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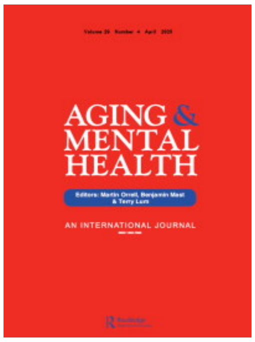

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Living with dementia and other long-term conditions: what works for patient-caregiver dyads? A realist review

Melanie Handley[a], Greg Windle[a], Elspeth Mathie[a], Honey-Anne Greco[a], Ben Underwood[b], Claire Surr[c], Karen Harrison Dening[d], Steve Milton[e], Amit Pujari[f], Reda M. Lebcir[g], Jennifer Lynch[a], Lucy Beishon[h,i,j], Elizabeth L. Sampson[k,l,m], Reinhold Scherer[n] and Claire Goodman[a]

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ABSTRACT

Objectives: Globally, increasing numbers of people are living with multiple long-term conditions. When dementia is a co-occurring condition, contact with services is complicated due to cognitive difficulties and is often achieved as a dyad (person-carer). This realist review aimed to explain how dyads living with dementia alongside other long-term conditions are enabled to access and navigate health and care systems.

Method: An iterative, three-stage approach synthesised evidence from empirical studies and stakeholders with lived and professional experience (ethics reference 23/LO/0829).

Results: Evidence from 61 studies and stakeholders (30 participants, 68 consulted) built and refined five programme theories for how health and care systems can achieve continuity of support, anticipate adverse events and maintain quality of life. Belief that concerns would be listened to and acted upon led dyads to seek assistance. Time and permission to discuss priorities, prognosis and acceptable levels of burden enabled uncertainties to be managed as a shared endeavour. The collective capacity of the dyad was enhanced by peer support, expertise they accrued and professionals who helped anticipate points of change.

Conclusion: Despite years of system changes, structural factors still create excessive burdens for dyads accessing services and constrain professionals' ability to respond to complex needs.

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KEYWORDS
Dementia; multiple-long term conditions; carers; dyads; health and care systems

Introduction

Globally, the number of people living with multiple long-term conditions is growing, particularly in older adults (Chowdhury et al., 2023). This causes considerable personal, financial and resource burden. The majority of people living with dementia in the United Kingdom (UK), will also be living with other long-term conditions (Browne et al., 2017; Bunn et al., 2014; Sabatini et al., 2024). Care encounters and regimens for managing long-term conditions are often complex. These become more challenging when also living with dementia as cognitive difficulties, such as poor short-term memory, reduced ability to plan and sequence actions, and diminished communication impact a person's ability to use and benefit from health and care services. Timely access to services that can identify and respond to new concerns and provide appropriate, ongoing management and treatment often requires the involvement of an unpaid carer—for example family member, friend or neighbour. This support can include organising and co-attending appointments, monitoring or implementing care and treatment plans, and communicating across multiple different services (Jelley et al., 2021; Price et al., 2024).

Multiple-long term conditions are defined as the presence of two or more co-existing chronic conditions (Boyd & Fortin, 2010). While services are often organised around one condition, the interactions and fluctuations between conditions have implications for self-management, treatment and ongoing support. The way different conditions present, such as steady decline or acute episodes with periods of recovery, affects the support unpaid carers provide for someone who is also living with dementia. This may require a level of medical understanding and include fundamental personal care (Surr et al., 2020). The reliance on an unpaid carer is more likely for people who are older and increases as the conditions, and particularly dementia, progress (Spiers et al., 2021). Therefore, people will typically navigate health and care systems as a dyad—the person living with dementia and their unpaid carer.

Dyadic partnerships vary in terms of their living circumstances (co-habiting, living separately, caring at a distance), and whether their relationships are supportive or not (Ablitt et al., 2009). While acknowledging that support can differ and be provided by a network of people, for the purposes of this review

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the term 'carer' will be used to recognise the role of the primary person providing non-paid support to someone living with dementia alongside other long-term conditions. It is not uncommon for the carer to be living with their own long-term conditions and at times the caring roles within the dyad may be reversed (Wang et al., 2014). Often, this will be a long-term challenge with dyad relationships often characterised by co-dependence and reciprocity (De Maria et al., 2022). When and how dyads are able to access the health and care services they need are determined by the characteristics of the dyad, the support available, their level of health literacy, and their socio-economic and cultural capital (Giebel et al., 2024). It is difficult to systematically involve and assess the needs of both members of the dyad when most services are organised to address individual patient encounters to address single conditions. This is particularly problematic in the context of dementia given the carer plays a central role to the care coordination and disease management process.

Living with and supporting someone with multiple long-term conditions including dementia exacerbates existing social, cultural and economic inequalities and can also lead to new inequalities due to the physical, emotional and financial impact of self-managing and supporting people to self-manage conditions (Sabatini et al., 2024; Woodward et al., 2023). This is compounded by the known inequalities experienced by people living in rural and coastal areas (Whitty, 2023). There is an extensive evidence base on the challenges of navigating health and care services when living with dementia, but most innovations to improve access occur at a local level and do not address how the wider system needs to adapt and accommodate the needs of people living with dementia alongside other long-term conditions. This realist review asked how access and navigation of health and care services works (or not) for dyads living with dementia and managing other long-term conditions.

Methods

How health and care systems address the needs of people with multiple long-term conditions including dementia and their carers is variable. Often new services are superimposed on ones designed for younger populations with a focus on cure. To work with, rather than control for this complexity, realist review draws together evidence from diverse sources using theory to build explanatory accounts of what works, for whom and in what circumstances (Pawson, 2006). An iterative three-stage process undertaken between August 2023 and September 2024 scoped and tested key ideas in the evidence to deliver a context-sensitive account of what is needed for services to adapt and deliver effective pathways for care. The Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) quality and publication standards (Wong et al., 2014) guided the development of this review.

