could illuminate how a category was constructed even when their findings could not support prevalence, causal, or transferable claims.

Data extraction and constant comparison

Extraction captured study design, setting, participants, relevant medication-management activity, construct definitions, measurement or assessment methods, temporal features, main findings, contradictory or null observations, author-stated limitations where available, applicability boundaries, and the exact claim that each evidence unit could and could not support.

Constant comparison was then used across evidence units and evidence traditions. Interpretive synthesis guidance emphasises making explicit how reported concepts are transformed rather than presenting review-level categories as though they originated unchanged in the primary studies [16]. Accordingly, source descriptions such as “support,” “assistance,” “medication management,” “capability,” or “responsibility” were not treated as equivalent by default.

Comparison proceeded in three directions: within evidence units, to examine relationships among reported tasks, actors, and contexts; across evidence units, to identify recurrence and contradiction; and across conceptual traditions, to determine whether ostensibly similar terms represented the same underlying phenomenon. Particular attention was paid to negative cases, including evidence in which high levels of medication work were routinised or in which assistance coexisted with meaningful autonomy.

Development of synthetic constructs

Six synthetic constructs were developed through repeated comparison.

Distributed medication work refers to medication-related activity whose successful completion is spread across more than one actor, even when the patient remains the nominal manager. The construct includes practical activity as well as information gathering, monitoring, coordination, interpretation, and communication.

Conditional independence describes situations in which a person remains substantially self-directing but that independence relies on background assistance, routines, technologies, accessible professionals, or family backup.

It differs from simple dependence because decision authority and substantial work may still remain with the patient.

Reactive delegation describes transfers of medication responsibility that occur after deterioration, error, uncertainty, crisis, or perceived risk rather than through deliberate prospective planning.

Invisible coordination work captures the organisational and relational activity required to connect prescriptions, supplies, information, clinicians, caregivers, and everyday routines when that activity is omitted from narrow descriptions of taking medicines.

Responsibility without integration describes arrangements in which patients or caregivers are expected to perform consequential medication work

without equivalent access to information, decision authority, professional coordination, or structured support.

Finally, routinised workload versus experienced burden distinguishes the existence of work from its subjective or functional consequences. Repetitive medication activity may become incorporated into everyday routines, whereas similar or smaller workloads may become burdensome when capacity is reduced or uncertainty, fragmentation, and competing demands increase.

Across the constant-comparison process, recurring tensions in the source literature were transformed into higher-order constructs while retaining the evidentiary conditions that limit each interpretation (**Table 2**).

Table 2. From source concepts and contradictions to synthetic constructs in medication self-management

Synthetic construct	Source concepts brought into comparison	Contradiction or interpretive problem	Interpretive transformation	Explanatory function
Distributed medication work	Self-management tasks; caregiver assistance; medication organisation; information seeking; monitoring; clinician communication	A single nominal “self-manager” may coexist with multi-actor performance	Reclassifies medication management according to who performs constituent work rather than who is formally designated as responsible	Makes multi-actor labour visible without presuming loss of patient agency
Conditional independence	Capability; autonomy; assistance; routines; adherence aids; family backup	Assistance can coexist with substantial autonomy	Separates decision authority and self-direction from complete absence of support	Explains why binary independent/dependent classifications can misrepresent medication management
Reactive delegation	Errors; cognitive decline; safety concerns; increasing supervision; caregiver takeover	Responsibility transitions are often described after disruption rather than before it	Treats delegation as a temporally contingent response rather than a fixed role	Identifies when work shifts and why responsibility arrangements may lag behind changing need
Invisible coordination work	Prescription management; supply; communication; reconciliation; appointments; monitoring; problem solving	Coordination frequently disappears inside broad labels such as “support” or “self-management”	Identifies coordination itself as medication work	Reveals organisational labour that is poorly represented by medication-taking measures
Responsibility without integration	Family responsibility; discharge guidance; service contact; information access; role ambiguity	Work may be transferred without equivalent authority, information, or professional connection	Distinguishes allocation of responsibility from integration into the care system	Identifies a structural condition under which delegated medication work becomes fragile

Routinised workload versus experienced burden	Treatment workload; habitual routines; capacity; uncertainty; multimorbidity	Considerable work may be manageable, while smaller workloads can become overwhelming	Separates the amount/existence of work from its experienced burden	Prevents the review from treating all medication labour as intrinsically harmful
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Synthesizing argument

The synthesizing argument was developed by examining relationships among the six constructs rather than ranking them as sequential stages. Distributed medication work provides the broadest descriptive departure from an individualised account, but it does not by itself establish either burden or dependence. Conditional independence explains why substantial assistance may be compatible with patient control. Reactive delegation introduces a temporal dimension by showing that responsibility can change when capacity, safety, or circumstances shift.

