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Original Article

The Hidden Labour of Making Multimorbidity Care Coherent: A Qualitative Study of Patients Navigating Fragmented Internal Medicine Pathways in Indonesia

Tan Liwei[1], Celvin Angkasa[1], Dewi Asih[1]

[1] Universitas Prima Indonesia, Indonesia

***Corresponding author: Celvin Angkasa, celvinangkasa@unprimdn.ac.id**

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ABSTRACT

Background: Multimorbidity is often managed through disease-specific services, requiring patients to coordinate information, appointments, medicines, referrals, and competing clinical priorities across fragmented pathways. This study explored the largely invisible coordination work undertaken by adults with multimorbidity navigating internal medicine care in Indonesia. Methods: A qualitative descriptive design was used with analytic material comprising 14 adult participant profiles representing diverse combinations of chronic conditions. Semi-structured accounts addressed movement between primary and specialist care, appointment management, information transfer, medication changes, conflicting recommendations, and family involvement. Data were analysed using reflexive thematic analysis informed by treatment-burden and cumulative-complexity perspectives. Results: Five interrelated themes were identified: becoming the courier of one's own medical history; appointment choreography and time poverty; reconciling contradictory clinical plans; family members as shadow coordinators; and continuity as a scarce clinical resource. Participants described substantial cognitive, administrative, temporal, and interpretive work required to maintain continuity across services. Medication-related uncertainty and unclear responsibility for reconciling competing recommendations created circumstances with potential safety implications, while family support and relational continuity increased patients' capacity to navigate fragmented care. Conclusion: Fragmented multimorbidity care can transfer substantial coordination work to patients and families. Strengthening informational and relational continuity, clarifying responsibility for cross-condition reconciliation, coordinating transitions, and providing targeted navigation support may reduce avoidable treatment burden and improve patient-centred care. Keywords: multimorbidity; qualitative research; care coordination; treatment burden; continuity of care; internal medicine; Indonesia

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INTRODUCTION

Multimorbidity, commonly understood as the coexistence of two or more chronic health conditions in the same individual, challenges healthcare systems that remain largely organised around individual diseases, specialty-specific pathways, and condition-specific treatment targets. For people living with combinations of diabetes, hypertension, cardiovascular disease, chronic kidney disease, respiratory disease, and musculoskeletal conditions, these diagnoses are experienced simultaneously rather than as discrete clinical problems. Indonesian National Health Insurance data demonstrate substantial clustering of chronic conditions within the population, while recent evidence from Indonesian adults with multimorbidity indicates that treatment nonadherence reflects interactions among treatment complexity, patient-level circumstances, and health-system factors rather than individual motivation alone (1,2).

An important consequence of multimorbidity is the work required from patients to make multiple components of care practically manageable. Patients may need to maintain medication lists, transport clinical information between services, attend multiple appointments, monitor treatment changes, obtain medicines and investigations, interpret competing recommendations, and involve family members in day-

to-day care coordination. This workload is captured by the concept of treatment burden, which describes the effort required to manage healthcare and the effect of that work on patients' functioning and wellbeing (3,4). The cumulative complexity model further proposes that difficulties arise when healthcare workload exceeds the patient's available capacity, including time, financial resources, health literacy, mobility, social support, and ability to organise care (5). From the perspective of minimally disruptive medicine, clinically appropriate care should therefore seek not only to achieve disease-specific objectives but also to reduce unnecessary healthcare workload and increase the feasibility of treatment in everyday life (6).

These issues are particularly relevant to healthcare systems in which patients move repeatedly between levels of care. Within the Indonesian national health insurance system, primary care performs an important gatekeeping function and referrals structure access to higher-level services. Research examining Indonesian general practitioners' experiences has shown that effective gatekeeping depends not only on formal referral rules but also on coordination and relationships across levels of care (7). Qualitative evaluation of the Referral Back Programme has similarly identified continuing challenges involving communication, medicine access, digital infrastructure, staffing, and feedback between services (8). Such organisational factors may interact with the treatment complexity already experienced by people with multimorbidity, increasing the amount of work required from patients to maintain continuity across encounters (2).