Three review questions sought to understand:

1. What is the current scale of evidence and the theoretical underpinnings related to health and care service navigation across dyads journeys of living with dementia alongside other long-term conditions?
2. How can systems and structures of care be designed to improve their responsiveness to dyads and build resilience for them and the system?
3. What aspects of health and care services and systems work, for whom and in what circumstances?

Phase 1: Development of initial programme theories

Use of substantive theories. Consultation with stakeholders representing people living with dementia alongside other conditions, carers and professionals working in services, repeatedly identified challenges of navigating health and care systems that reflected two established theories: Burden of Treatment (May et al., 2014) and Diagnostic Overshadowing (Jones et al., 2008). Burden of Treatment explains the work of patients and their supporters for managing long-term conditions, including the necessary interactions with health and care services. Diagnostic Overshadowing describes how a primary condition becomes the dominant focus for explaining symptoms, and a barrier to investigations and referrals for other conditions. While not specific to dementia, these theories provided the lens for building programme theories related to living with multiple long-term conditions and being supported to access care as part of a dyad.

Scoping searches. Scoping searches focused on identifying sufficient evidence for articulating initial theories to inform later comprehensive and systematic theory-driven searches (see below). Therefore, scoping searches of two health and care databases, PubMed and CINAHL, were conducted to identify a range of existing theories and seminal studies related to the use of health and care systems when living with dementia alongside other long-term conditions (supplementary file 1).

In recognition of the influence the Health and Social Care Act (2012) on UK service commissioning that aimed to support collaboration and partnership-working to integrate services, literature reviews and primary studies that were fully or partially UK-based, published since 2012 and considered dyads were prioritised for inclusion. Theories and studies were mapped across the NHS Well Pathway for Dementia (NHS England, 2018) using excel and Visio to identify where evidence clustered. Core concepts described in multiple studies across the pathway were: (i) getting into and being recognised in the system, (ii) facilitative service networks, (iii) care decisions for dynamic condition trajectories, and (iv) prioritising what matters to the dyad. Search terms of the main concepts (dementia, multiple long-term conditions and carers) were combined with search terms for the four theory-based concepts (i–iv) (supplementary file 1). These concepts also refined selection criteria and informed data extraction.

Phase 2: Retrieval, review and synthesis

Theory-driven searches of health, social care and multidisciplinary databases PubMed, CINAHL, Scopus, Cochrane Library, NIHR Library and Google Scholar were conducted to identify UK-based studies to test the tentative theories. Forward and backward citation techniques of key texts and knowledge from authors supplemented systematic database searches.

Selection and appraisal of documents. Search results were downloaded into Rayyan (Ouzzani et al., 2016). Two authors (MH, GW) independently screened titles and abstracts with

10% checked for consistency. Where eligibility was unclear, documents were included for full-text review. Full texts were screened by three authors (MH, GW, HG) with 10% randomly double screened. The process of theory refinement meant inclusion criteria continued to evolve throughout the review process. Studies were included if they described:

- The work of the dyad together or separately in self-managing long-term conditions when living with dementia;
- Experiences of navigating health and care services for long-term conditions when living with dementia;
- Professional management of multiple long-term conditions in older people and those living with dementia.

As the majority of people living with dementia are also living with other conditions, studies were included if they did not specify other long-term conditions. Studies were excluded if they only described; the epidemiology of long-term conditions, community and physical activities that were not linked to health or care services, or prevention strategies for reducing the risk of developing dementia or other conditions.

Uncertainties were discussed with another author (CG) erring on favouring inclusion if there was discussion of the system response to this group that could inform theory development.

Data extraction and synthesis. Data were extracted by three reviewers (MH, GW, HG) using a bespoke form with 10% double extracted. Full texts and data extraction forms were uploaded into NVivo to support inductive, deductive and retroductive analysis. Discussions with authors and stakeholders developed the coding framework that progressed from themes and demi-regularities to context-mechanism-outcome configurations associated with each programme theory.

Phase 3: Testing and refining of programme theories

Theories were tested through realist-informed interviews (*n* = 25), five co-production workshops (*n* = 5), discussions with a patient and public involvement advisory group (*n* = 9) and five stakeholder consultation workshops (*n* = 59) (Table 1). Professionals were identified by knowledge from the project team, internet searches and suggestions from regional organisations such as the NIHR Applied Research Collaboration, East of England. Carers of people living with dementia were recruited through invitations to participate *via* local charities and third sector organisations. Co-production participants were recruited *via* existing research networks. An interview schedule explored the resonance of programme theories with those living with, caring for someone or working with people living with dementia alongside other long-term conditions. Ethical permission for interviews and co-production workshops was obtained (London—Bromley Research Ethics Committee, reference 23/LO/0829). Interview and co-production workshop participants provided written informed consent. The Patient and Public Involvement advisory group was convened by SM through Innovations in Dementia and met five times.

Table 1. Summary of stakeholder participation and consultation activities.

Stakeholder characteristics	Participation	*N*
Participants		
Carers	Interviews	7 (spousal = 4, adult child = 3)
Professionals	Interviews	18 (health care = 4, social care = 4, voluntary sector = 5, system navigators = 2, commissioner/policy = 3)
People and carers living with dementia alongside other long term conditions	Co-production workshops	5 (1 person with dementia)
Public and professional involvement/consultation		
People living with dementia alongside other long term conditions	Advisory Group	9
People and carers living with dementia alongside other long term conditions and professionals	Consultation Workshops (5 (2 were held with people with lived experience and professionals, 2 with people with dementia and carers, 1 with carers only))	59 (4 people living with dementia, 32 carers, 23 professionals)

Findings

Description of included papers

The search process and results are set out in an adapted PRISMA diagram reflecting the scoping and theory-driven searches (Figure 1). Across all searches, a total of 8336 records were identified. Following deduplication and screening, 73 papers from 61 studies were included. Supplementary file 2 contains the list of included studies and their characteristics including the domain of the NHS England Well Pathway for Dementia, health or care setting and contribution to the programme theories.