Invisible coordination work and responsibility without integration extend the analysis beyond the patient-caregiver dyad. They direct attention to institutional arrangements through which medication work is placed outside clinical settings while remaining only partially connected to professional information and authority. The final distinction between workload and burden prevents these observations from becoming a predetermined critique in which all self-management is assumed to conceal harm.

The emerging argument therefore treats medication self-management as a potentially distributed accomplishment whose visible and invisible contributors vary across context. Whether this distribution constitutes support, collaboration, delegation, burden, or unsafe transfer cannot be inferred from the label “self-management” itself. Those interpretations require evidence about who performs specific work, who has decision authority, what support is available, and whether the arrangement remains viable as circumstances change.

Reflexivity

The review began from concern that conventional self-management language might understate patient and

caregiver labour. That starting position created a risk of reading all assistance as hidden dependence or all medication work as excessive burden. Reflexive comparison therefore actively sought evidence that challenged the initial critique.

Two safeguards were used. First, work and burden were kept analytically separate so that routinised or willingly undertaken activity was not automatically reframed as problematic. Second, assistance and independence were not treated as opposites. Evidence of family involvement was interpreted according to the type of work performed, the location of decision authority, and the participant’s retained role rather than being counted as proof that “self-management” was false.

The synthesis also avoided converting recurring qualitative patterns into prevalence estimates. The included evidence is concentrated in older people, cognitive impairment, multimorbidity, family caregiving, and transitions of care. Constructs developed from this literature may provide useful questions for other medication-management contexts, but their occurrence and importance outside those settings require empirical examination.

Methodologically, the review records only search and screening numbers actually recoverable from the executed search process. Database-wide hit totals that were not available in the executed environment were not reconstructed retrospectively. This limitation narrows claims about search exhaustiveness but protects the interpretive synthesis from false precision.

The iterative relationship among retrieval, comparison, appraisal, and construct development is summarised in **Figure 1.**

