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Original Research Article

The fragmentation of health and social care for people with dementia and their carers: An 8-European-country qualitative study

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ABSTRACT

Background: People with dementia and their carers often fail to receive the right care and can be delayed receiving the right diagnosis. A disconnect between health and social care systems and professionals is one of the main reasons. However, it remains unclear how health and social care services fail to connect, and what examples of good practice may support improved care service connectivity more widely.

Methods: This qualitative study involved semi-structured interviews with health and social care professionals, unpaid carers, and people with dementia from eight European countries (Czech Republic, Ireland, Italy, Lithuania, Netherlands, Poland, Portugal, United Kingdom). Data were analysed by six researchers using framework analysis guided by the Dementia Inequalities Model as underpinning theory.

Results: A total of 86 participants took part between October 2025 and February 2026, including health (n = 22) and social care professionals (n = 13), unpaid carers (n = 37), and people with dementia (n = 14). Five themes were generated: (1) Lack of adequate formal structures of connection; (2) Silo working; (3) Lack of knowledge and awareness; (4) Impacts on unpaid carers; (5) Solutions to care fragmentation. There were notable similarities across countries and care infrastructures, including health care professionals often working in silo within their care sector, whilst solutions varied across countries.

Conclusions: This is the first study to have shown detailed care fragmentation in dementia across Europe. Some solutions to support linked up care delivery need to be explored in greater detail, with a potential of adaptation to other country settings.

Introduction

Over 12 million people with dementia live across Europe (Alzheimer [1]), with many more people affected by the condition by providing unpaid care. Globally, over 57 million people are estimated to live with dementia ([2] Dementia Forecasting Collaborators), with numbers continuing to rise. Unfortunately, many people with and those caring for someone with dementia experience inequalities and barriers in

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accessing diagnosis and care [3].

Dementia inequalities can be mapped onto three different levels: individual, social and community, and society and infrastructure, as detailed in the co-produced Dementia Inequalities Model [4]. Individual-level barriers include age, gender, financial and educational background, as well as dementia subtype. Social and community-level factors include living situation (having a carer or not) and stigma within the community. Society and infrastructure-level factors focus on a lack of health and social care professional communication and service linkage, lack of information provision and lack of adequate services to meet the person with dementia's or unpaid carer's needs. Whilst evidence has amply focused on individual-level factors leading to inequalities in diagnosis and care ([5]; Readman et al., under review [6]) as well as community challenges [7], infrastructure issues that go beyond lack of service availability and geographical distance are less specifically evidenced [8,9], especially across different infrastructure contexts, or countries.

Some research has focused on European-wide challenges in dementia care, providing highly useful insights on a comparative level. Schmachtenberg et al. [10] evidenced variations in care provision for dementia across 17 European countries, with Belgium, Greece, Ireland, Portugal, and Romania experiencing different levels of service provision across regions. Moreover, on a healthcare level, Austria, Denmark, and Germany are said to have dementia-specific outpatient services across the country, yet limited inpatient services. Besides the availability of services, or lack thereof, across and within different countries, services where often found to be challenging to access regardless of availability and could also be found to be not dementia-friendly [10]. Service availability and other barriers were also evidenced in a comprehensive multi-angle qualitative study with over 260 people with dementia, unpaid carers, and care professionals across eight European countries [3]. Attitudes towards dementia and services were found to create a barrier towards accessing care, putting the onus on the person themselves to seek care and support. These primary findings were corroborated in a recent systematic review, highlighting similar key barriers in accessing dementia care across Europe [11].

Whilst there is some comparative evidence into service and access inequalities in dementia on a European level, precisely how care services are interlinked or are failing to do so for people with dementia and their carers across a range of countries has received little attention to date. Research from Canada on older adults reported how primary care and community-based social care services were inefficiently linked up, resulting in difficulties in accessing the right care for patients [12]. Findings were corroborated for people with dementia in the same Northern American part of the world. Interviewing 47 stakeholders, including people with dementia, King et al. [13] reported system fragmentation hindering people from accessing care, as well as a lack of adequate services meeting the needs of people with dementia. Poor care coordination has been corroborated by a 10 European country survey with dementia researchers and students as well as consultations with two European-wide stakeholder groups with people with dementia and unpaid carers [5]. However, whilst evidence points to the issue of poor health and social care professional communication and linkage in dementia, to date, no research has evidenced this in detail across multiple European countries, looking at the different elements of potential care fragmentation.

Therefore, the aim of this qualitative study was to provide the first, detailed cross-country evidence on the type and level of (dis)connect between health and social care services for people with dementia and their carers across eight European countries, and identify examples of good practice. Findings from this large qualitative study can support the development of targeted interventions and system changes to improve connectivity between the oftentimes fragmented health and social care systems, utilising effective approaches from one country to modify them for other country settings.

Methods

Design

This qualitative study involved semi-structured interviews, which were primarily conducted remotely via Microsoft Teams.

