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Long-term health conditions and their impact on people with sleep disturbances and dementia

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Abstract

Background Sleep disturbances are common for people with dementia and can be distressing for them and their family. People with dementia live with an average of five other long-term conditions (LTCs). Little is known about the impact of LTCs on dementia and sleep. We aimed to explore this within the DREAMS START (Dementia Related Manual for Sleep; Strategies for relatives) trial of a multi-component intervention delivered to family carers, to consider how symptoms of LTCs impacted on carer ability to implement DREAMS START intervention strategies.

Method We conducted a qualitative interview study recruited participants from the intervention arm of the DREAMS START trial in English NHS sites. Participants were 17 family carers of people with dementia, other LTCs and sleep disturbances. We used a semi-structured topic guide and conducted interviews, analysed using reflective thematic analysis.

Results We identified two overarching themes. Firstly, there was a complex interaction of LTCs, sleep and dementia. LTCs including pain, interacted with dementia symptoms to worsen sleep and physical symptoms. Carers reported dilemmas about whether to give analgesia, primarily understanding their relatives' sleep disturbances in terms of dementia diagnosis. Secondly carers were exhausted from lack of sleep and physical health difficulties made it harder to, for example, increase daytime activity for their relative.

Conclusions There is a complex relationship between LTCs, dementia and sleep and the effect of LTCs in someone with dementia may be underestimated. It is important that families know that people with dementia need adequate analgesia. In addition, tiredness and illness in family carers may mean they need support to implement strategies, or they will be unable to break the cycle of exhaustion.

Keywords Dementia, Sleep, Carers, Pain, Diabetes, Qualitative, Long-term conditions

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Introduction

The number of people living with dementia worldwide is projected to rise from 57 million in 2019 to more than 150 million by 2050 [1]. In the UK, the number of people living with dementia is estimated rise to 1.7 million by 2040, which is approximately double the number in 2023 [2]. Sleep disturbances occur in over a quarter of people with dementia living at home, and are related to brain changes, mood disturbances, daytime inactivity and long-term conditions (LTCs) [3, 4]. Sleep disturbances in people with dementia include waking up at night, day/night reversal, distress behaviours at night and excessive daytime sleepiness [5]. Since most people with dementia are looked after at home by family, sleep disturbance can also negatively impact the carer's sleep and wellbeing [6]. Family carers (referred to as carers in the rest of this paper) report being woken at night by people with dementia, having trouble falling sleep after being woken, and high levels of daytime fatigue [7, 8].

People with dementia have complex health needs, and most are living with multiple additional illnesses [9–11]. LTCs are defined as health conditions with no cure and that impact on a person's day-to-day life [12], but that may often be managed by medications [13]. In a recent UK study, people with dementia had a mean of 4.6 other LTCs in addition to their dementia [14]. Living with multiple LTCs alongside dementia is associated with lower quality of life [15], worse prognosis and clinical presentation [16] and increased service use and associated costs [17, 18]. As is the case with sleep disturbances in dementia which can have multiple and interacting underlying causes, interactions between LTCs and dementia are complex and have been theorised to be impacted by multiple factors including lifestyle, social, environmental, carer/family, mental health, physical health, polypharmacy, and severity and type of dementia [19, 20]. People with multiple LTCs often have sleep disturbances [21–25], and individuals with more LTCs have more disturbed sleep [26]. This relationship may be bidirectional as these illnesses and associated pain may cause or contribute to sleep disturbances [27, 28], and prolonged sleep disturbances could increase the likelihood and severity of symptoms of LTCs [21, 29]. Additionally, increased pain associated with many LTCs can be difficult to identify when people are living with dementia and is often inadequately treated. Family carers face significant challenges in how to recognise pain and manage pain medication for their relative, reporting hesitancy or deviation from prescribed medication plans [30], which may in turn further impact on management of sleep disturbance.

Potential interactions between dementia and LTCs may result in greater illness burden for people with dementia and their carers [31]. Carers whose relatives needed support to go to the toilet in the night or who had recently

fallen, had worse sleep [6]. Sleep disturbances in people with dementia predict the breakdown of care and care home admission, and physical illness may also increase the likelihood of the people with dementia moving into a care home [6, 32].