Care coordination is therefore not solely an organisational or professional activity. Studies involving clinicians managing multimorbidity have described difficulties integrating multiple recommendations, reconciling disease-specific guidelines, establishing responsibility for coordination, and making decisions when clinical priorities compete (9-11). From the patient perspective, access, communication, coordination, and continuity are central components of patient-centred multimorbidity care, although patients' preferences and ability to participate in care vary according to their circumstances and available capacity (12). Continuity is also multidimensional, incorporating relational, informational, and management continuity; patient-reported continuity has been associated with important health outcomes across healthcare settings (13). For people managing several interacting conditions, a technically available clinical record may therefore be insufficient if responsibility for interpreting treatment changes and reconciling competing plans remains unclear.

Evidence on integrated and patient-centred approaches also suggests that patients should participate in defining what successful coordination is intended to achieve rather than simply being expected to compensate for fragmented services themselves (14). Qualitative research from other tiered or fragmented healthcare systems has shown that patients develop practical strategies for navigating facilities, records, referrals, appointments, and diagnostic pathways, demonstrating that substantial organisational work can occur outside formal clinical encounters (15,16). Patient-navigation interventions may increase patients' confidence and involvement in managing care, although navigation should supplement rather than obscure the need to address underlying fragmentation within healthcare systems (17). These findings indicate an important distinction between patient participation in care and the transfer of unresourced coordination responsibility to patients and families.

Despite increasing recognition of treatment burden, continuity, referral-system challenges, and patient navigation, less attention has been directed towards the specific work through which adults with multimorbidity make fragmented internal medicine care coherent in the Indonesian context. Existing Indonesian evidence has primarily characterised multimorbidity patterns, treatment adherence, gatekeeping, and referral implementation, whereas international qualitative studies have demonstrated broader navigation and coordination challenges (1,2,7,8,15,16). Examining coordination as work provides an opportunity to identify not only where fragmentation occurs, but also what patients must remember, transport, organise, interpret, negotiate, and sacrifice for apparently separate encounters to function as a continuous course of care. This study therefore explored the largely invisible coordination work performed by adults living with multimorbidity while navigating internal medicine pathways in Indonesia. The study asked how patients made fragmented care workable, to whom coordination responsibilities were

effectively transferred, and what occurred when the demands of coordination approached or exceeded available patient and household capacity.

MATERIALS AND METHODS

A qualitative descriptive design was used to examine how adults living with multimorbidity experienced and managed the coordination of care across internal medicine pathways. The study focused on the work occurring between clinical encounters, including the transfer of information, organisation of appointments, management of medication changes, interpretation of potentially conflicting recommendations, and mobilisation of family support. Treatment-burden and cumulative-complexity perspectives were used as sensitising concepts for interpreting the relationship between healthcare workload and patient capacity. Reporting was organised with reference to the Consolidated Criteria for Reporting Qualitative Research (COREQ), as appropriate to an interview-based qualitative study (18).

The analytic material comprised 14 adult participant profiles, identified as P1 through P14, representing women and men aged 38 to 76 years who were living with two or more long-term conditions. Conditions represented across the profiles included diabetes mellitus, hypertension, coronary disease, heart failure, chronic kidney disease, chronic obstructive pulmonary disease, osteoarthritis, dyslipidaemia, obesity, and anaemia. The profiles also varied in employment status, travel burden, digital confidence, and availability of family support, thereby providing variation in circumstances relevant to healthcare coordination.

The sample size of 14 profiles was considered in relation to the focused nature of the study question and the relatively specific case content. This rationale was informed by the principle of information power, according to which the adequacy of a qualitative sample depends on the information contributed in relation to the study aim rather than on a predetermined numerical threshold alone (19). No numerical frequency threshold was used to determine whether a pattern constituted a theme.

A semi-structured interview framework addressed six areas relevant to multimorbidity coordination: movement between primary and specialist care; organisation of appointments; transfer of clinical information; medication changes; experiences of conflicting or unclear recommendations; and the role of relatives in coordinating care. Accounts were organised around these domains and included prompts intended to identify the work performed between healthcare encounters. Examples included, “What did you need to do next?”, “Who knew about that change?”, and “What would have happened if you had not managed it yourself?” The emphasis was therefore placed on practical coordination activity rather than solely on satisfaction with individual clinicians.

The material was analysed using reflexive thematic analysis (20). In the initial stage, accounts were read and coded for concrete coordination activities, uncertainty, emotional responses, barriers to completing healthcare tasks, and actions taken to prevent care from becoming disconnected. Codes were then compared across participant profiles to distinguish recurring service problems from the additional work generated for patients by those problems.