Of the 61 studies, 17 were evidence reviews (7 = systematic reviews, 4 = realist reviews, 4 = scoping reviews, 2 = not specified) and 44 were primary research studies (38 = qualitative, 4 = mixed-methods, 2 = quantitative). The majority of studies focused on supporting well (*n* = 42), with studies based in primary and community care (*n* = 15), social care (*n* = 5), outpatient, hospital and emergency services (*n* = 11), mental health services (*n* = 3), care homes (*n* = 1) or reporting a variety of clinical encounters (*n* = 7). Seven were classified as diagnosing well, three living well and five dying well. Studies reported findings for dementia plus other long-term conditions (*n* = 19), only dementia (*n* = 39) and multiple long-term conditions in older people (*n* = 3). Nineteen studies reported the additional conditions participants were living with alongside dementia. Nine focused on dementia plus one other co-occurring condition (cancer, diabetes, COPD, chronic heart condition, chronic kidney disease) and ten did not specify, reporting multiple conditions. Twenty-nine primary studies described the dyad, reporting the relationships of 952 dyads: 471 (49%) were spousal, 406 (43%) parent/child, 39 (4%) family other (e.g. sibling, in-law, or second-degree relative), six (>1%) were friends, 12 (1%) reported no carer and 18 (2%) relationships were unclear. Eight studies also reported living arrangements for a total of 108 dyads: 79 were co-located and 29 lived separately.

Challenges across system levels

At the level of the dyad, the challenges of accessing and navigating health and care services were related to how a person's cognitive capacity affected their ability to self-manage symptoms and/or treatments, the status of their different conditions

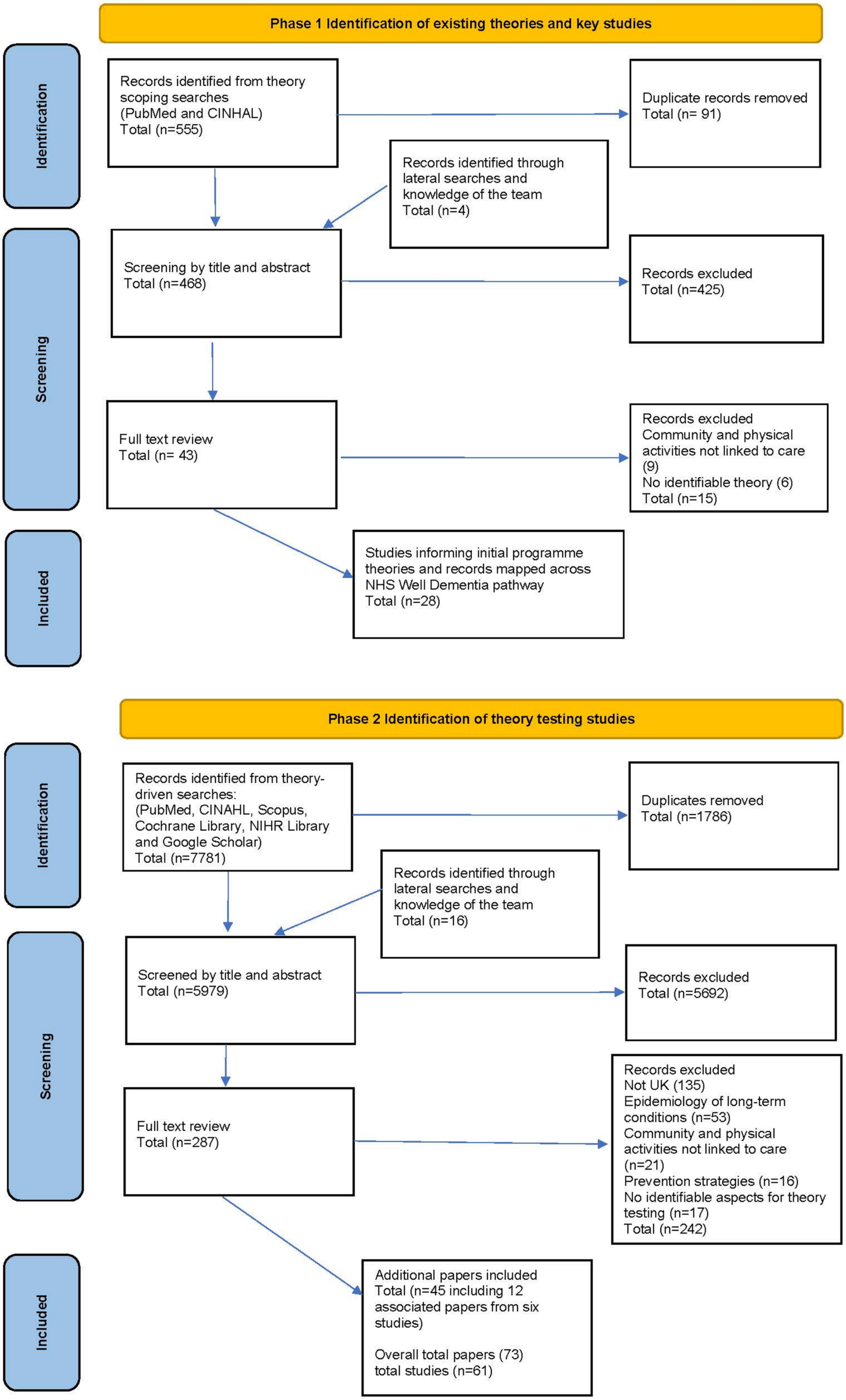

Figure 1. PRISMA diagram of scoping and theory-driven searches.

and circumstances of the dyad. Understanding how dementia affected the person was more important than knowing the type of dementia or even how long the person had lived with a diagnosis. Table 2 sets out how dyadic partnerships could support use of services depending on how a person's cognition was affected by dementia. A simplified diagram of the interacting characteristics of dyads, services and systems are set out in Figure 2.