Tackling sleep disturbances is therefore important not only for people living with dementia but also for their carers. Non-pharmacological approaches are recommended as first-line treatment for sleep disturbances for people living with dementia ([33, 34]. Medication brings risks of drug interactions and side effects in people prescribed multiple medications; this is particularly relevant to those living with multiple LTCs [35–37].

Building on our earlier successful feasibility RCT [3], we recently completed randomised controlled trial (RCT) of DREAMS START (Dementia Related Manual: Strategies for Relatives), a multi-component non-pharmacological intervention aimed at improving sleep disturbances in people with dementia delivered to their carers [38]. DREAMS START is a six-session, manualised (facilitators work through a manual personalising the content to the unique needs of the recipient) intervention delivered by supervised, non-clinical graduates to carers. Strategies are tailored and include increasing comfort, light exposure, increasing routine, relaxation, activity, looking after yourself and making a future action plan. It helped both people with dementia and their family carers' sleep compared to usual treatment [39]. It addresses the multiple potential causes of sleep disturbances in dementia; however, it was not specifically developed to address the interplay between dementia and LTCs and we are unclear how the presence of additional LTCs may impact on how the intervention is experienced and implemented.

To our knowledge, no previous research has sought to understand the impact of LTCs on the relationship between dementia and sleep and how this may relate to interventions. We aimed, in this qualitative sub-study of the DREAMS START trial, to explore carers' experiences of their relative's sleep disturbances in the context of LTCs, and how it affected implementation of intervention strategies to improve sleep.

Methods

Design

We conducted a qualitative, semi-structured interview study, with a subsample of carers who participated in the DREAMS START RCT.

Ethics

London (King's Cross) National Research Ethics Service approved the DREAMS START RCT (reference: 20/LO/0894) on 21st August 2020 and a substantial amendment to conduct this sub-study was approved on 6th June 2022. All participants gave written or verbally recorded

informed consent prior to interviews. All participants had capacity to consent to participate.

Settings and participants

We invited family carers of people with dementia with LTCs who participated in the intervention arm of the DREAMS START RCT to take part in the sub-study after completing 8 m follow up assessment (trial protocol and results are reported elsewhere [38]). Trial inclusion criteria were that the participants with dementia (any type and severity) had to score 4 or more on the Sleep Disorder Inventory (SDI) [40], had a sleep problem which they or their carer found was a problem, and that they lived at home with someone present at night. For this study, we defined an LTC as any condition that has no cure, but that can be managed by medication, such as diabetes, high cholesterol and high blood pressure, heart conditions, or arthritis (Rookes et al., 2022). We used medication lists of participants with dementia, collected as part of the trial, to identify those being potentially treated for LTCs; an approach taken in previous studies [41, 42]. All participants with dementia prescribed ≥ 5 medications were eligible, and then their carer was invited to participate. We aimed to recruit a diverse sample in terms of carer and people with dementia age, ethnicity, and familial relationship. We included completers and non-completers of the DREAMS START intervention. We aimed to include completers and non-completers of the intervention as we were interested in whether people did not complete the sessions as a result of their own or their relatives' LTCs and the impact upon engagement and completion of the intervention and experience of its suitability.

Data collection

We gave carers a choice of where to be interviewed face-to-face in participants' homes or university premises, or remotely by phone or video call. AB conducted interviews using a semi-structured guide developed by the research team (see Appendix A) which focused on carers and their relative's experiences of LTCs, the extent to which these affected relative's sleep and their own sleep, and how LTCs impacted on their experience and engagement with DREAMS START. We ceased interviewing when we reached thematic sufficiency, the point at which no new themes emerged from the data [43]. Interviews were audio recorded, transcribed verbatim, anonymised and entered into NVivo 12 software. We also included data pertaining to LTCs from a separate sub-study of the main trial, aimed at widening South Asian carer's access to the trial and intervention (referred to as the widening access study in the rest of this paper).