Participants and recruitment

Eligible participants included people living with dementia (any type and stage of dementia), unpaid carers currently caring for someone with dementia; health care professionals (including general practitioners (GPs), psychologists, psychiatrists, occupational therapists, nurses, and physiotherapists); and social care professionals (including support workers, frontline staff, activity coordinators, managers in home care, day care, respite and residential care settings) from the Czech Republic, Ireland, Italy, Lithuania, the Netherlands, Poland, Portugal, or the UK. These countries and representatives of these countries are part of the INTERDEM Network, a European network of psychosocial dementia researchers. In particular, researchers from these countries are part of the INTERDEM Taskforce on Inequalities. Thus, we have been connected prior to securing funding for this research study. These eight countries complement one another due to their cultural and geographical diversity across Europe, and provide different viewpoints and experiences about different care systems. Participants were recruited via emailing and approaching established support groups for carers, social care organisations, municipalities, social media, as well as via established networks of different stakeholders, such as the Liverpool Dementia & Ageing Research Forum, Meeting Center Wroclaw, Poland, Centre of Gerontology and Czech Alzheimer Society, NGO Demencija Lietuvoje (Dementia in Lithuania).

Data collection

We co-produced two topic guides – one for people with dementia and unpaid carers and one for health and social care professionals. Two skeleton topic guides were developed based on the gap in the literature and informed by the Dementia Inequalities Model [4], which was reviewed by the entire study team, including one unpaid carer. Topic guides included questions on (1) participants' background and experiences of dementia care; (2) perceptions of the adequacy of support, system effectiveness, and training needs; and (3) the extent and quality of integration and coordination between health and social care services, including examples of collaborative practice and service fragmentation. Topic guides were developed in English first and were then translated into Polish, Dutch, Lithuanian, Portuguese, Italian, and Czech. The English topic guides are attached in the appendix.

Semi-structured interviews were conducted remotely via Microsoft Teams or in person, based on the preference of the participants. Informed consent was taken at the beginning of the interview. To ensure that people with dementia had capacity to consent, the researcher asked the person with dementia whether they understood what the study was about and to describe it in their own words, and ensure that the person understood that participation was voluntary and could be stopped at any point without any reason. Interviews were audio-recorded in the language of each participating country and automatically transcribed via Microsoft Teams; all transcripts were then checked against the recordings for accuracy. For non-English-speaking contexts, transcripts were translated into English by the researcher who had conducted the interviews in that country.

Data analysis

Six researchers (CG, MRR, CT, MB, FM, KL) coded the data using framework analysis [14], underpinned by the Dementia Inequalities Model [4]. Given the large sample size, each researcher first coded a

random selection of anonymised transcripts and met to discuss emerging codes. This was to familiarise themselves with the data. We then generated a list of codes, which were non-exclusive and additional codes could be added where necessary. This thematic framework, which was informed by the Dementia Inequalities Model, was used to guide the analysis of the outstanding transcripts, leading to indexing across the remaining transcripts. Researchers met throughout the analysis and discussed the topics and codes, and clustered codes into individual themes, guided by the research question. Transcripts were coded in Microsoft Word using comments to highlight quotes and codes. Researchers extracted key quotes into a table to guide the overall selection of the most relevant quotes for each theme and subtheme, again a necessity given the large sample size.

Ethics

Ethical approval was first obtained from the University of Liverpool ethics committee [Ref: 16256], as the study was led by this University and country. Approved study documents were then translated into other languages, where required, and submitted to the respective University ethics committees for approval to collect data in each country and to then share the fully anonymised data with the lead. Ethics approvals were obtained from Czechia: Etická komise Gerontologického centra; Ireland: Dublin City University Research Ethics Committee; Italy: Comitato di Bioetico dell'Università di Bologna [0410037]; Lithuania: Kaunas Regional Biomedical Research Ethics Committee [BE-2–129, 2025–11–18]; Netherlands: FHML Research Ethics Committee [FHML-REC/2025/118]; Poland: Bioethics committee of Wroclaw University [KB 385/2025]; Portugal: Faculty of Medicine of the University of Porto/ RISE-Health [364/CEFMUP-RISEHealth/2025].

Results

Overview of sample

Eighty-six participants from eight European countries took part in this study across 84 interviews, with two interviews being conducted with an unpaid carer and partner with dementia together (thus two dyadic interviews) in the Netherlands. This included 22 health care and 13 social care professionals, 14 people with dementia, and 37 unpaid carers. Interviews per country ranged from six (Italy) to 17 (Lithuania). Participants were on average 52.3 (+/- 16.3) years old [Range: 23–89]. The majority of participants were female (n = 64; 74.4%) and White Caucasian (n = 77; 94.1%). An overview of the sample characteristics by role (person with dementia, unpaid carer, health or social care professional) is provided in Table 1. Table 2 provides an overview by country, to demonstrate the variation in roles and backgrounds by county.

Qualitative findings

We generated five themes with different subthemes: (1) Lack of adequate formal structures of connection; (2) Silo working; (3) Lack of knowledge and awareness; (4) Impacts on unpaid carers; (5) Solutions to care fragmentation. Quotes are displayed in Table 3 by theme and subtheme.

Lack of adequate formal structures of connection

Formal structures and legislation. Across countries, there appears to be a lack of any formal guidance or infrastructure that clearly connects health and social care services for people with dementia. Participants could name several difficulties in how health and social care were connected, whilst there was no reference to any formal infrastructures or connective pathways that would enable health and social care professionals to work together.