Programme theories

Exemplar evidence from stakeholders for each programme theory are presented in Table 3. Programme theory contributions from included studies are detailed in supplementary file 2 and additional examples of stakeholder evidence are provided in supplementary file 3, with links indicated in brackets, e.g. (PT1.1).

Table 2. Impact of dementia on contact with health and care services and the role of carer in the context of multiple long-term conditions.

Cognitive domain impaired	Examples of how dementia impacts contact with health and care services	Role of carer
Memory	Recalling events, consultations, treatment and advice	Remind about appointments, medication, share information/history across services
Learning	Using new equipment, incorporating new medication administration regimens, using online systems to make appointments	Supporting use of new equipment, making appointments
Language	Reporting issues, comprehending advice, impact on written and verbal skills	Reporting concerns and observations, understanding and applying advice
Attention	Difficulty concentrating during consultations	Maintaining continuity during consultation Orienting focus to conversations
Executive function (planning, decision making)	Sequencing events (e.g. use of remote monitoring), understanding choices for treatment decisions	Support decision making
Visuospatial	Navigating services	Getting to appointments, navigation of care environments
Social cognition	Maintaining relationships with professionals	Building and maintaining relationships
Sensory	Overwhelming environments	Anticipate and where possible mitigate

Programme theory 1: Trust that concerns will be listened to with suitable actions taken

(Studies = 34)

Timely contact with services to investigate and address health and care concerns are complicated by service capacity and belief that something can and will be done (context). Dyad knowledge of where to go for support, their ability to engage with services (mechanism resource) and having confidence that their concerns are legitimate encourage help seeking (mechanism reasoning). This in turn may lead to actions or treatments that can maintain health, prevent decline, support recovery from an acute episode or avoid crisis (outcome).

A major challenge for dyads across all points of the pathway was gaining initial access to services that could account for all their health and care support needs. For the carer, difficulties when seeking assistance from professionals were explained through three linked mechanisms: (i) that they believed the need was justified and that they would benefit from services involvement, (ii) being able to identify the service most likely to address the health or care need and (iii) having the resources and knowledge to work around system structures and practices that could not accommodate additional support when living with dementia. For the person with dementia, it was continuity of contact and confidence that not everything was explained by their dementia diagnosis.

Help seeking for symptoms of dementia before receiving a diagnosis were often complicated by the presence of other long-term conditions in either or both members of the dyad. This was compounded by internalised stigma and normalisation of difficulties attributed to ageing by both the person with dementia and their carer and services approached (PT1.1). These issues were further amplified for ethnic minority and socioeconomically deprived groups, reported as related to previous hostile experiences from services and a lack of understanding of dementia within their community, particularly if language impacted access to information (PT1.2). A lack of flexibility in services' capacity to address multiple concerns in one encounter, and the dyad's reluctance to add to the work of what were perceived as overstretched services also created hesitancy for help seeking (PT1.3). Additionally, dyads needed to believe that services' advice or responses for their concerns were

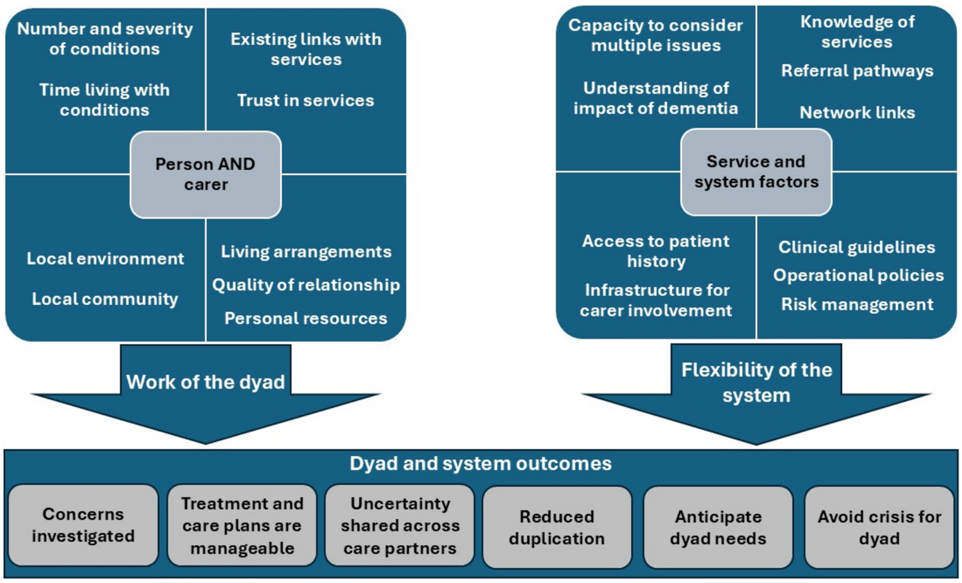

Figure 2. Dyad characteristics and system factors related to access and navigation of health and care services when living with multiple long-term conditions including dementia.