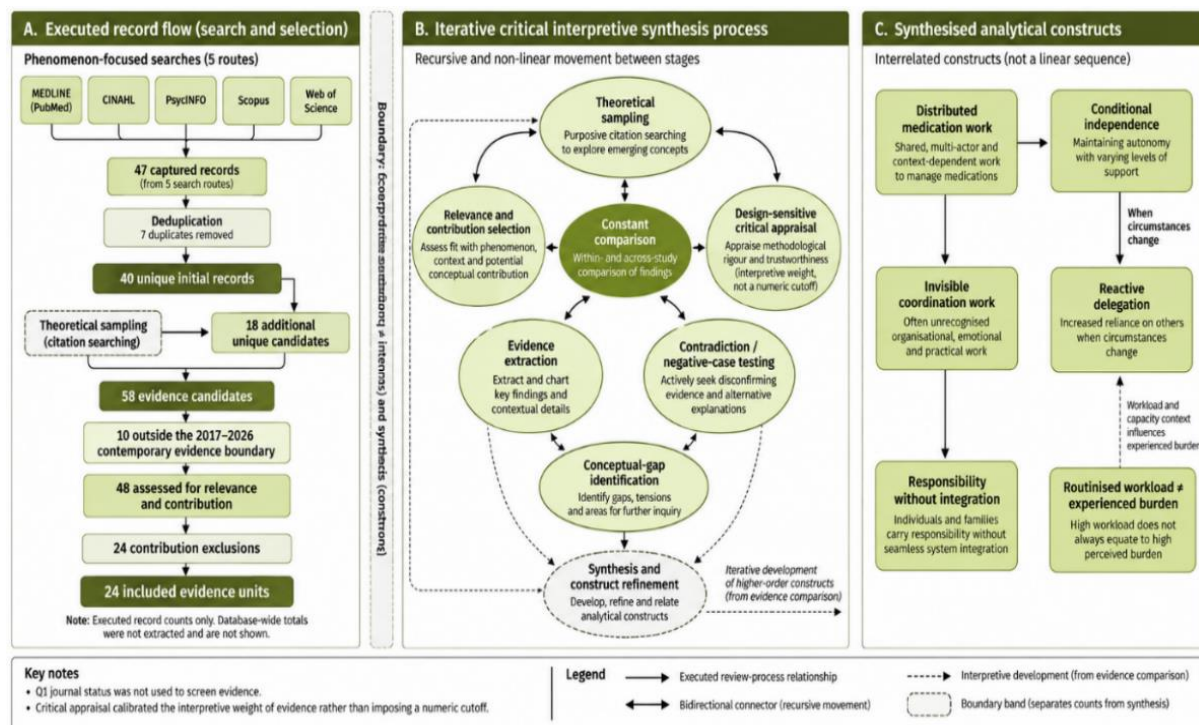


Figure 1. Iterative critical interpretive synthesis process linking search, theoretical sampling, comparison, and construct development

Findings: Landscape of the literature

The included evidence did not use “medication self-management” consistently. Some studies operationalised it as functional capability, others as a collection of behaviours, while patient-work and treatment-burden traditions examined a broader set of activities surrounding medicines. Among older adults with cognitive frailty, basic medication-management capability could remain relatively strong even while knowledge and self-monitoring weaknesses persisted [17]. Home-care users receiving multidose dispensing similarly demonstrated that receiving assistance did not necessarily displace self-management or perceived autonomy [18].

Transition research widened the analytical frame further. Work-system characteristics, regimen demands, support, and patient capacity were associated with how older adults managed medicines after hospital discharge [19].

Yet available self-management assessment tools often concentrated on adherence, cognition, physical ability, and task performance rather than the full relational and organisational work surrounding medication use [20]. Similar limitations are visible in tools developed for older adults with sensory impairment [21].

Treatment burden also resisted simple classification. Longitudinal evidence showed that high or low treatment burden could coexist with different levels of self-care, demonstrating that workload and self-management are not positioned on a single continuum [22]. Across these traditions, the central difference was therefore not merely methodological. What researchers chose to measure determined which forms of medication work became visible.

The resulting conceptual landscape is summarised in **Table 1**.

Table 1. How contemporary medication-management traditions make medication work visible or invisible

Literature cluster	Primary object of attention	Medication work most readily visible	Work liable to remain obscured	Typical assumption about independence	Interpretive consequence for this review
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Functional self-management capability	Ability to perform medication tasks	Reading, selecting, organising, remembering and administering medicines	Coordination, negotiation, contingency planning and invisible family backup	Independence is often inferred from demonstrated task capacity	Capability cannot be assumed to represent the full work system
Adherence-oriented self-management	Execution of prescribed regimens	Taking medicines as directed and maintaining routines	Interpretation, adjustment, information seeking and role negotiation	Successful regimen execution is frequently treated as individual performance	Correct execution may conceal distributed work
Patient-work literature	Activity required to make healthcare function in everyday life	Cognitive, practical, informational and relational work	Institutional allocation of that work	Independence is not necessarily the organising category	Makes hidden activity analytically available
Treatment-burden literature	Workload and its consequences	Treatment tasks, disruption, emotional and financial demands	Work that is substantial but successfully routinised	Capacity moderates whether work becomes burdensome	Work and burden must remain distinct
Caregiver medication-management literature	Contribution of unpaid carers	Administration, monitoring, organisation, information and communication	Work embedded in ambiguous or taken-for-granted family roles	Support may be treated as peripheral to the patient's "self"-management	Reveals distributed accomplishment
Transition and coordination literature	Movement of medicines and responsibility across settings	Reconciliation, information transfer, role changes and follow-up	Ongoing household coordination after formal transition	Responsibility may be assumed to transfer cleanly	Makes discontinuities and delegated work visible

Patient medication labour

Patient medication labour extended well beyond swallowing medicines. Across the evidence, patients organised supplies, interpreted instructions, incorporated regimens into daily routines, monitored effects, decided when to seek information, coordinated with clinicians, and adjusted competing demands. Earlier patient-work and concept-mapping studies showed that these activities combine material and cognitive work with social relationships and access to care.

The evidence also cautioned against treating the existence of work as proof that self-management is inherently oppressive. Some older adults routinised substantial medication activity and described it as ordinary rather than burdensome. By contrast, uncertainty, multimorbidity, reduced capacity, fragmented services, or regimen complexity could transform manageable work into difficult work. The synthesis therefore distinguishes medication labour from experienced treatment burden.