Moreover, in some countries, especially in the Netherlands, legislation was considered a challenging hurdle to overcome when trying to access care. Some legislation from local, municipal, and country-level service and finance provision was at odds with one another and professionals and carers were confused about where and how to access care. This bureaucratic burden highlighted how systems could be at odds with one another, highlighting a lack of adequate connection on this higher system level.

Even when the correct professionals are in place, UK and Portuguese settings for example were reported to be continuously understaffed both in the health and social care sector, so that adequate link up between both sectors often fails.

Onus on individuals

Both care recipients and care professionals across different countries, including Poland, Czech Republic, Ireland, and Lithuania expressed that the onus to provide all support and link up was often placed on a single care professional. This was predominantly the GP. Many carers and people with dementia considered their GP to be the one point of contact that should know everything about the dementia and what to do next. Due to a lack of adequate service connectivity and structures in place, professionals were thus sought out to provide this critical linkage. However, in many cases this did not happen, as care professionals did not connect or did not know how to connect people with a diagnosis with appropriate next steps and services.

This perceived responsibility for care coordination was not only limited to primary care but extended across other professional roles in specialist settings. This reflects a broader systemic reliance on individual practitioners to bridge gaps in provision. For example, a psychiatrist in Lithuania described how the boundaries of clinical responsibility became blurred, with an implicit expectation to assume responsibility for broader social care needs:

Unpaid carers often had to play the connector between the individual with dementia and care providers. This required the unpaid carer to be proactive and actively engage with services and seek advice about the dementia and support available. Thus, not having an unpaid carer could make navigation of services more difficult. Unpaid carers having to act as communication bridge was not unique to any country, but was apparent across countries.

Table 1
Participant characteristics by background.

	People with dementia (n = 14)	Unpaid carers (n = 37)	Health care professionals (n = 22)	Social Care professionals (n = 13)	Total sample (n = 86)
Age	71.6 (+/-14.5) [47–83]	59 (+/-15.4) [23–89]	40.7 (+/-9.8) [27–59]	45.8 (+/-9.1) [30–56]	52.3 (+/- 16.3) [23–89]
Gender					
Female	6 (42.9%)	29 (78.4%)	18 (81.8%)	11 (84.6%)	64 (74.4%)
Male	8 (57.1%)	8 (21.6%)	4 (18.2%)	2 (15.4%)	22 (25.6%)
Ethnic background					
White Caucasian	10 (83.3%)	32 (94.1%)	22 (100%)	13 (100%)	77 (95.1%)
Other	2 (16.7%)	2 (5.9%)			4 (4.9%)

Table 2
Participant background by country.

Country	Sample size	Role (n)	Gender (female n (%))	Age [Mean(SD)]
Czech Republic	10	PLWD = 2 Unpaid Carer = 3 Health care professional = 4 Social care professional = 1	6 (60%)	54.00 (16.90)
Ireland	10	PLWD = 3 Carer = 6 Health care professional = 1	6 (60%)	Not reported
Italy	6	PLWD = 1 Unpaid Carer = 2 Health care professional = 4	4 (66.67%)	54.33 (21.57)
Lithuania	17	Unpaid carer = 8 Health care professional = 4 Social care professional = 4	17 (100%)	48.44 (9.51)
Netherlands	12 (n = 14, with 2 dyads)	PLWD = 2 Unpaid carer = 6 Health care professional = 4 Social care professional = 2	9 (75%) (note gender not specified for n = 2)	58.22 (18.34) (note not specified for 3 participants, including 2 dyads)
Poland	7	PLWD= 2 Unpaid carer = 1 Health care professional = 1 Social care professional = 3	4 (57.14%)	58.71 (22.24)
Portugal	10	PLWD = 2 Unpaid carer = 2 Health care professional = 4 Social care professional = 2	9 (90%)	51.30 (18.37)
UK	12	PLWD = 2 Unpaid carer = 7 Health care professional = 1 Social care professional = 1 Third sector professional = 1	8 (66.67%)	51.92 (17.65)

Note. PLWD = People living with dementia

Table 3
Quotes by themes and sub-themes.

Theme	Sub-theme	Quotes
(1) Lack of adequate formal structures of connection	*Formal structures and legislation*	*"I think people often feel lost, so I'd say no (about receiving adequate support). So, as we're even talking about coordination between services, I think it often depends a lot on the goodwill of the professional they're dealing with to be able to navigate the various types of support effectively, both in terms of health and social services. (…) Because there doesn't seem to be a more formal protocol."* ***Portugal ID10, health care professional*** *"And also with the case managers, there are always a few case managers who supervise that, the whole conversation. And they also sometimes disagree with each other, no then you have to do this, no then we have to go there, you have to do it this way. But above all, start on time. Really three, four months in advance, before you need something, you really have to get it arranged."* ***Netherlands ID12, unpaid carer*** *"so I think at the bare bones they've got the equipment to do it, they've got the professionals to do it but how they actually, I think the number of professionals probably is an issue as ever when it comes to NHS and social care. You know everyone's understaffed as far as they're concerned and I find that we can have waits of up to 2 years to speak with a social worker about a specific patient."* ***UK ID01, pharmacist*** *"The main problem is that my colleague (a social worker at a main hospital), however much she wants to help, is simply too overloaded."* ***Portugal ID03, health care professional***
	Onus on individuals	*"doctors, for example, should know that there is such a place as the meeting center, as nursing homes, both day and full-time, where they could also direct caregivers"* ***Poland ID01, music therapist*** *"The doctor is there, buried in the computer, and maybe she doesn't really explain what this is about or what you're entitled to"* ***Lithuania ID10, Unpaid carer*** *"You are supposed to be a doctor, you are supposed to do your direct work: treatment, differential diagnostics, … prescribing medication, but in* reality you are doing social work in such a ward. It is emotionally difficult, and there is really a lot of this kind of demand that this person with social problems is your problem and you should solve everything" **Lithuania ID04, health care professional** *"Of course, you'd want as little running around as possible, because these things … say, you go to the family doctor, then you go to specialists, then you go somewhere else, and on top of that you're going together with a person who has Alzheimer's … well, those things are not simple."* ***Lithuania ID10,***