Table 3. Exemplar quotes for each programme theory.

Programme theory	Quote
1. Trust that concerns will be listened to with suitable actions taken	[husband's experience of cancer treatment with co-occurring dementia] every stage was a struggle … started with things like bowel prep at home, to attending early on the day of the actual investigation, to waiting in a waiting area to the procedure itself, and then the expected recovery process. Everything was a major challenge. (Carer 6, Co-production workshop)
2. Recognition of dementia and the dyad in the system	about 3 years ago I had cataract removed… when it came to the to the time of the operation I was put in a side ward and my wife wasn't allowed in, I was starting to get in a panic because my wife converses, cause I forget what people say, particularly doctors… [after the operation] I had two eye shields and I kept them on all day and I went out that night with my brother-in-law, still with these patches on, and everybody was looking at me… When I went back to see the specialist again he said, 'No, you should have only kept him on for an hour or so.' Well, I didn't know, so he said 'I told you.' I said, 'well, I've got dementia.' He didn't bear that in mind. (Person living with dementia and cancer, co-production workshop)
3. Working together to understand and agree acceptable levels of burden and risk	she was telling me there were two drugs that she wanted him on. And I said to her, 'you know, he's on,' and I went through a few things, and she went, 'Oh. Okay, we better not put him on that.' …. I just said about the other things to make sure that she was aware. And I was glad I did, but the spironolactone I looked it up when it appeared on his prescriptions, and it would have totally… The spironolactone is a diuretic. Now he already goes to loo all night. He hasn't got any swollen ankles, and it pushes your potassium right up and [husband's] diet that he's been on very successfully is absolutely packed with potassium. It means he wouldn't be able to have his banana and yoghurt and granola, nutty granola in the morning (Carer 4, interview)
4. Care co-ordination and collaboration for multiple, interacting issues	I've got the Parkinson's Nurse has been brilliant… she tries to look at him as a whole and she would always ring me back within two or three days, whereas I can't guarantee I'll get an answer from anybody else. I've also got an Admiral nurse now, but the Admiral Nurse and the Parkinson's Nurse don't talk to each other. They're not from the same team. We had an OT [Occupational Therapist] come round earlier on this month and I didn't know where she'd come from. She's part of the community team, but she's taken over from another OT that we saw who came to talk about the hospital bed. They've all been very good, but they keep changing. (Carer 1, interview)
5. Preparation and support to increase the collective capacity of the dyad to self-manage	The reason we want the assessment doing is at nighttime, because during the days he's got the care they're paying for. But at nighttime he's getting up and someone doesn't get sleep. I go over at the weekend, and I don't get sleep… that is absolutely exhausting… if he sleeps, he'll sleep for an hour, an hour and a half, then he's up, wanting to push his team because he thinks he's going to work. So, to me if he just got the night care. Then I'd stop booking everybody because we care for him during the day. Then he's happy at home, we can manage that. He can stay in his own home. (Carer 2, interview)

credible and relevant to their situation. Without evidence of professionals addressing their worries and including their concerns into assessment of needs, onward relevant referrals or care planning, dyads doubted anything could or would be done. This was often informed by previous experiences of services' inaction and a belief that the additional work required to make contact would be pointless. Delays making contact for support where needs had changed and additional input was necessary could result in crisis situations, either for the person with dementia as exacerbation of symptoms were ignored, or for the family carer as they became overwhelmed as the lack of support around the home accumulated (PT1.4). In the literature, interviews and workshops, it was advice from peers and professionals who they had regular contact with that helped legitimise their need and signposted them to available help. When accompanied with advice for how to communicate with the service, carers had increased confidence to seek help (PT1.5). Another enabler identified by service recipients was if the individual practitioners were supportive and able to take action in the past, increasing the likelihood of future contact by the dyad (PT1.6).

Arranging the initial appointment or subsequent engagement with consultations, assessments and decision-making were labour intensive activities. Appointment systems and advice lines involved long waits on the telephone and complicated online triage systems were time consuming and anxiety provoking. Carers spent considerable time organising the logistics of attending appointments and anticipating how disruption to a person's routine could impact consultations, creating an additional emotional burden for the carer and anxiety for the person with dementia of the additional work being generated for the carer. Consequently, carers reported having to persuade and argue with services for accommodations for the dyad's situation, such as being able to book appointments outside of existing systems and requests for home visits (PT1.7). Clinical environments were invariably disorientating for people living with dementia, particularly finding clinics, following instructions when undergoing assessments and protracted waiting times in noisy rooms. Investigations and procedures could be difficult for people with dementia to understand and tolerate, and policies and protocols meant services used to enable access, such as volunteer transport, were poorly linked to the primary service (PT1.8). To mitigate this required the involvement of carers able to anticipate problems and negotiate with people working in services to make access possible. Not all carers had the knowledge or skills to work around these system constraints.

Programme theory 2: Recognition of dementia and the dyad in the system

(Studies = 31)

It is difficult for services to plan for and accommodate dementia and dyads in the system where this information is not documented, their specific needs not acknowledged and there is no expectation that reasonable adjustments will be made (context). Individual staff who understood how to accommodate the dyads' needs and were willing to adapt their approach, the treatment plan and work related to follow up outside of protocols and typical practices (mechanism resource) could create an environment or space to work effectively with dyads (mechanism response) that would be more likely to lead to constructive encounters and completed investigations (outcome).