Patterns of meaning were subsequently developed into candidate themes. Theme development was interpretive rather than dependent on the numerical frequency of individual codes. For example, maintaining photographs of prescriptions, transporting investigation results, repeating clinical histories, and tracking previous treatment changes were initially represented by distinct codes but were subsequently interpreted as related expressions of patients functioning as carriers of clinical information between services. Candidate themes were reviewed against the overall dataset for conceptual coherence and meaningful variation between participant accounts. Final interpretation focused on the relationships among healthcare workload, patient capacity, continuity, safety-related uncertainty, and responsibility for coordinating care, informed by treatment-burden and cumulative-complexity perspectives (3-5).

Ethical approval was obtained from Universitas Prima Indonesia. Participant material was presented using identifiers P1 through P14, and directly identifying personal information was not included in the manuscript.

RESULTS

Participant Characteristics and Overall Thematic Structure

The analytic material comprised 14 adult participant profiles aged 38 to 76 years with at least two long-term conditions. The profiles represented different combinations of cardiometabolic, cardiovascular, renal, respiratory, and musculoskeletal conditions, together with variation in employment status and availability of family support. Some participants described managing coordination independently, whereas others relied on spouses, children, or grandchildren for practical and informational support.

Five interrelated themes described how fragmented care was made workable: becoming the courier of one's own medical history; appointment choreography and time poverty; reconciling contradictory clinical plans; family members as shadow coordinators; and continuity as a scarce clinical resource. These themes were interconnected rather than independent. Failures in information transfer increased the work required at subsequent appointments; multiple appointments intensified time and financial demands; contradictory treatment recommendations required patients to undertake informal reconciliation; and limited continuity increased dependence on patients and relatives to reconstruct previous clinical decisions.

Table 1. Participant Profile Characteristics

ID	Age	Sex	Condition mix	Work status	Coordination support
P1	62	Female	Diabetes, hypertension, CKD	Retired	Daughter assists
P2	55	Male	Diabetes, coronary disease, dyslipidaemia	Driver	Limited support
P3	71	Female	Heart failure, hypertension, osteoarthritis	Retired	Son assists
P4	44	Female	Diabetes, hypertension, obesity	Shop worker	Independent
P5	68	Male	COPD, coronary disease, hypertension	Retired	Spouse assists
P6	59	Female	Diabetes, CKD, hypertension	Homemaker	Daughter assists
P7	38	Male	Diabetes, hypertension	Office worker	Independent
P8	73	Female	Heart failure, CKD, osteoarthritis	Retired	Grandchild assists
P9	51	Male	Diabetes, dyslipidaemia, hypertension	Self-employed	Independent
P10	64	Female	COPD, diabetes, hypertension	Homemaker	Spouse assists
P11	47	Female	Diabetes, CKD, anaemia	Teacher	Independent
P12	76	Male	Coronary disease, heart failure, CKD	Retired	Children assist
P13	57	Male	Diabetes, hypertension, osteoarthritis	Market trader	Spouse assists
P14	69	Female	Diabetes, coronary disease, hypertension	Retired	Daughter assists

Abbreviations: CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease.

Theme 1: Becoming the Courier of One's Own Medical History

Participants described routinely carrying clinical information between healthcare professionals and facilities. This work included keeping photographs of prescriptions, carrying printed laboratory results and referral documents, retaining appointment cards, and maintaining handwritten notes. The burden did not arise only from records being physically unavailable. Participants also described uncertainty about whether a clinician had seen the most recent medication change, investigation result, or recommendation, leading them to maintain parallel personal records as a safeguard against discontinuity.

P1 described using a mobile phone to preserve medication information: “I have all the medicine photos in my phone since I have no idea which list they will look at.” P11 similarly described repeatedly communicating kidney-test information to different clinicians: “I repeat to you that something is lacking, in case they are already aware of it.” These accounts suggested that informational continuity depended partly on patients remembering which information had changed and determining what needed to be reproduced at each encounter.

The limitations of this role became more apparent as clinical complexity increased. P12 carried a folder containing healthcare documents to each visit but remained unable to explain why a particular medicine had previously been stopped. Carrying the information therefore increased the likelihood that records would reach another clinician, but it did not necessarily provide the patient with the clinical reasoning required to reconcile decisions. Participants consequently functioned as carriers of clinical evidence without necessarily possessing the authority or expertise to integrate that evidence into a unified treatment plan.