Data analysis

We adopted a reflexive thematic analytic approach using the six step approach of identifying themes and patterns within the data, considering research positionality and context [44]. To incorporate reflexivity AB and MM kept diaries during data collection, documenting how their personal and professional characteristics may be affecting interview responses, and this was actively discussed with the wider team [45]. The six stages of our analysis proceeded as follows, although the process was iterative rather than linear. Step 1: Familiarisation with the data: Before and during the analysis, AB and MM listened to audio recordings of the interviews, read and re-read the transcripts, checking against the recordings in order to increase familiarisation. PR, GL and LW additionally each read at least 25% of the transcripts. At this stage we all made notes on our initial thoughts from the transcripts. Step 2: Coding the data AB independently and systematically coded each transcript into meaningful fragments labelling initial codes. LW coded 25% of the sample at the initial coding stage and used then an initial coding framework was developed by AB and LW based on the research questions of the study This was reviewed and refined by the wider team and AB then revisited the transcripts to align the coding within the coding frame. Step 3 Combining codes into themes and reviewing (Step 4): GL, PR, SA, LW and AB met regularly to develop overarching themes, AB and LW developed initial themes related to the research questions and would bring these to meetings where we would further refine as a team and resolve any discrepancies, revising iteratively, during this process and alongside the written drafting of this paper (Step 6) we named and defined our themes (Step 5). We adopted this reflective team-based approach, ensuring that each team member was involved in each step of the process to increase the credibility and dependability of our analysis [46, 47]. To contextualise our sample and analysis AB extracted from interview data the number of LTCs both the carer and the person with dementia were reportedly living with (see Appendix B).

In terms of researcher reflexivity, interview data for this study was collected by AB and MM, young women with a psychology degree from South Asian backgrounds, neither were qualified clinicians or healthcare professionals. This may have impacted on how participants related to them during the interview, especially when discussing health related issues, something we took into consideration during our analysis. During our team-based discussions, we would situate our conversations to recognise the different perspectives we were bringing for example as practicing clinicians (GL and PR) and would reflect on our different roles within the project team.

Table 1 Characteristics of people with dementia and their family carers

ID	Relationship	Carer sex	PLWD sex	Carer ethnicity	PLWD ethnicity	Carer age	PLWD age	PLWD admitted in care home at time of interview (Y/N)	Type of dementia diagnosed	Severity of dementia (CDR)	Number of medications prescribed	List of prescribed medications
Daughter 1	Child	F	F	British	Black/Black British	61	87	N	Alzheimer's Disease	Moderate	7	Amlodipine Atorvastatin Co-tenidone Lansoprazole Memantine Metformin Ramipril
Daughter 2	Child	F	F	Black/Black British	Black/Black British	-	94	N	Vascular Dementia	Severe	11	Aspirin Amlodipine Bimatoprost (eye drops) Doxazosin Insulin Melatonin Omeprazole Pregabalin Procyclidine Risperidone Rivastigmine
Daughter 3	Child	F	F	White British	White British	49	87	Y	Alzheimer's Disease	Moderate	5	Lactulose Memantine Nitrofurantoin Paracetamol Risperidone
Husband 1	Partner	M	F	White British	White Other	74	75	N	Alzheimer's Disease	Mild	7	Donepezil Gliclazide Insulin Melatonin Memantine Mirtazapine Venlafaxine
Daughter 4	Child	F	M	South Asian	South Asian	53	87	Y	Alzheimer's Disease	Mild	5	Famotidine Ferrous fumarate Levetiracetam Promethazine Senna
Sibling 1	Sibling	F	F	White British	White British	89	89	Y	Alzheimer's Disease	Moderate	6	Cholecalciferol Ferrous fumarate Lansoprazole Mirtazapine Paracetamol Prednisolone

Table 1 (continued)