This distinction preserves patient agency. Patients may deliberately accept and value medication responsibility. The critical question is whether analyses recognise the work involved and whether individuals possess sufficient capacity, resources, information, and support to perform it safely.

Caregiver labour

Caregiver participation made the distributed nature of medication work particularly visible. Informal caregivers undertake both direct and indirect medication activities, including obtaining and organising medicines, monitoring use, communicating with clinicians, gathering information, and contributing to decisions [23]. Rural caregiving evidence further shows that these tasks are conditioned by geographical access, service availability, caregiver knowledge, and family circumstances [24].

In serious illness and end-of-life care, medication management can involve practical, physical, emotional, and knowledge work extending across repeated changes in condition and treatment [25]. Cognitive decline makes role transitions particularly consequential. Patient-caregiver dyads described transfers of responsibility that were frequently prompted by medication errors or increasing concern, while preserving autonomy remained important to patients and families [26]. Primary-care encounters involving patients, caregivers, and clinicians likewise showed that medication responsibility is negotiated among actors rather than simply transferred from one person to another [27].

Caregivers may nevertheless remain poorly integrated into formal medication systems. Home-based family caregivers reported substantial responsibility while navigating restricted information, fragmented contacts, and uncertain professional support [28]. Observation of family medication practices also identified safety vulnerabilities alongside the safeguards caregivers themselves created [29]. Where more than one caregiver participates, cognitively demanding tasks and decision authority can become unevenly distributed between primary and secondary caregivers [30].

The wider synthesis confirms that caregiver work ranges from supervision to extensive responsibility and varies with regimen complexity, recipient capability, family structure, and available support [31]. Discharge interventions for carers of people with dementia remain heterogeneous [32], while attempts to evaluate discharge guidance emphasise preparedness, coordination, and medication information [33]. Reviews of available caregiver resources show that broader medication-management responsibilities are not consistently represented in the information provided to families [34]. Taken together, this evidence does not support treating caregivers simply as optional “support.” Their activity can constitute part of the medication-management system itself. At the same time, caregiver involvement varies greatly, and the synthesis does not imply that every instance of self-management depends on unpaid care. Across contexts, caregiver medication work includes physical, cognitive, emotional, and organisational dimensions [23, 25, 31].

Assumptions of independence

The evidence challenges a binary distinction between independent and dependent medication management. A person may make treatment decisions, maintain routines, and retain substantial control while relying on another person for transportation, prescription collection, checking, reminders, or contingency support. Conversely, a patient who appears technically capable may struggle with knowledge, monitoring, uncertainty, or coordination that functional assessments do not capture.

This pattern is captured by conditional independence. Independence is conditional when self-direction is sustained through supporting arrangements that remain backgrounded in conventional descriptions. The construct does not imply that autonomy is illusory. It

identifies the difference between autonomy and complete self-sufficiency.

Evidence from multidose dispensing, cognitive frailty, multimorbidity, and cognitive decline also shows that independence can change over time. Responsibility may remain stable until an error, deterioration, hospital transition, or accumulating workload exposes a mismatch between demands and capacity. This temporal instability means that self-management status should not be interpreted as a fixed personal trait.

Structural delegation of work

Medication work is shaped not only within households but also by decisions made across healthcare organisations. Medication changes during transitions of care involve patients, families, and professionals whose participation and decision roles may not align cleanly [35]. Digital prescribing and coordination systems similarly redistribute communication and follow-up responsibilities across professional and organisational boundaries [36].

The synthesis therefore distinguishes assistance from structural delegation. Structural delegation occurs when healthcare arrangements place practical responsibility for maintaining medication continuity outside formal services. Such delegation can be appropriate and desired, but its safety depends on whether information, authority, access, and professional backup accompany the transferred work.

When they do not, responsibility without integration can result. A patient or caregiver may be expected to notice discrepancies, obtain clarification, coordinate supplies, monitor effects, or communicate changes while remaining peripheral to the information systems and decision structures needed to perform those tasks effectively.

What conventional self-management language makes invisible

Three forms of invisibility recur across the evidence. First, actor invisibility occurs when medication management is attributed to a patient while substantial work is performed by caregivers or other household members. Second, task invisibility occurs when adherence or administration measures omit information seeking, monitoring, coordination, negotiation, and contingency work. Third, structural invisibility occurs when responsibilities generated by service fragmentation

or organisational design appear as ordinary patient or family duties.