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Table 3 (*continued*)

		unpaid carer
		"It's been difficult. Luckily enough, because of my working experience I was able to navigate the system and I already had a lot of information about services, things and how to ask for support or so." ***UK ID12, Carer***
	Referral breakdowns	*"I didn't even realise until several months later that, there's actually a huge gap there in the post-diagnosis support."* ***Ireland ID07, unpaid carer***
		"at the neuropsychology clinic many services do not even know they exist, so they make a generic referral with the words: cognitive stimulation activities are recommended, but not in such a service, or perhaps Alzheimer's coffee, day center" ***Italy ID06, Psychologist***
		"the time that he was hospitalised and it took forever. Absolutely forever to try and get him out of hospital. Because there was no, we had to wait for the care package because it was at that point that I was no longer able to really look after him because he needed a bit more care than I could give, and that was a struggle. So I would say we had to wait in hospital, he was in hospital probably about three months when he shouldn't be." ***UK ID08, unpaid carer***
(2) Silo working	Silo working	*"I believe that from a medical standpoint they're getting the right care, from a social standpoint it's really tricky for me to say anything other than no. So some people do but we see all sorts of horror stories and trying to fight to get them the appropriate care that they need is really challenging because you're trying to get, they never, social care never try to communicate with us and try to or when they do it's because they've decided that they're going to do the medical decision and that we need to treat them for a Urinary Tract Infection (UTI), God damn UTIs and people blaming it for everything."* ***UK ID 01, pharmacist***
		"As far as social workers' documentation is concerned, I have no idea if they make any records, how it works, I have no insight into that at all. In fact, it's not connected at all" ***Czech Republic ID05, doctor***
		"If you ask for something extra, they get annoyed, and it doesn't always work out. Of course, as I say, it's harder for a social worker, then we contact the relative and ask them to speak, because the doctor isn't willing to talk with us. And sometimes it's the opposite: they call, you know, and say, 'we were at the doctor, our doctor isn't listening, maybe you, as social workers, try,' so all sorts of situations happen." ***Lithuania ID02, home care worker***
		"the healthcare and social systems are mostly not connected. So when a patient with dementia goes to the doctor, there are usually no social workers there, just the doctor or a nurse." ***Czech Republic ID05, doctor***

Table 3 (*continued*)

		"So, in Portugal, my feeling is that everything is very fragmented [in what regards care and information], and people feel this fragmentation in their day-to-day lives; there needs to be greater coordination." ***Portugal ID01, social care professional***
	Lack of signposting	*"I would say it wasn't easy, like you really had to search for what to do, how to find the things they want from you… where exactly… hmm, but then again, maybe it was also because when you don't have experience with it or something, you don't know where to turn."* **Czech Republic ID02, unpaid carer**
		"You go everywhere yourself, you look for everything yourself" **Lithuania ID12, unpaid carer**
		"I quite dislike working independently, and having asked several social workers, "Could you explain to me the whole special needs procedure, so I can just make templates?" Such very clear paper guidelines, step-by-step explanations, would really be desirable, and, you know, not a single social worker helped me with this issue. …But such information, even in leaflet form, I haven't seen anywhere, and it is necessary. It is necessary for those people who want to raise the question of where to place their parents." ***Lithuania ID04, health care professional***
		"There is no communication. There are two separate services, 2 separate systems. They are funded different, like it's entirely different and there's no shared link communication link between them at all." ***UK ID11, unpaid carer***
		"you need signposting, you need somebody at the other end to sound reassuring, calm you down, ask what's going on and try and get you some help. But that doesn't happen with dementia." ***UK ID03, unpaid carer***
		"If the right help isn't always given or sign posted early enough It's not until there's a safety element or a danger element that the decisions are made for you, or for families." ***UK ID09, social care worker***
(3) Lack of knowledge		*"I feel like there is ageism here, like if this was a younger person in that situation, maybe someone would care more. Whereas actually she's 90. It's like, oh, well, So what? Like she's either going to move into a care home or die soon anyway"* ***UK ID11, unpaid carer***
		"Yes, hospitals in general, well how to say, well, I understand, the workload in a hospital is large, I understand everything, but the attitude towards an old person is, you know, shocking. That most often it's like: "What can you do, an old person, let them die…" Well no, we cannot be like that." ***Lithuania ID07, Senior Social Worker***
		"I think there needs to be a cross-disciplinary approach here. I think this training should start right from