ID	Relationship	Carer sex	PLWD sex	Carer ethnicity	PLWD ethnicity	Carer age	PLWD age	PLWD admitted in care home at time of interview (Y/N)	Type of dementia diagnosed	Severity of dementia (CDR)	Number of medications prescribed	List of prescribed medications
Wife 1	Partner	F	M	East Asian	South Asian	71	73	N	Alzheimer's Disease	Moderate	8	Atorvastatin Bisoprolol Clopidogrel Donepezil Isosorbide Losartan Memantine Risperidone Apixaban Atorvastatin Bisoprolol Cephalexin Paracetamol Temazepam Trimethoprim
Son 1	Child	M	F	White British	White British	45	87	N	Vascular Dementia	Severe	7	Apixaban Atorvastatin Bisoprolol Cephalexin Paracetamol Temazepam Trimethoprim
Wife 2	Partner	F	M	White Other	White Other	74	83	N	Vascular Dementia	Moderate	5	Apixaban Amlodipine Atorvastatin Bisoprolol Lansoprazole
Wife 3	Partner	F	M	South Asian	South Asian	83	93	N	Alzheimer's Disease	Mild	5	Fluticasone propionate Insulin Paracetamol Tamsulosin Vitamin B12
Son 2	Child	M	F	White Other	White Other	58	87	N	Alzheimer's Disease	Moderate	5	Apixaban Levothyroxine Macrogol Paracetamol Zopiclone
Husband 2	Partner	M	F	Black British	Black British	88	86	N	Alzheimer's Disease	Mild	5	Aspirin Cholecalciferol Ferrous fumarate Quinine Simvastatin
Daughter 5	Child	F	F	White Other	White Other	36	79	Y	Alzheimer's Disease	Moderate	6	Badlofen Donepezil Hypermellose (eye drops) Memantine Omeprazole Promethazine

Table 1 (continued)

ID	Relationship	Carer sex	PLWD sex	Carer ethnicity	PLWD ethnicity	Carer age	PLWD age	PLWD admitted in care home at time of interview (Y/N)	Type of dementia diagnosed	Severity of dementia (CDR)	Number of medications prescribed	List of prescribed medications
Husband 3	Partner	M	F	White British	White British	70	70	N	Vascular Dementia	Mild	5	Amlodipine Atorvastatin Clopidogrel Donepezil Losartan
Wife 4	Partner	F	F	White British	White British	78	78	N	Unspecified dementia	Very mild	5	Alendronic acid Atorvastatin Clopidogrel Donepezil Vitamin B12
Husband 4	Partner	M	F	White British	White British	79	77	N	Alzheimer's Disease	Very mild	5	Amoxicillin Donepezil Diprbase Paracetamol Vitamin D3
Son 3	Child	M	M	South Asian	South Asian	63	96	N	Dementia with Lewy Bodies	Mild	16	Aspirin Cholecalciferol Fencino (fentanyl) patch Ferrous sulphate Glizade Hyromellose (eye drops) Lactulose Mirtazapine Nebivolol Omeprazole Paracetamol Perindopril erbumine Primidone Senna Simvastatin Tamsulosin

PLWD = Person living with dementia; CDR = Clinical Dementia Rating Scale

Results

Study participants

Between September 2022 and August 2023, we identified 38 DREAMS START intervention arm carers who could potentially participate in this study, 14/38 consented and participated from sites in London, Essex and Sussex. 18 reported being too busy or not interested, 4 too busy caring for their relative who was unwell, and 2 agreed to be interviewed but did not attend on the day. We also included data from 3 carers interviewed for the widening access sub-study.

Of the 17 interviewed, 15 carers had completed all 6 intervention sessions, 1 withdrew prior to the 1st session and 1 withdrew after the 1st session. People with dementia and their carer's characteristics are presented in Table 1 below. Carers reported that their relatives had an average of 5.6 (range = 2–10) LTCs. The most common conditions were diabetes, cardiovascular including high blood pressure and high cholesterol, issues with mobility, arthritis, mental health issues such as anxiety and depression, and pain. Three of the carers interviewed also mentioned their own health conditions during the interviews.

Qualitative findings

Qualitative findings are organised into two overarching themes highlighting the complexity of the relationship between LTCs in dementia and sleep, and how these impact DREAMS START implementation.