Theme 2: Appointment Choreography and Time Poverty

The work associated with healthcare extended substantially beyond the duration of a clinical consultation. Participants described preparing referral documents, arranging transport, completing laboratory investigations, collecting medicines, and attending separate follow-up appointments while simultaneously managing employment and household responsibilities. P4 explained, “A single appointment has the potential of occupying the entire day, and another clinic will need a different day. It is not my job only.” P13, who worked as a market trader, described attendance as an economic trade-off: “When I close the stall I lose the income. Sometimes I decide on which appointment seems most important.”

The cumulative effect of this work was more important than any single episode of waiting or travel. For working participants, repeated appointments competed with employment and income-generating activities. Older profiles more commonly described challenges related to mobility and fatigue. When appointments could not be coordinated, participants sometimes had to decide which health problem or clinical recommendation to prioritise. The resulting pattern represented a practical form of rationing in which the feasibility of following a recommendation depended not only on clinical need but also on available time, mobility, transport, finances, and competing responsibilities.

Theme 3: Reconciling Contradictory Clinical Plans

Medication changes were described as the most anxiety-provoking form of fragmentation. Participants reported circumstances in which different clinicians focused on different disease priorities, including blood-pressure control, renal function, and cardiac symptoms. Recommendations could therefore appear contradictory when the reasoning underlying a change was not communicated clearly across encounters or to the patient.

P6 described uncertainty over whether a medication should be continued after receiving information about deteriorating kidney measures: “I should continue it but then I learned that the kidney figures were not good so I did not know which of the instructions was the last one.” P2 described retaining two versions of a medication list until a later consultation clarified which plan should be followed. These experiences indicate that participants were not merely required to remember medication names; they also had to determine whether different instructions represented deliberate clinical modification, outdated advice, or unresolved disagreement.

This responsibility created both cognitive burden and perceived safety risk. Participants described deciding whether to continue or delay a medicine, contact another healthcare professional, seek clarification from a pharmacist, or wait for a subsequent appointment. P10 summarised the dilemma directly: “When two doctors are saying different things, then I am the one who makes the decision and I am not the doctor.” Participants also expressed concern that attempts to manage contradictory advice could subsequently be interpreted as nonadherence. The theme therefore reflected the transfer of unresolved clinical uncertainty into patients' everyday medication management rather than evidence that participants themselves had authority to reconcile competing clinical plans.

Theme 4: Family Members as Shadow Coordinators

Family members frequently performed practical and interpretive coordination work. Children, spouses, and grandchildren helped organise documents, remember appointments, accompany participants to consultations, review messages, and retain information from previous clinical encounters. P8 described the contribution of her granddaughter: “My granddaughter keeps a record of dates and reads through the messages, without her I would miss things.” P3 similarly relied on her son to connect recommendations from different visits when attending consultations.

Family involvement expanded the capacity available to coordinate care, but it also revealed variation between participants with and without such support. Participants managing care independently had fewer opportunities to delegate appointment organisation, documentation, and information recall. P5 reflected on this difference: “My wife asks me the questions that I forget. I have seen other older people standing and waiting alone and I wonder what they do.” Family members therefore functioned as an informal coordination infrastructure that compensated for discontinuities between formal services.

Reliance on household support also suggested a potential source of inequity in the ability to navigate fragmented care. The same level of service complexity may be more manageable for a patient with a digitally confident relative who can attend appointments and organise documents than for another patient with similar clinical needs who must coordinate care alone. Family support was therefore not simply an interpersonal preference but an important component of the practical capacity available to manage healthcare workload.

Theme 5: Continuity as a Scarce Clinical Resource

Participants valued encounters with clinicians who were familiar with their history because continuity reduced the amount of information that had to be reconstructed at every visit. Familiar clinicians were described as more able to recognise previous treatment decisions, understand competing priorities, and interpret current problems in the context of earlier care. P14 characterised the value of a familiar clinician as being able to consider more than the immediate blood-pressure measurement, whereas repeated encounters with unfamiliar clinicians generated concern that earlier decisions might not be recognised.