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Table 3 (*continued*)

		the family doctors. Because when families first notice the changes, they don't rush straight to a neurologist or a psychiatrist; they go to their family doctor. So, this awareness needs to start right with the family doctor." ***Portugal ID07, social care professional***
		"I had to fight for every piece of information I got… And you were given no lead. So I have to say that from then on, everything that was done for [my husband] was led by our family… And every… Very, very little. Great sympathy now, you know, from the GP and everything but there was nobody pointing us in services, or… for example, going to, to Dublin, to one of the specialist clinics, was never mentioned." ***Ireland ID05, unpaid carer***
		"come to think of it I don't know how I would engage with them [social care]. Whether I would then need to get a referral from the GP for her to access or if there is maybe a team that I need to liaise with in the local authority for her to. And I guess that's where we get to the point of crisis." ***UK ID11, unpaid carer***
		"there is little knowledge available. And this is something that appears very often, that in fact the only places where these people find out where to get funding, how to arrange a decision, how to arrange funding, that there is respite care at all, they find out in the support group from other caregivers. They learned a lot about this by accident, or again from some friend. So this knowledge is very low, it's also fragmentary." ***Poland ID02, person with dementia***
(4) Impacts on unpaid carers		*"because the worst is this: if you have children, grandchildren who support you, OK, but when you are alone where do you hit your head? That is, I say, if I stop, what happens here in this house?"* ***Italy ID03, Carer***
		"I, for example, was running home during my lunch break, coming back, feeding him, and then running back again, but all the time you're on edge" ***Lithuania ID10, Carer***
		"Myself and my sister at this point, are literally vibrating, not knowing what's going on. Feeling like we're not being listened to, feeling like we're not being believed, feeling like we're mad. Because really, it's so strange, the things we're saying. That it feels like we're just kind of being… Being dismissed, and that…" ***Ireland ID07, Carer***
		"But, sometimes I don't know whether it's because maybe I am very self-sufficient and very independent, so I don't always ask. But to be honest with you, I I've had to do an awful lot of chasing and getting things, getting diagnosis corrected, getting medications corrected. I think if you was a person on your own it must be very difficult." ***UK ID12, Carer***
		"I also think that, in bureaucratic terms, there's a lot that's always far too long and difficult for people to deal with, especially as these people are in such a vulnerable position. I often feel that they don't even bother applying for certain forms of support (such as informal carer status) or using certain services, because they think it's all going to be so difficult – and it already is so difficult." ***Portugal ID08, Health care professional***
(5) Solutions to care fragmentation	*Solutions to care fragmentation*	"linked us to the case manager. Which is connected to their practice. Well that lady comes every two or three months. We do this in consultation, always make a new appointment. And we just have a very nice contact with them. And so far that is the only care we receive from someone external." ***Netherlands ID12, Person with dementia and unpaid carer***
		There would have to be one person to guide people. Maybe a nurse who would visit people, or someone at the primary care clinic who would tell people what to do. People have to find out everything themselves. I still have my daughter, but if I were alone, I wouldn't find that information. It seems to me that people in Poland don't really know what forms of care exist." ***Poland ID07, person with dementia***
		"Maybe just a person that would say, OK, this is where we are. This is what this is, what you need to do and these are the people that you can get in touch with and the and sort of like know what you need because I don't know. I didn't know what I needed. […] At the moment, you know, you've got your social worker, you've got your occupational therapist, you've got your memory, nurse, you've got your care providers. You've got the GP, you've got, they're all. They're all there. But there's nobody sort of like telling you know the full picture." ***UK ID08, unpaid carer***
		"It would make a huge difference to have someone who, in a way (…) someone to manage my case. Someone to act as a link, someone to help me get in touch with both the social services and the health services… and that's why I think there's a real need for that role [of a case manager]. In other words, someone who ultimately helps the family navigate the healthcare and social services systems, knowing what kind of support is available (…) but without having to go from one place to another, without having to be burdened with more bureaucracy." ***Portugal ID10, Health care professional***
		"And because we are a gerontology center and we work with a range of services, this interconnectedness is normal for us. If something like this existed everywhere, it would be better covered." ***Czech Republic ID04, nurse***
	Third sector / non-profit organisations	*"And he went there [Alzheimer's cafe], And that was when we suddenly started getting help and*

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Table 3 (*continued*)

	information.… he just went there, maybe once a week, or maybe twice a week. They had, you know, they sang and did things like that that interested him. But they followed his progress. And their note-taking was exemplary." ***Ireland ID05, Carer***
Multi-disciplinary team working	*"I think one team handling everything would be ideal, where a person enters one system with home care, both social and medical. That would be ideal. And then who does what, because now there's some duplication."* ***Lithuania ID13, unpaid carer***
Training for paid and unpaid carers	*"I have the impression that there is a lack of this awareness at this basic level of doctors who primarily take care of these patients, often for many years, that they probably don't have such knowledge, awareness."* ***Poland ID01, Social care professional***

Referral breakdowns

Diagnosis was described as a critical transition point requiring coordinated support; however, many participants reported limited continuity into post-diagnostic care, with formal support pathways and handover to social care being unclear and lacking. This often left people with dementia and families feeling as though they were left to manage on their own during a period when guidance and follow-up support was expected. Participants often characterised this period as marked by a gap in ongoing support provision, reflected in accounts of delayed realisation that appropriate support was not in place.