These are not merely semantic problems. Language influences what researchers measure, what clinicians assess, whose capacity is evaluated, and whose need for support becomes legitimate. A person described as independently self-managing may therefore occupy a

medication arrangement that depends on invisible coordination, while a caregiver described as providing “support” may hold substantial operational responsibility.

Table 3 operationalises these mechanisms without treating them as prevalence categories.

Table 3. Mechanisms through which conventional self-management language can obscure medication work

Conventional representation	Work obscured by the representation	Actor whose contribution may disappear	Responsibility displaced or normalised	Practice consequence if left unexamined
“The patient self-manages medicines”	Supply management, checking, monitoring, communication and backup	Family caregiver or household member	Ongoing maintenance of regimen continuity	Capability may be overestimated and support needs missed
“Adherent/non-adherent”	Interpretation, prioritisation, problem solving and negotiation	Patient	Resolving treatment-work conflicts	Behaviour may be judged without understanding workload
“Caregiver support”	Organisation, surveillance, decision work and clinician contact	Informal caregiver	Safety-critical medication management	Caregiver preparedness and information access may remain unassessed
“Independent with assistance”	Background work sustaining apparent independence	Patient-caregiver dyad	Contingency and compensatory work	Independence may be treated as stable when it is support-dependent
“Discharged with medications”	Reconciliation, clarification, access and implementation work	Patient and family	Transition coordination	Formal transfer may be mistaken for completed medication continuity
“Medication education provided”	Applying information under uncertainty and changing conditions	Patient or caregiver	Translation of advice into workable routines	Information provision may be confused with usable capacity
“Family manages medicines”	Need for authority, system access and professional integration	Caregiver	Transfer of formal work into unpaid care	Responsibility may exceed decision rights and available support

Synthesizing argument

The evidence supports a reinterpretation of medication self-management as a variably distributed accomplishment. The patient may remain central, but the work required to make medicines usable can extend across caregivers, professionals, technologies, and organisational arrangements.

The six synthetic constructs describe different aspects of that accomplishment. Distributed medication work identifies multiple contributors. Conditional

independence explains how autonomy can coexist with assistance. Reactive delegation captures temporally changing responsibility. Invisible coordination work reveals activity omitted by narrow task models. Responsibility without integration identifies a structural mismatch between expected work and system connection. The distinction between routinised workload and experienced burden prevents work itself from being pathologised.

Their relationship is represented in **Figure 2**.