Studies reported that staff could be unaware a person had dementia, and were even less likely to know how dementia impacted them as existing patient records and communication about patients at the point of referral did not adequately record dementia diagnosis or its effect on the person (PT2.1). Disabilities related to dementia, for example memory impairments or difficulties in planning and organising that impact actions to manage other conditions, could be difficult for professionals to identify in single encounters. Services where there was not an explicit assessment of cognitive abilities, such as memory, needed a carer to provide that information. Without this input, problems were overlooked, and assumptions made about a person's ability to retain and follow advice (PT2.2). Although it is possible to record carer status in medical records and guidance on how to include carers exists (Hanna et al., 2016), we found no evidence of how this information is used in practice. There were individual examples of what was possible when professionals who did understand how the person's dementia affected their ability to be part of care discussions, treatment plans and ongoing contact with the service. They would then use creative solutions and their professional authority to accommodate the person's needs (PT2.3). This included working together to identify preferred appointment times or moving follow-up appointments to telephone or video call consultations and methods for highlighting the diagnosis on patient notes (PT2.4). However, this kind of flexibility was discretionary and difficult to achieve within the structures and capacity of the system, such as targets, waiting lists and protocols.

Where there was recording of a person's dementia in the system, this led to an expectation by the person or carer that professionals would act on this information. Examples from interviews and workshops suggested that to prepare and plan for a person with dementia, services relied on individual professionals employed specifically to work with people affected by dementia, such as Admiral Nurses (PT2.5). For non-dementia specialist services, knowing that the person had dementia was not enough to adapt everyday practice to accommodate the person's needs, such as providing aftercare instructions for cataract surgery in different formats and supporting flexible visiting for carers during hospital admissions. When the carer was recognised within the system, this reduced the likelihood of missed appointments and promoted shared decision making between care partners (PT2.6). There was still an unspoken expectation and reliance that the carer would retain and share information with different professionals, providing the linkage across the health and care encounters. With fragmented data systems, carers reported how their involvement could avoid inappropriate or dangerous interactions between treatments and conditions, a responsibility that placed an additional burden on carers to provide accurate and relevant accounts of the person's case history (PT2.7).

Programme theory 3: Working together to understand and agree acceptable levels of burden and risk

(Studies = 29)

Clinical pathways and treatments can be burdensome and need to be balanced against risks related to inaction and the priorities of the dyad (context). Discussions between care partners that clarify options, likely prognosis and promote the agency of both members of the dyad (mechanisms resource) may help the dyad to feel their priorities have been listened to and feel able to cope with what is agreed (mechanism response). This may create a shared responsibility between the dyad and the system meaning that it is easier for the dyad to live with the uncertainties and potential risks of diverging from recommendations (outcome).

The structure of appointments and consultations often means discussions focus on one aspect of a person's health and care. This had the potential to overlook the priorities and preferences of the dyad and how they might incorporate treatment and lifestyle advice into their day-to-day lives. Consequently, instructions for managing conditions were unrealistic for the dyad to follow (PT3.1). When there was time for discussion and shared decision making on how to manage different care and treatment, plans were more likely to be feasible and adhered to.

The decisional capacity of the person with dementia will change over time and for different decisions. However literature, interviews and workshops highlighted how it was common for the person with dementia to be excluded from decision-making from the point of diagnosis regardless of cognitive abilities; people living with dementia reported being frustrated when professionals made assumptions about their capacity to understand the implications of decisions based on their diagnosis (PT3.2). Studies highlighted that for professionals to involve and include the person with dementia alongside the carer they required skills that could steer conversations and provide debate about options between the person with dementia and their carer using their professional knowledge to support the conversation (PT3.3). Few services or professionals were trained or prepared to work with dyads where one person had cognitive loss. Decision making tools that facilitate the agency of the person with dementia and carer to define their concerns and priorities provided a resource that could structure conversations and help to address implicit power imbalances between carer and patient and the dyad and the professional (PT3.4). Discussions that systematically set out the concerns of each person involved in decision making could also help those involved reach agreement on the way forward. However, some professionals highlighted that they lacked confidence when working with people living with dementia, particularly when answerable to national guidelines for the management of conditions that did not account for multiple, interacting illnesses. This could lead to restricted access to treatments, such as cataract surgery and reluctance to adapt treatment recommendations (PT3.5). For dyads, and particularly the carer, this could lead to treatment plans that they were unable to maintain leaving them feeling anxious and creating conflict as they attempted to fulfil care regimes (PT3.6).

Access to certain services was affected by professionals' perceptions of the burdens to the person or their expectations about how dementia might affect a person's ability to engage with and cope with treatment plans. This was commonly reported in deliberations over aggressive or onerous treatments, such as dialysis or chemotherapy, or when referring to rehabilitation services, for example following a fall (PT3.7). Access to treatments with the potential to improve a person's quality of life through cure or rehabilitation applied if the long-term condition was visual impairment or cancer, often following assessment of risks, best interests and benefits with dyads. When cancer was the long-term condition, this included carers' opinions for quality of life or capacity to care (PT3.8).

Programme theory 4: Care co-ordination and collaboration for multiple, interacting issues

(Studies = 26)

Processes and networks that promote co-ordination and collaboration across different specialities involved with supporting the dyad (context) enable discussion, assessment and learning beyond single condition issues, building working relationships across the disciplines (mechanisms resource) that can encourage proactive and anticipatory approaches centred on the needs of the dyad (mechanism reasoning). This is likely to lead to timely investigations of health concerns and reduce service duplication and unnecessary referrals (outcome).

The complexity of living with dementia alongside other long-term conditions can be understood through use of comprehensive assessments and/or the input from multiple specialists. Studies exploring the potential of multidisciplinary working across different points of conditions trajectories highlighted that the commitment to this approach needed to be embedded in the wider system infrastructure, such as shared care records, planned multidisciplinary meetings, resources to support shared working and learning, and co-location of services (PT4.1). It was thought that use of these approaches would aid primary and community care networks to address people's priorities, reduce treatment burden and reduce inequalities in accessing health care. A lack of co-ordination between services could lead to duplication of work and delays in receiving support as linking to services relied on professionals' knowledge of and networks in the system (PT4.2).