In addition, referral processes were frequently described as generic and insufficiently operationalised, with limited clarity regarding how, or where, to access appropriate services. In practice, this often resulted in broad recommendations that did not translate into clear pathways of care.

Unpaid carers and people with dementia could evidence severe difficulties surrounding hospital discharges. For many, no care plans or adequate handovers were in place to enable the person with dementia to be either safely discharged into their own home with social care provision, or into a care home. Carers could feel reluctant to have their relative with dementia suddenly enter a care home, when they were living at home before the hospital stay. This could cause distress to carers, and the need to swiftly find a suitable care home.

Silo working

Care services and practitioners were mostly reported to work in silo, within their team and/ or within their care service and sector, not allowing for easy cross-over and link up between health and social care. This could cause difficulties in connecting between care sectors and allowing for patient/client information to be passed on from health to social care professionals, or vice versa. Some examples included challenges in communication between professionals, reluctance to engage across sectors, and difficulties coordinating clinical and social support needs.

These challenges were described as bidirectional, in which there were reports of both health and social care professionals struggling to engage with one another. Some care professionals have witnessed frustration and annoyance, with a notable lack of sufficient social care provision evidenced for example in Lithuanian and Czech care settings, especially where the person with dementia then required to be linked up with social care.

Across interviews, there was a clear sense of frustration with current systems and a willingness to engage more collaboratively. Participants called for improved communication within and across sectors, shared guidance, and clearer pathways across services.

Lack of signposting

Carers and people with dementia from different countries often complained about the lack of signposting to suitable services. This responsibility was primarily considered to be the role of the health care practitioners or GPs, as carers and people with dementia did not know where to access support from.

However, health care professionals were often unable to signpost people with dementia or their carers to suitable services for lack of knowledge about where to signpost to. Some care professionals even asked for clear guidance and routes to social care, but were not provided with them, making it challenging to effectively support people affected by dementia.

A lack of signposting has also led to people reaching crisis point. This could be avoided by ensuring carers and people with dementia know how to access community-based care provision, such as admiral nurses, domiciliary care, or support groups, from the point of diagnosis. However, a lack thereof leads people to not receive the care they need, deteriorate faster and result in poorer health outcomes.

Lack of knowledge and awareness

Health and social care staff perceptions, and attitudes towards dementia were often described as shaped by ageist assumptions and limited awareness across care contexts. At times unpaid carers perceived that people living with dementia were treated as though they were less deserving of active intervention, with advanced age contributing to a sense that decline was inevitable and care efforts were less meaningful. This was reflected in accounts of dismissive attitudes within healthcare settings, where older patients could be viewed as beyond help rather than in need of continued support.

Gaps in knowledge and training were also identified, particularly at early points of contact such as family doctors, who are often the first professionals approached by families noticing changes. A lack of cross-disciplinary awareness and education could therefore limit timely recognition and appropriate responses to dementia.

There was also a notable lack of knowledge about social care services and how to access them. Unpaid carers across different countries often did not know how to engage with social care services or professionals in the first place, and thus struggled accessing social care, such as social workers or home care, without any guidance or support. Unpaid carers had to work hard to obtain any information about what services were available and were frustrated by the lack of support.

Impacts on unpaid carers

Caring for someone with dementia, especially as the condition progresses, places growing demands on the carer. In addition, experiencing difficulties in accessing the right care services and having to support the person with dementia to navigate the system was found to be challenging and burdensome by unpaid carers.

Carers often felt lost and were unsure what to do or where to go or who to speak to get more information and support. This was not restricted to individual countries, but experienced across the Czech Republic, Italy, the Netherlands, Poland, Ireland, Lithuania, Portugal, and the UK. Whilst unpaid carers can often be on their own having to manage the care and care navigation, even where unpaid care was shared amongst family members, the same feelings of distress and lack of support were experienced.

Some care professionals also recognised the impacts on unpaid carers. There is widespread recognition that navigating the care systems can be difficult and is oftentimes impeded by bureaucracy, including long form completion to access support, including financial means. Reducing these challenges and form completion, which can be time consuming and detract from the time needed to care for the relative with dementia, was considered important to create more accessible care systems that interconnect.

Solutions to care fragmentation

Across countries, some existing solutions or practices were mentioned that helped to support the connectivity and access to connected care services for people with dementia and carers. In the Netherlands and the UK for example, care coordinators or link workers were found to support people affected by dementia access care, by providing a consistent point of contact from the point of diagnosis.

In many cases, this solution does not exist (yet), but carers and people with dementia as well as care professionals have expressed a desire for a single point of contact to help navigate the care system. This would help reduce unnecessary burden on carers to identify suitable services and care settings themselves.

Meeting centres and well-connected gerontology centres were mentioned by some health care professionals in Poland, Italy, and the Czech Republic as one way to connect care services and enable people with dementia to receive more linked-up support.