Theme 1: complex interaction of LTCs, sleep and dementia

LTC symptoms impact on sleep disturbance

Carers repeatedly highlighted how the consequences of LTCs, such as pain and incontinence directly impacted their relative's sleep. Pain often interfered with people with dementia being able to fall asleep or woke them during the night, a daughter, caring for her mother with Alzheimer's disease explained.

I mean, there's the back pain... yeah, it has happened that she complained about having pain, especially before going to bed. Daughter 5.

It is difficult to ascertain whether incontinence experienced by people living with dementia is due to their diagnosis of dementia, a separate LTC, or a combination of the two. Nevertheless, this symptom was described by carers as extremely disruptive to the person with dementia's and often the carer's sleep. Some carers experienced their relative waking up multiple times to go to the toilet or needing assistance with cleaning themselves and changing bedding, as explained by a wife caring for her husband with moderate Alzheimer's disease.

[incontinence] happens sometimes in the middle of the night, that's terrible, it takes one and a half to two hours to give him shower, to clean him and then clean all the beddings. Wife 1.

LTC symptoms and dementia-related symptoms interact to worsen sleep

Carers described a 'perfect storm' of interaction between sleep issues, LTCs and dementia, which compounded the health burden experienced by people with dementia and carers. Carers attributed nighttime waking of people with dementia to their LTCs combined with dementia. For example, one daughter explained that her father, who has dementia and diabetes, would get up in the night looking for food, whilst also lacking awareness of his condition.

So, my dad, he has Alzheimer's and he's diabetic so at night-time, he'd get up several times during the night looking for food or just wandering around, he'd go downstairs and also, he's at high risk of falling. Daughter 4.

A son described how his mother walked around her house at night until completely exhausted, which he thought was due to the dementia and associated restlessness. This constant moving worsened the pain because of her arthritis which made her more restless.

Lately, there's been a lot more wandering at night, so she will just literally wander around the house continuously. And all the aches and pains that probably come with arthritis, and pain, and whatever else comes with... the pain triggers the dementia, which triggers the pain. Son 1.

Dementia as the primary reason for sleep disturbances

Often carers did not connect their relative's sleep difficulties to their physical health, framing their relative's difficulties in terms of the behavioural and cognitive symptoms of dementia. Carers would often talk about how there seems to be 'nothing wrong' with their relative physically or would minimise physical symptoms, which may impact on how they choose to manage these problems and the complex interaction between them.

I don't think the other health issues [are impacting on sleep] they're more physical or mechanical, I call them... So, in a physical kind of way, she's not doing too bad. But yeah, it's the- it's the mind, you know. Son 2.

Carers often attributed sleep difficulties to dementia, and not the LTCs or pain. For example, one wife, caring for her partner, felt that the pain that their relative was

experiencing with a hernia and arthritis, but not prescribed pain medication, had less impact on sleep than the dementia had despite their relative reporting pain.

Within the last few weeks, she has had extreme pain, was bent over double in pain... It's very intermittent, it sometimes keeps her awake at night, I think it's not too bad. Sometimes, well, she will say- this is because she has problems with her hips as well. That, and I just think the fact that she just doesn't sleep very well sometimes. It is almost exclusively to do with the dementia. Wife 4.

The dilemma of medications

Carers discussed the dilemmas they faced in terms of medications prescribed to their relatives both for sleep and for pain and other LTCs, highlighting that medication for dementia, sleep and LTCs often does not help or produces side effects. Carers felt they bore responsibility of weighing up the risks and benefits of medications, especially for medications prescribed 'as needed,' particularly for painkillers, as this son explained.

It does help her get off to sleep for a few hours. But I notice that if she has it for two or three days running... her daytime behaviour just changes. She becomes more confused. She's looking a bit more lost... Last night, I didn't give her any medication at all because I saw that she was a bit confused. I thought I'm going to give her a couple of days off. But then, you know, I have a night which is just absolutely terrible. And I'm exhausted. Son 2.

The challenge of weighing up the relative risk and benefits of medication for pain was exacerbated by people with dementia being unable to clearly recognise or communicate their level of pain. Carers reported advice which they experienced as conflicting from doctors, so felt they had to make the decision for themselves based on trial and error. One daughter explained that despite receiving professional advice regarding pain management for her mother's pain, she chose not to follow it for fear of her mother becoming addicted to painkillers, potentially leaving pain untreated which impacted on her mother's sleep.