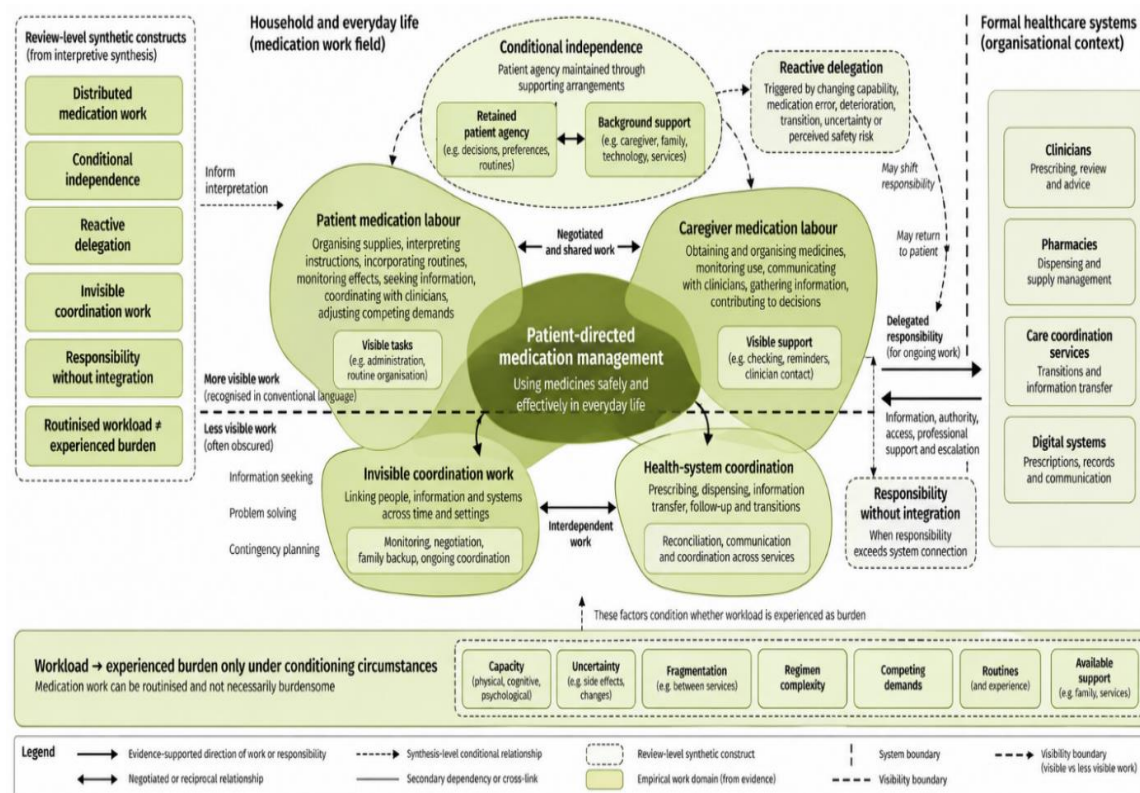


Figure 2. Medication self-management as a distributed accomplishment: visible work, obscured work, and conditional responsibility

Results and Discussion

This synthesis suggests that medication self-management literature can over-individualise an activity whose successful performance is frequently relational and organisational. The strongest evidence does not support abandoning the concept of self-management. It supports specifying what is being self-managed, by whom, with what assistance, and under what conditions.

Treatment burden provides an important boundary. Work becomes burdensome through interactions among workload, capacity, uncertainty, and support rather than through task volume alone [37]. Health professionals similarly identify service organisation and responsiveness as factors that can either reduce or intensify treatment burden [38]. Across the synthesis, burden therefore depends on context rather than following automatically from the existence of medication labour [7, 22, 37].

The review also reframes caregiver participation. Caregiver work is not adequately represented by counting whether a caregiver is “involved.” Its

significance depends on what work is performed, whether responsibility is planned or reactive, what authority accompanies it, and whether health systems recognise caregivers as participants in medication management.

These findings matter because the language of independence can conceal both capability and vulnerability. Patients may retain genuine autonomy through well-designed assistance. Conversely, apparently independent management may depend on fragile arrangements that become visible only after illness progression, error, transition, or caregiver unavailability.

Conceptual and practice implications

Conceptually, medication self-management should be analysed as a configuration of work, agency, support, and responsibility rather than as a purely individual behaviour. Studies should specify which medication activities are being measured and distinguish task performance from coordination, monitoring, interpretation, and decision work.

Clinical assessment should likewise ask who actually performs each consequential medication activity. A patient may remain the principal decision maker while another person performs organisational or monitoring work. Identifying that distribution can reveal where education, access, contingency planning, or caregiver support is required.

Services should also distinguish delegated responsibility from integrated responsibility. When patients or caregivers are expected to coordinate medicines across organisational boundaries, they require usable information, identifiable professional contacts, and realistic escalation routes. The appropriate aim is not maximal professional control or maximal patient independence, but medication arrangements whose work and authority remain aligned with available capacity.

Limitations

The included evidence is concentrated in older adults, multimorbidity, cognitive impairment, family caregiving, transitions of care, and predominantly qualitative or mixed-method designs. The synthetic constructs therefore identify recurring interpretive patterns rather than population prevalence or causal effects.

The executed search used reproducible captured-record routes but did not provide native database-wide hit totals or complete export-based screening arithmetic for every possible database. Search exhaustiveness cannot therefore be claimed. Critical interpretive synthesis is also necessarily shaped by reviewer judgement in sampling, comparison, and construct development.

Finally, terminology varied substantially across the evidence. Medication work, treatment burden, self-management, capability, support, autonomy, and responsibility were not measured equivalently. This heterogeneity motivated the synthesis but also limits direct comparison.

Conclusion

Medication self-management is often real, valued, and genuinely patient-directed, yet it is not always performed by the patient alone. Contemporary evidence shows that medication use can depend on practical, cognitive, relational, and organisational work distributed among patients, caregivers, and healthcare systems.

The central analytical problem is therefore not whether self-management is an inaccurate concept, but when its

language hides the work required to sustain it. Independence may be conditional, responsibility may shift reactively, coordination work may remain invisible, and patients or caregivers may assume consequential responsibilities without equivalent integration into formal care.

A more precise account of medication self-management should preserve patient agency while identifying who performs the work, how responsibility changes, what support makes independence possible, and when workload becomes burden. Making those relations visible offers a stronger foundation for research and medication-care design than treating self-management as an individual attribute alone.

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