Third sector / non-profit organisations

Third sector and non-profit organisations were frequently described as offering a point of entry into care and information that was not readily available through formal health systems, particularly at earlier stages of need. Participants highlighted how community-based initiatives, such as dementia cafés, could provide both social engagement and ongoing monitoring, creating supportive environments that respond to individual interests while also tracking changes over time. Such organisations were therefore seen as bridging gaps in formal provision and were highly valued by carers and people living with dementia.

Multi-disciplinary team working

Multidisciplinary team (MDT) working was commonly discussed in relation to improving coordination and reducing fragmentation in dementia care. Participants often expressed a preference for more integrated models of support, where a single team could oversee both health and social care needs. This was seen as a way of improving continuity and avoiding duplication across sectors.

Training for paid and unpaid carers

Many participants highlighted a lack of training for paid (health and social care professionals) and unpaid carers, which could contribute to difficulties in navigating the link between health and social care services. One way to address this would be to provide targeted training for carers and care professionals about what services are available and how to access these. This would address some of the issues raised concerning carers placing the onus often on the primary care professional they are familiar with – the GP.

Discussion

This is the first study to document the detailed fragmentation of health and social care in dementia across Europe, as well as some system-level solutions to tackle this disconnect and create better service linkage and access. Based on diverse experiences from people directly affected by dementia, caring for someone with the condition, and those providing professional health or social care, dementia care was found to be highly fragmented and disconnected across all eight countries (Czech Republic, Ireland, Italy, Lithuania, Netherlands, Poland, Portugal, United Kingdom).

Across all countries, there appeared to be a lack of formal structures that effectively linked up health care services, including GPs, physiotherapy, psychology, inpatient and outpatient hospital services, with social care providers such as day, home, respite, and residential care. Considering the high levels of care needs in dementia as the condition progresses [15], and not having access to social care further increasing unmet care needs [16], it is critical for formal guidance and infrastructures to be in place connecting health and social care. This advances previous limited evidence from five North American jurisdictions in Canada, which found equally disconnected care systems for people with dementia [13]. King et al. [13] specifically found that care providers often struggled understanding their roles in supporting people with dementia, therefore failing to connect. There were also tensions noted between clinical and non-clinical care providers due to a lack of collaborative pathways. With a prior dearth of knowledge about the care system linkage in Europe, the present study thus identifies areas of care fragmentation, specifically for dementia.

In light of the lack of clear structures linking up health and social care services across countries such as Italy, Poland, and Czech Republic [17], the onus is placed on the individual to navigate the care system and find the right care and support. Many people with dementia and unpaid carers perceived that their family doctor or GP should have that responsibility and is thus failing to provide adequate care. This was corroborated by various health care professionals across different countries, reflecting the impression that GPs, the care professional people tend to see the most, is responsible for navigating people through the care system once a diagnosis is made by professionals. Research from different countries and care systems into the expectations and perceptions of GPs roles indicates strong variations, with an overall lack of sufficient support provided by GPs [18,19]. Whilst GPs across different practices in California for example considered themselves an important professional in providing care, they were often constrained by system-level issues [19]. By contrast, in Portugal, GPs did not consider themselves to have a core role in providing or signposting to dementia care [18]. As opposed to GPs, primary care nurses in England felt they had a substantial role in supporting people with dementia and their families in navigating the system and in providing care and support where possible [20]. Given the hierarchy of general practice, and frequent lack of resources and adequate knowledge about dementia, primary care nurses often faced challenges in providing suitable care for those with dementia, however. Considering the vast amount of knowledge required to adequately support someone with dementia, a targeted professional role, such as trained primary care nurses, would therefore be one suitable solution.

Indeed, dementia link workers have been evidenced in some countries including the UK as a solution to improve care service linkage and access to care. To date, evidence to the effect of dementia link workers is sparse [21]. Albeit limited evidence exists, findings from the US, Germany, the UK and Netherlands [22-26] do indicate the benefits of dementia link workers in helping to support and connect people with dementia and their family carers with services and information, whilst also providing a single point of contact. Limited economic evidence exists, which is restricted to the US care system [26], indicating lower total cost of care compared to usual care. Link workers therefore seem a suitable, and likely cost-efficient solution, as they are not necessarily clinically trained, unlike Admiral nurses (specialist dementia nurses) for example [27], thus reducing the costs of such roles. Whilst limited other solutions have been discussed by participants, such as Meeting Centres [28], solutions are lacking and link workers appear one of the more promising avenues to pursue.

Without identifying, testing, and implementing these and other possible solutions to address care fragmentation, unpaid carers remain having to carry out additional caring duties and roles by helping people with dementia to navigate the care system. Unpaid carers across all countries highlighted their strains in needing to identify the best ways to access care, besides already providing care and support to their relative. Outside of this role, unpaid carers often face high levels of carer burden [29] and unmet care needs [30], especially when the person with dementia is in the more advanced stages and closer to care home admission [31]. Therefore, ensuring clear coordination between health and social care will not only benefit the person with dementia directly, or the care professionals by knowing how to better liaise and connect, but also the many unpaid carers looking after people living with dementia. In some cases, where systems fail to connect, third sector and non-governmental organisations may be able to fill some of those roles and address some

unmet needs, although there should be no system reliance on third sector providers.