Interviews with professionals highlighted a belief that multidisciplinary approaches with the right mix of representatives could lead to cohesive plans and reduce the burden on dyads to organise and chase provision. However, it was unclear from the evidence what constituted a suitable mix of professionals, how dementia specialists should be included or how the involvement of the dyad should be structured to ensure the dyad's circumstances were adequately considered while not impacting the provision of health and care for other patients in the system (PT4.3). Co-ordination and communication did not necessarily require formal meetings. The literature and stakeholder interviews highlighted how the actions of individual professionals who extended their work and exploited their networks in this way made a difference. This included, initiating contact with other key professionals working with the dyad to link the different aspects of the dyads' circumstances and better inform clinical decision making (PT4.4). Existing professional networks were easier for facilitating timely discussions than when working relationships did not exist. These actions were often prompted by discussions with the dyad during clinical encounters that highlighted existing treatments and care plans from other services (PT4.5). Where the structure of the consultation did not permit carers to share information or provide them with the space to share their experiences beyond the presenting issue, treatment plans could have negative consequences.

Programme theory 5: Preparation and support to increase the collective capacity of the dyad to self-manage

(Studies = 37)

The work of managing progressive long-term conditions becomes increasingly complex and isolating over time (context). Preparation and support that can increase the collective capacity of the dyad to respond to the transitions as conditions progress (mechanism resource) and the capacity of the dyad to accept and incorporate changes to their routines (mechanism response) will impact how long the dyad can self-manage or be supported to manage (outcome).

The dyad is often expected to manage increasingly complex regimes, from the taking of multiple medications at different times of the day and with different administration requirements, to the use of medical equipment to monitor and manage disease progression and recognise deterioration (PT5.1). Dyads without medical or nursing backgrounds often referred to treatments and procedures using medical language, demonstrating an expertise developed over time that could inform care decisions. In interviews and workshops, carers and people living with dementia shared stories of how they had learnt to manage different care tasks and conditions through self-directed research and discussion with others in similar situations (PT5.2). These informal networks of support were often discovered by the work of the carer rather than through connections by services.

Changes to routines for treatments or deterioration in either member of the dyad changed the nature of how self-management was achieved, requiring increased support from the carer and input from formal services (PT5.3). When this change was not anticipated and planned for, this could lead to difficulties. Professionals expressed frustration that the system was organised to respond to crises rather than accommodate brief or incremental changes of circumstances that could help to sustain the dyad's current situation for longer (PT5.4). Studies recommended that regular, planned contact with the dyad by professionals could help to anticipate needs and points of transition, such as needing to alter medications or identify increasing levels of burden early. However, there was limited evidence of systematic (re)assessment of the cognitive and physical load related to self-management, the carer's situation or the support that could be organised (PT5.5).

Stakeholders were acutely aware of the importance of the carer's own health to prevent or delay a change in the dyad's situation. Often this relied on coordinating a carer's use of health and care services with times when they knew the person with dementia would be safe, such as attending day care or during visits from family and friends (PT5.6). Carers reported being unable to attend their own appointments or take other family members they also cared for to check-ups. They worried that without company or supervision, the person could become distressed or put themselves at risk leading to a negative or harmful situation. This meant that as the person with dementia's condition(s) worsened, carers were faced with choices that would impact their own health and financial situation, such as giving up work or funding additional support, a situation that generated inequalities.

The use of professional carers and organisations for specific tasks was dependent on the availability and quality of services in the local area, how the person with dementia's needs were assessed and if it linked to the carers' situation, and whether the dyad could afford any financial costs (PT5.7). Where services were funded through the local authority, service agreements and assessment criteria could either lead to inflexible care arrangements that did not meet the needs of the dyad or were liable to funding being refused. This constant, underlying concern that funded provision would be withdrawn caused considerable anxiety for carers (PT5.8). Some examples in the literature, interviews and workshops reported that the use of home care to manage the increasing burdens often required collaboration between the unpaid and paid carer (PT5.9). Home care organisational policies prevented staff from completing aspects of tasks related to health conditions, such as administering short courses of antibiotics or helping someone with mobility issues to use stairs to access bathroom facilities In these instances, the carer continued to be responsible for these tasks. The availability and proximity of the carer to monitor and, where necessary, assist with completion of these tasks were key, particularly where there were changes to professional personnel and scheduled visits.

Discussion

The realist review of a vast and detailed literature of self-management and caring when living with dementia alongside other long-term conditions addressed how interactions within the dyad effect access to and contact with services to achieve continuity of support, anticipate adverse events and quality of life. Although the literature included people with dementia and/or their carers living with different long-term conditions, we did not identify markedly different experiences by disease type or severity. Even though the focus of the review was on the dyad, how people with dementia understood the relationship was underrepresented in the evidence reviewed and the stakeholder workshops. This was despite their participation in the latter and efforts to give them equal voice. The limited development of different methods of including people with dementia affects how theory is developed due to their perspectives and experiences not being included (Collins et al., 2023).