Because if she gets codeine once a day, and with the paracetamol three times a day, that may well work for her, but I don't want to give that to her on a daily basis... I'm sure that the consultant at the pain management clinic will tell me that she should take it on a regular basis, but I've got to balance- I've got to live with her, I've got to balance that out if she gets

hooked, that's going to irritate her mood. Daughter 2.

Theme 2: LTCs get in the way of implementing DREAMS START

People with dementia's physical health interferes with implementing DREAMS START

People with dementias' physical health symptoms sometime impeded carers trying out DREAMS START strategies. Some people were not physically mobile, or experienced pain while moving, which was a barrier to increasing their physical activity or accessing natural light, although chair-based exercise and phototherapy (bright light) lamps were provided as part of the intervention. These were not always used by carers. One son, caring for his father who was prescribed 16 medications and living with dementia with Lewy Bodies commented:

But yes, a lot of this... quite a few of the things that are mentioned in the books and the sessions, my dad could not really do because of his age- he's quite elderly- and he's not that physically mobile... I mean for us it's, you know, if there was anything physical, that was in the in the booklet- say if it's walking for... daily walks or physical exercise- my dad couldn't do that. Son, 3.

We had the [phototherapy] light. I would have loved that to have really worked but it was so bright you know... but it was just too bright for her, and she has macular degeneration. Daughter 3.

Impact of LTCs makes behaviour change challenging

DREAMS START is delivered to carers so that they can support their relative to make changes to improve sleep, or they can implement changes themselves, such as changes to bed and rise routines. When people with dementia had additional health conditions, requiring care and support, carers felt this added to the challenge of caring. This was especially so for children caring for parents with dementia, where there was a shift in the power and dynamics in relationships.

As far she is concerned, I am basically telling her what to do, and she doesn't like it. When she should eat, when she wants to eat when she pleases, and I say we have to keep an eye on her diabetes and blood sugar... sometimes, I have to use stronger measures, and so I say, "No, come on. You have to move. You have to- you've got to do this; you can't do that." Daughter 2.

Carers sometimes worried about people with dementia's complex health needs impacting engagement with DREAMS START

Many carers reported their own sleep was disturbed by worry and anxiety about their relative's complex health needs. They reported being constantly vigilant in case their relative woke again, especially in the context of previous falls. This would then negatively impact their day-to-day functioning, mood, and energy levels. This was especially so for the older, spousal carers, who more often had their own health conditions. Carers sometimes found their role in putting DREAMS START into practice burdensome.

...even when she is asleep, there's this constant worry, so I struggle to fall asleep at the same time. So, it's just a mixture of everything. So, yeah, it does affect my sleep. Once they started sending through- "can you fill this in, can you fill that in," and, you know, everything in the night, tracking your sleep, I just didn't have time. Son 1.

Carers also found that the more tired they felt, the less effectively they implemented strategies.

The reason why they're probably not as effective as they should be is that sometimes...it's- because strategies- because I find that when I need to do it [implement strategies from DREAMS START], I'm so extremely tired. Husband 1.

Carers health impacted on implementation of DREAMS START

Carers having poor health, such as living with diabetes or cancer, impacted how able they felt to implement the strategies from DREAMS START. One daughter reported difficulty in doing anything on top of the housework, such as helping her mother be more active during the day.

If I wasn't diabetic [and] so tired, then there'd be more I could do, or- I'm just- you know, as I said, I wake up and I'm tired, and I just want to go back to bed... when I've finished with the work, all I want to do is just go in my room and go to sleep. Daughter 1.

A son who was living with cancer reported similar issues with implementation due to disrupted sleep.

I'd be getting out of bed at half 6, maybe having had half an hour to an hour's sleep, and then you got the whole day ahead and you're dealing with my own illness and all the things that need to be done in a normal day... and to be honest, there was a couple of

times when I couldn't do it [DREAMS START]. Son 2.