Limitations

This qualitative study benefits from having collected data from eight European countries and from multiple stakeholder groups (people with dementia, unpaid carers, health and social care professionals), with a large sample size. Given the eight different countries and languages, one limitation is the number of researchers who conducted the interviews, as this may have led to some inconsistencies in conduct despite the provision of a semi-structured interview topic guide. Moreover, data had to be translated into English, without back translation. This may have affected the standard of English and thus apprehension of translated interviews, with possible nuances in languages having been lost in translation. Considering the sample itself, whilst the study as mentioned benefitted from a large sample size for qualitative research, the number of participants per country was ten or below. Given the wide variety of circumstances and geography within countries, views will not be exhaustive for each country, but instead present a sample of experiences. Similarly, social care professional views were relatively underrepresented compared to health care professional views. Future research should explore issues in the care fragmentation of dementia in greater detail in each country and across similar regions of Europe, for example in Eastern or Southern Europe. Lastly, also considering the sample itself, ethnic variation was limited. The majority of participants were White Caucasian, which fails to account for evidenced ethnic challenges in accessing dementia care [32,33]. Future research needs to specifically assess care fragmentation from a migration and minority ethnic viewpoint. Aligned with this demographic characteristic, no reference to rarer dementia subtypes, such as primary progressive aphasia, frontotemporal dementia, or Parkinson's disease dementia, were made by participants. Future research also needs to specifically focus on how care fragmentation is affecting those living with and caring for someone with a rarer subtype of dementia, so non late-onset Alzheimer's disease dementia.

Conclusions

This is the first study to have shown care fragmentation for people with dementia and their unpaid carers across Europe, pointing to various types and levels of failed connections, resulting in continued barriers to accessing necessary care and placing unnecessary additional demands on unpaid carers. Whilst interviews in each country are not always representative of the entire country, the variety and number of interviews clearly shows the size of the problem of care fragmentation in dementia. This requires urgent attention, including by national policy makers to embed clear guidance and system infrastructure to connect health and social care services better. Future research needs to generate evidence on some of the discussed or existing interventions/solutions in individual countries to support improved health and social care integration, which can have implications that go beyond dementia, but will be relevant for other clinical populations also.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix

TOPIC GUIDE for health and social care professionals

O READ TO THE PARTICIPANT AHEAD OF THE INTERVIEW. "We know that people living with dementia and their carers often experience difficulties in accessing the right care and support. We would like to talk to you about your experiences and views, both good and bad, how health care services, such as doctor or hospital services, and social care services, such as home care, day care, respite care, and nursing homes, deliver linked up care and support for people with dementia and their carers.

We are interested in how these services are connected, or not, and what can be done to improve their linking up. It may be that there are positive examples from one country that could give ideas for adaptation for other European countries."

1. What is your professional background and in what capacity do you work with people with dementia or their carers in health or social care settings?
2. What have been your experiences of accessing social care (such as day care, home care, or residential care)? Do you feel you have received any guidance or support from health care providers?
3. Do you feel that people with dementia and their carers receive adequate support? If not, could you elaborate please where any shortcomings are?
4. Do you think the health and/or social care system is equipped well enough to support people with dementia with their needs? Do you have any examples?
5. What do you think are the training needs for health and/or social care professionals on dementia?
6. Are you aware of any ways in which people with dementia or their carers are connected between health and social care providers/professionals?

7. Do you work closely and collaboratively with other professionals / organisations as part of a bigger team with health/social care? If so, is this occasional or routine?

If YES
7.1 Could you tell me a bit about how that works?

1. In your opinion, what would good integration between health and social care services look like?
2. Can you tell me about a time when a lack of coordination between services may have affected care/working practices?

TOPIC GUIDE for people with dementia and unpaid carers

TO READ TO THE PARTICIPANT AHEAD OF THE INTERVIEW. "We know that people living with dementia and their carers often experience difficulties in accessing the right care and support. We would like to talk to you about your experiences, both good and bad, of accessing health care services, such as your doctor or hospital services, and social care services, such as home care, day care, respite care, and nursing homes.

We are interested in how these services are connected, or not, and what can be done to improve their linking up. It may be that there are positive examples from one country that could give ideas for adaptation for other European countries."

1. What were your experiences in receiving care professional support from the point of diagnosis?
2. What have been your experiences of accessing social care (such as day care, home care, or residential care)? Do you feel you have received any guidance or support from health care providers?
3. What are your experiences of engaging with health care professionals? How do you feel you have been supported?
4. What are your experiences of engaging with social care professionals? How do you feel you have been supported?
5. What are your experiences of trying to navigate between the health and social care system and services?
6. Have you experienced any challenges in accessing care services (health or social care) throughout your / your relative's dementia journey?
7. Thinking about your experiences of accessing care after the diagnosis, were you/was your relative directed towards specific care services or professionals? For example, was there one person in particular who helped you to get the services you needed?
8. In your opinion, what would an ideal and coordinated care system look like?
9. How do you feel health and social care professionals communicate with one another?
10. Is there anything about your experiences with health and social care services that you would like to see improved?
11. Is there anything else that is important to you that we have not covered yet?

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