P7 distinguished between continuity for relatively simple problems and continuity when multiple conditions interacted, indicating that changing clinicians was easier when a single issue was being managed than when treatment decisions involved competing conditions. This distinction suggested that continuity reduced healthcare workload by decreasing the need to repeat histories, reconstruct medication changes, and explain previous clinical trade-offs.

Participants' accounts also distinguished between access to services and access to integrated care. Although participants could interact with multiple healthcare services, this did not necessarily mean that one clinician or team assumed responsibility for reconciling the overall plan. Fragmentation became particularly burdensome when several clinicians contributed disease-specific recommendations but responsibility for integrating those recommendations remained unclear. In these circumstances, relational continuity functioned as an additional source of patient capacity because a clinician familiar with previous decisions provided a credible point of reference when uncertainty arose.

Table 2. Themes, Patient Coordination Work, and Service Implications

Theme	Patient coordination work	Service Implication
Courier of medical history	Carrying records, retelling changes, tracking results	Strengthen informational continuity and medication reconciliation
Appointment choreography	Scheduling, travel, waiting, prioritising visits	Coordinate appointments and recognise time burden
Contradictory clinical plans	Comparing advice, seeking clarification, managing uncertainty	Clarify responsibility for cross-condition decisions
Family shadow coordinators	Booking, accompanying, remembering, interpreting	Assess coordination-support needs and provide navigation assistance where required
Continuity as a scarce resource	Reconstructing history and rebuilding contextual knowledge	Protect relational continuity for patients with complex care needs

DISCUSSION

This study identified patient and household coordination as a central mechanism through which fragmented multimorbidity care was made practically workable. Five interrelated themes showed that participants carried clinical information between services, organised multiple appointments, attempted to interpret potentially contradictory treatment plans, relied on relatives for practical and informational support, and valued continuity because it reduced the need to repeatedly reconstruct previous decisions. Taken together, these findings suggest that fragmentation redistributes part of the work of clinical integration from healthcare organisations to patients and families. The burden was therefore not limited to the number of diagnoses or appointments; it arose from the additional cognitive, administrative, temporal, financial, and interpretive work required to make separate episodes of care function as a coherent treatment pathway.

These findings are consistent with treatment-burden and cumulative-complexity perspectives, which conceptualise patient difficulty not simply as failure to adhere but as a potential mismatch between healthcare workload and the capacity available to perform that work (3-5). Minimally disruptive medicine

similarly emphasises that treatment plans should be evaluated in relation to their feasibility within patients' everyday lives rather than only according to disease-specific clinical targets (6). Qualitative research from other fragmented and tiered healthcare systems has also shown that patients develop informal strategies for moving information, documents, referrals, and clinical knowledge between services (15,16). The present findings extend this perspective by showing how such navigation work becomes particularly consequential when several chronic conditions require simultaneous management and when patients must interpret how recommendations from different encounters relate to one another.

The theme of becoming the courier of one's own medical history demonstrates that informational availability and effective coordination are not equivalent. Participants could carry photographs of prescriptions, laboratory results, referral papers, and personal notes while remaining uncertain about whether the receiving clinician had access to the most recent decision or understood why a previous treatment had changed. Continuity of care includes informational, relational, and management dimensions, and patient-reported continuity has been associated with important healthcare outcomes (13). The findings therefore suggest that electronic or paper access to information, although necessary, cannot by itself ensure coordinated multimorbidity care if responsibility for interpreting longitudinal information and reconciling competing plans remains unclear.

The most clinically concerning accounts involved contradictory or apparently contradictory medication recommendations. Previous qualitative research with clinicians has shown that multimorbidity creates difficulties when disease-specific guidelines, competing priorities, and responsibility for coordination must be reconciled within a single patient (9-11). In the present study, these professional coordination problems were reflected downstream in participants' accounts of uncertainty over which instruction was current, whether a medicine should be continued, and whom they should contact for clarification. Treatment-burden frameworks are relevant because such uncertainty adds cognitive and organisational workload to the practical demands of treatment (3-5). These accounts should not be interpreted as direct evidence that medication errors or adverse events occurred; rather, they identify circumstances with potential safety implications when unresolved clinical uncertainty is transferred to patients who do not possess professional authority to reconcile competing recommendations.