Discussion

Main findings

To our knowledge, this is the first qualitative study to explore the intersection of LTCs, sleep and dementia. In our analysis we consider how these factors interact and are experienced by carers providing care for relatives living at home. We also explore how these factors impacted the DREAMS START sleep intervention. For carers, the presence of additional LTCs added to the challenge of sleep disturbances in their relatives with dementia and often meant they faced dilemmas regarding medication and symptom relief, how to respond in the night and how to reduce potential risks, such as of falling. Our findings align with others about the effects of pain [27] and incontinence [48] on sleep for people with dementia and highlight how carers own sleep is affected, which can also lead to anticipatory worry and difficulty getting back to sleep after care is delivered [6]. Carers explained how the interaction of dementia and LTCs is particularly marked in relation to sleep disturbance and illustrated the associated greater burden and worse quality of life in people with dementia and carers [15, 16]. As most of the carers were living with their relatives, they were likely to be disturbed at night and it was common for carers to talk about their own sleep being disturbed. Carers of people living with dementia are known to have worse sleep than age matched non carers, and this may be more marked for female carers who were a majority of our sample [49]. Female carers may be more likely to deliver personal and practical care and support due to additional social expectations, especially for those with higher levels of dependency [50] and in the context of additional LTCs this may be intensified.

Carers tended to conceptualise symptoms of LTCs and dementia as distinct, potentially overlooking the impact of LTC symptoms and the complex interactions between LTCs and dementia and attributing the primary cause of sleep disturbance to dementia. Additionally, people with dementia are less able to recognise and communicate physical unmet needs, and they may be overlooked [51]. These findings have implications for how these potentially treatable symptoms may be undertreated. Combining a biomedical and a psychosocial approach increasingly underpins multicomponent approaches [52, 53], including DREAMS START [38]. Dunn et al. (2022) present a syndemic (synergistic-endemic) framework which highlights that conditions do not exist in parallel but are experienced through interacting factors, with greater consequences than singular conditions in isolation. They refer to interacting factors of dementia type and severity, the carer and family, polypharmacy, physical

health, mental health, environmental, social and lifestyle factors [19]. This aligns with our findings which elucidate the complexity of factors underpinning the interaction of sleep, dementia and LTCs although carers often presented more unidimensional explanations which led to more limited opportunities for strategies and potential action. The DREAMS START intervention incorporates all of the different factors included in Dunn's conceptual model and through the development of personalised strategies there is potential to tailor and target the intervention, including those with additional LTCs.

DREAMS START intervention reduced sleep disturbance in both people with dementia and carers in the intervention versus usual treatment arm, yet this sub-study highlighted challenges for carers of putting DREAMS START into practice in the context of multiple LTCs. The pervasive nature of exhaustion amongst carers, many of whom had their own health conditions, was striking, and for many got in the way of them having the energy or patience to facilitate behavioural changes and make decisions in relation to their relative's sleep. Research has identified carers with worse sleep tend to have lower scores on tests of 'fluid' cognitive functioning, including processing speed, which has implications for how carers can perform complex tasks in relation to their relatives or their own functioning [54]. Our findings align with this and reiterate the importance of carers making time for themselves and focusing on ways to improve their own sleep in order to continue to support their relatives, a key focus of the DREAMS START intervention.

Strengths and limitations

People with dementia usually live with multiple LTCs with 80% reporting an average of 3.8 additional diagnoses [14] and it is important to explicitly consider this, as we did in this study. As we were recruiting from an existing RCT population we were not able to separately analyse those with a particular type of dementia, severity of dementia or taking particular medications and their complex interplay. Instead, we focused on the lived experiences of family carers and how this impacted on how they implemented DREAMS START. We plan further work exploring the specific needs of those living with Dementia with Lewy Bodies or Parkinson's disease who have higher levels and sometimes differing symptoms of sleep disturbance and experience more physical symptoms than those with Alzheimer's disease [4]. A limitation was that, to reduce burden on people with dementia and carers we did not routinely collect detailed medical history or measure pain in the trial. Additionally, all of those interviewed were recruited from the South of England and in total this was a relatively small sample of 17 family carers of people experiencing sleep disturbances who had engaged in the DREAMS START

intervention, potentially limiting the transferability of our findings [47]. We were unable to explore differences between groups of carers with different characteristics, for example child versus partner carers, and although not an objective of our research, we did not identify any patterns in our dataset. As this was a sub-study from a larger existing trial and we did not want to over-burden existing participants, we attempted to adopt a position of 'methodological pragmatism' making decisions collaboratively and transparently within the team, informed by what would provide the best answers to our research questions but also what was workable in practice [55].