The five programme theories set out the factors likely to address known challenges related to burden of treatment, overshadowing and recognising the needs of both members of the dyad. These are summarised as: (1) trust that concerns will be listened to with suitable actions taken, (2) the characteristics and needs of dementia and the dyad are known to the system, (3) all care partners understand and agree acceptable levels of burden and risk, (4) responsibility for joining up dyad needs is recognised as a system responsibility, and (5) the collective capacity of the dyad is enhanced by peer support, expertise accrued over time and professional support to anticipate points of change. These five programme theories highlight key considerations for designing health and care systems that can address the predicted needs of the UK's ageing population living with multiple long-term conditions, often in areas of the country where services are less well resourced (Whitty, 2023). These are that systems need to: (i) adapt from patient and single conditions services to ones that can accommodate multiple conditions and patients' support networks, (ii) reduce the reliance on the actions of individual professionals and capacity of dyads to navigate the system by embedding proactive approaches, and (iii) identify ways to reduce duplication and waste to design services that are patient- and carer-focused. Achieving this requires the characteristics and needs of the dyads to be routinely documented and linked across multiple services, including social care, with systems that alert practitioners to additional support needs. The review found that professionals could accommodate and address the needs of the dyad, and in particular how living with dementia complicated access to care. However, this was represented as additional to their core work and not a requirement. The programme theories demonstrate that to achieve and sustain recognition and equitable support for people living with dementia and additional long term conditions and their carers requires a cultural and system change.

Interventions that are likely improve the health and care system, people living with dementia and their carers are well documented in the research literature (Kishita et al., 2018; Laver et al., 2017; Walter & Pinquart, 2020) however the accounts of the experience of care presented here have not radically changed in over a decade (Parker et al., 2011). Examples of good practice were discussed, but these were due to the actions of individual professionals, were part of service configurations for other long-term conditions and were not consistent across the UK. System changes that understand the capacity of the dyad to self-manage and engage during contact with services as well as consideration of the presence of other conditions could improve the experience, coordination and outcomes of care. Examples of how systems can anticipate the pathway and plan the work, exist with cancer and stroke services (Langhorne et al., 2017). Taking this learning to build care systems that can accommodate multiple long-term conditions, particularly when one condition is dementia, will require consideration of structural challenges of planning more efficient services and system integration across health, care and community services.

Consistent with previous research and across stakeholder interviews, workshops and patient and public involvement discussions was the considerable time and effort of the dyad to access and navigate the care they needed, becoming experts in to how navigate and obtain the support needed (Funk et al., 2019). Much of the learning came from informal routes, often peers who had experienced the same problems. Attempts at more integrated care in recent years have tended to focus on commissioning new roles and professionals who can link dyads to relevant services and help them navigate the complexity of the system (Giebel et al., 2023). However, we found professional networks of those providing the roles were limited and 'successful' navigation of the system was often experienced as by-passing appointment and triage practices. The lack of systemic proactive approaches to linking dyads to the support they needed is likely to increase inequalities for those lacking the ability to build effective relationships with people who can fast-track them through the system (May et al., 2016).

Implications for policy, practice, and future research

Recommendations from studies included in this review often suggest small scale changes that would make a significant difference for those working in and using services, such as identifying the person's needs ahead of appointments to anticipate how to accommodate them. However, evidence of where these recommendations had been implemented and been successful were limited. Implementing system change is complex and is often experienced as top down by those working in services. Knowing what 'ought' to happen and the desire to improve services has resulted in a constant cycle of trialling initiatives and interventions that have not challenged wider systems in which services are embedded. Lack of consideration of what needs to be in place to facilitate changes often means the good intentions are short-lived and do not become embedded. This leads to a workforce that is weary and distrustful of new ways of working. Strategies that assess the potential of innovations are needed to take account of factors that affect the impact and sustainability of whole system approaches (Günay et al., 2021).

This review has demonstrated the key elements and principles of dyad focused interventions that are likely to be effective in addressing the impact of living with multiple long-term conditions including dementia. However, it has also shown that to achieve change requires more than knowledge mobilisation. Systems modelling and simulation techniques can draw on routine data to test theories of what works before implementation offer a novel and largely untested approach. By combining the extensive evidence of what could improve access to care with the expertise of disciplines such as health care researchers, systems engineers and mathematical scientists offers a way of anticipating how service innovation might impact health and care systems (Aujla et al., 2024; Newton et al., 2024). By using the evidence presented here of what works and drawing on patient and other relevant data, mathematical models can be developed and computer simulation used to test various solutions at system level.

Limitations

While intuitively better management sustains health and exacerbations of symptoms will challenge continuity of activities that stabilise health, it was beyond the scope of this review to test this assumption. Few studies reported measurable outcomes of how improved access and navigation of services benefitted dyads' health and wellbeing. Instead, reporting was limited to process outcomes that, while important, were unclear if they changed the outcomes for service users. Similarly, claims of what ought to work, such as longer appointments, are untested. However, repeated messages from the literature and stakeholders established that excessive work to gain access to the right professionals was of itself exhausting and could contribute to decline in the health and wellbeing of the dyad, suggesting less burdensome access is beneficial.

While the study focused on the experience of dyads, we were unable to recruit stakeholders as dyads in the time available for theory refinement. The individual voices of people who were part of a dyad did contribute to the theory refinement, but none were from the same dyad. This meant that aspects of shared experiences of service use might only have been represented from one perspective.

Conclusion

This review suggests that, while living with and managing different long-term conditions have their own individual challenges linked to specific tasks, treatments and how a person is affected, the experience of accessing and navigating services is remarkably similar. Despite years of research and service improvement efforts to address complex health and care needs (Bunn et al., 2018; Goodman et al., 2011; Trivedi et al., 2013), for those who are also living with dementia, little has changed. The burden to know where and how to secure necessary support remains the responsibility of the dyad, and, most often, the person's carer. When they do not have the resources to acquire timely support, this negatively impacts both members of the dyad. The sustainability of existing health and care systems in the UK increasing relies on unpaid carers.

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Data availability statement

The search terms and strategies are provided in the Supplementary Material to allow for replication. The data that support the findings of this study are available from the corresponding author, MH, upon reasonable request.

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