Family members emerged as an important source of additional coordination capacity. Relatives helped participants organise appointments, preserve documents, recall previous advice, interpret messages, and communicate information during consultations. Patient-centred multimorbidity research has shown that preferences and ability to participate in care differ according to individual circumstances and available support (12), while co-design approaches emphasise that meaningful patient participation should shape the organisation of care rather than simply transfer professional responsibilities to patients (14). Patient-navigation programmes may also increase patients' confidence and involvement in managing complex healthcare pathways (17). The current findings nevertheless demonstrate an important limitation of relying on informal support: coordination becomes partly dependent on household resources that are unevenly distributed. Patients without available, digitally confident, or practically involved relatives may therefore face greater difficulty managing the same degree of service fragmentation.

Relational continuity was experienced as a practical resource rather than merely a preference for seeing a familiar clinician. Participants described familiar clinicians as reducing the need to repeat histories, reconstruct medication changes, and explain previous trade-offs between competing conditions. This interpretation is consistent with evidence that continuity encompasses more than information transfer and is associated with meaningful health outcomes (13). For patients with multimorbidity, continuity may therefore reduce workload by preserving contextual knowledge across encounters. Conversely, technically available access to multiple services may remain poorly integrated if no clinician or team has sufficient longitudinal responsibility to interpret how disease-specific recommendations interact.

The Indonesian healthcare context adds particular relevance to these findings. Multimorbidity is present across chronic-disease combinations within the Indonesian insured population, and treatment nonadherence among adults with multimorbidity has been associated with interacting treatment, patient,

and health-system factors (1,2). Primary-care gatekeeping is intended to organise access to higher-level services, but Indonesian general practitioners have described coordination and relational factors as important determinants of effective gatekeeping (7). More recent evaluation of the Referral Back Programme has also identified challenges involving communication, medicine availability, staffing, digital infrastructure, and feedback between levels of care (8). The present findings suggest that the operational consequences of these system-level limitations may include additional work for patients who must preserve information, organise recurrent transitions, and manage ambiguity between services.

A practical implication is that coordination burden should be considered when evaluating the quality of multimorbidity care. Minimally disruptive medicine argues that healthcare should reduce unnecessary workload while supporting patients' capacity to undertake essential treatment tasks (6), and co-design evidence supports involving patients in determining how integrated care should function in practice (14). Services could therefore assess whether each transition creates additional patient work, whether the patient has sufficient capacity to undertake that work, who is responsible for reconciling the new plan with existing conditions, and how treatment changes will be communicated to subsequent clinicians. Such an approach would shift attention from expecting patients to compensate for fragmentation towards designing pathways that require less compensatory labour.

The study also has important limitations. The qualitative descriptive design was intended to provide an interpretive account of coordination work rather than to estimate the prevalence or frequency of particular experiences. The small and focused set of 14 participant profiles limits transferability beyond the represented clinical and social circumstances, and the findings should not be generalised to all adults with multimorbidity or all Indonesian healthcare settings. The analysis relied on participant accounts and therefore cannot establish whether perceived contradictions reflected objectively conflicting clinical decisions, incomplete communication, or other explanations. Similarly, reported uncertainty around medicines indicates potential safety concerns but does not demonstrate medication errors or adverse clinical outcomes. Family and clinician perspectives were not independently triangulated within the reported dataset, and the interpretation of themes necessarily reflects the analytic framework applied to the accounts. These limitations support a cautious interpretation in which the findings identify processes of coordination burden and perceived fragmentation rather than the frequency, causal effects, or clinical outcomes of those processes.

CONCLUSION

Adults represented in this qualitative study described substantial work required to make fragmented multimorbidity care coherent across internal medicine pathways. This work included transporting clinical information, organising appointments, interpreting medication changes, managing competing recommendations, and relying on relatives to compensate for discontinuities between services. The findings suggest that fragmentation becomes particularly burdensome when healthcare workload approaches or exceeds patient capacity and when responsibility for integrating cross-condition decisions is unclear. Rather than assuming that patients and families can indefinitely compensate for disconnected services, multimorbidity care should seek to reduce avoidable coordination work through stronger informational and relational continuity, clearer responsibility for cross-condition reconciliation, better coordination of appointments and transitions, and targeted navigation support for patients with limited capacity. The findings identify coordination burden as a potentially important patient-centred dimension of healthcare quality, while the clinical and safety consequences of that burden require further investigation.

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