Clinical implications and future directions

Our findings emphasise the need for clinicians and services to consider the impact of LTCs upon sleep in dementia routinely identifying and addressing potentially treatable symptoms. Interestingly, although prompted, carers did not have suggestions about adapting the intervention to account for the presence of additional LTCs, possibly because it is already considered within the intervention. DREAMS START has content on how to recognise pain and discomfort and adapting strategies for those less physically able. We plan future implementation research work which will include codesign workshops with those affected by dementia, sleep disturbance and LTCs to use the findings from this study to develop additional strategies to enhance the applicability of those living with additional LTCs. Future research work could also look at augmenting interventions, with potential additions for those for whom it is needed, for example combining with existing app-based interventions for managing pain [30]. We would recommend that clinical services discuss the presence and impact of LTCs with carers at the outset; and how the person with dementia may not identify pain or ask for analgesia. We would also suggest that in scaling up DREAMS START in clinical services, facilitators are provided with additional training and therapeutic strategies for overcoming barriers to behaviour change experienced by carers; and reiterating to carers what additional care and support may be available including assistive technology to reduce the impact of LTCs on sleep or related issues such as incontinence and falls. This implementation approach, whereby there is a process of dynamic learning and problem solving to address particular needs of populations and contexts [56] is one we have successfully adopted in previous knowledge translation and implementation work, where we have made peripheral not core changes to interventions to ensure sustainable implementation [57, 58]. An area for future research work would be exploring how passive technological interventions, such as bed sensors and minimally invasive ways to monitor sleep and movement may be a useful adjunct to multi-component

interventions such as DREAMS START and we are hoping to soon begin testing a minimally invasive wireless EEG headband, suitable for home use.

Conclusions

There is a complex relationship between LTCs, dementia and sleep. It is important that families know that people with dementia may not ask but still need medication for pain or strategies to manage incontinence. It can be explicitly discussed that needing analgesia is not the same as addiction. In addition, tiredness and illness in family carers may mean they cannot implement strategies to improve sleep and may need support to do this or they will be unable to break the cycle of being too tired to act and then not sleeping. This qualitative sub-study deepens our understanding of the interacting effects of dementia and LTCs on sleep disturbance and when considered alongside our DREAMS START RCT findings has potential to enhance applicability of the intervention for those with multiple LTCs alongside dementia in future implementation in health services.

Abbreviations

DREAMS START	Dementia Related Manual: Strategies for Relatives
LTCs	Long term condition
NICE	National Institute for health and care excellence
RCT	Randomised controlled trial

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12877-025-06045-x>.

Supplementary Material 1

Supplementary Material 2

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Author contributions

All authors made a substantial contribution to this work. PR and A.B drafted the manuscript. All authors were involved in revising the manuscript, giving final approval of the version to be published and agree to be accountable for all aspects of the work. A.B and M.M collected the data, and all authors contributed to the qualitative data analysis. G.L, PR and S.A conceived of the study and acquired funding and S.A and L.W supervised the delivery of the work.

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Data availability

Anonymised data will be available on request from the corresponding author.

Declarations

Ethical approval and consent to participate

London (King's Cross) National Research Ethics Service approved the DREAMS START RCT (reference: 20/LO/0894) on 21st August 2020 and a substantial amendment to conduct this sub-study was approved on 6th June 2022. This study was performed in accordance with the declaration of Helsinki and research was conducted in accordance with the protocol approved by the ethics committee. All participants gave written or verbally recorded informed consent prior to interviews. All participants had capacity to consent to participate..

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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