British Journal of General Practice

Sleep disturbance in dementia or mild cognitive impairment: a realist review of general practice

Aryankhesal, Aidin; Blake, Jessica; Wong, Geoff; Megson, Molly; Briscoe, Simon; Allan, Louise; Broomfield, Niall; Eastwood, Zenahrai; Greene, Leanne; Hilton, Andrea; Killett, Anne; Lazar, Alpar; Litherland, Rachael; Livingston, Gill; Maidment, Ian; Reeve, Joanne; Rook, George; Scott, Sion; Um, Jinpil; van Horik, Jayden; Fox, Chris

DOI: https://doi.org/10.3399/BJGP.2023.0171

To access the most recent version of this article, please click the DOI URL in the line above.

Received 05 April 2023 Revised 14 September 2023 Accepted 23 October 2023

© 2023 The Author(s). This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 License (http://creativecommons.org/licenses/by/4.0/). Published by British Journal of General Practice. For editorial process and policies, see: https://bjgp.org/authors/bjgp-editorial-process-and-policies

When citing this article please include the DOI provided above.

Author Accepted Manuscript

Sleep disturbance in dementia or mild cognitive impairment: a realist review of general practice

Authors:

Aidin Aryankhesal: BSc, MSc, PhD, Senior Research Associate, School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, UK, ORCID: 0000-0002-6695-227X

Jessica Blake: BA, MSc, Senior Research Associate, School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, UK, ORCID: 0000-0003-4819-0029

Geoff Wong: MA, MBBS, FHEA, MD(Res), FRCGP, Associate Professor of Primary Care, Nuffield Department of Primary Care Health Sciences, Oxford University, Oxford, UK, ORCID: 0000-0002-5384-4157

Molly Megson: MSc, Research Associate, Academy of Primary Care, Hull York Medical School, University of Hull, Hull, UK, ORCID: 0000-0003-3291-5961

Simon Briscoe: PhD, Research Fellow, University of Exeter Medical School, Exeter, UK, ORCID: 0000-0002-6982-4521

Louise Allan: PhD, Professor of Geriatric Medicine, University of Exeter Medical School, Exeter, UK, ORCID: 0000-0002-8912-4901

Niall M Broomfield: BA, PhD, ClinPsyD, Professor of Clinical Psychology, Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich, UK, ORCID: 0003-2599-3435

Zenahrai Eastwood: MBBS, AFHEA, Junior Research Associate, Faculty of Medicine and Health Sciences, Norwich Medical School, University of East Anglia, Norwich, UK, ORCID: 0000-0002-1863-9991

Leanne Greene: BSc, MSc, PhD, Senior Research Officer, Department of Rehabilitation, Aged and Extended Care, College of Medicine and Public Health, Flinders University, Australia, ORCID: 0000-0002-5383-4362

Andrea Hilton: PhD, PGCert, Reader and Programme Director, Faculty of Health Sciences, School of Paramedical PeriOperative and Advanced Practice, University of Hull, Hull, UK, ORCID: 0000-0001-7264-0857

Anne Killett: EdD, PGCert HEP, MA, Dip COT, Associate professor in occupational therapy, School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, UK, ORCID: 0000-0003-4080-8365

Alpar S. Lazar: BSc, MSc, PhD, Associate Professor, School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, UK, 0000-0003-3147-8229

Rachael Litherland: BA, MSc, Director, Innovations in Dementia, Exeter, UK, ORCID: 0009-0003-9747-6207

Gill Livingston: MBChB, FRCPsych, MD, Professor in Psychiatry of Older people, Faculty of Brain Sciences, Division of Psychiatry, University College London, London, UK, ORCID: 0000-0001-6741-5516

Ian Maidment: MA, BPharm, PhD, Professor in Clinical Pharmacy, Aston Pharmacy School, College of Health and Life Sciences, Aston University, Birmingham, UK, ORCID: 0000-0003-4152-9704

Joanne Reeve: FRCGP, PhD, GP and Professor of Primary Care, Academy of Primary Care, Hull York Medical School, University of Hull, Hull, UK, ORCID: 0000-0002-3184-7955

George Rook: BA, Lead, Lived experience of Dementia, UK

Sion Scott: MPharm, PhD, Lecturer in Behavioural Medicine, School of Healthcare, College of Life Sciences, University of Leicester, Leicester, UK ORCID: 0000-0001-7669-0632

Jinpil Um: PhD, Programme Manager, University of Exeter Medical School, Exeter, UK, ORCID: 0000-0002-6314-0508

Jayden van Horik: PhD, Clinical Trial Manager, University of Exeter Medical School, Exeter, UK, ORCID: 0000-0002-8319-911X

Chris Fox: MB BS Bsc MD MRCPsych Mmedsci, Professor of Clinical Psychiatry, University of Exeter Medical School, Exeter, UK, ORCID: 0000-0001-9480-5704

Corresponding author:

Chris Fox

Address: College House, University of Exeter, St Luke's Campus, Heavitree Road, Exeter,

EX1 2LU, UK.

E-mail: Christopher.Fox@exeter.ac.uk

Abstract

Background

Sleep disturbance (SD) is a prevalent condition among people living with dementia (PLwD) or mild cognitive impairment (MCI). Its assessment and management within primary care is complex due to the comorbidities, older age and cognitive impairment typical of this patient group.

Aim

This study aimed to explore how primary care clinicians assess, understand, and manage SD for PLwD or MCI; if and why such initiatives work; and how people and their carers experience SD and its treatment.

Design and setting

A realist review of existing literature was conducted in 2022.

Methods

Six bibliographic databases were searched. Context-Mechanism-Outcome Configurations (CMOCs) were developed and refined.

Results

Sixty records were included from 1,869 retrieved hits and 19 CMOCs were developed. Low awareness of and confidence in the treatment of SD among primary care clinicians and service users, combined with time and resource constraints, meant that identifying SD was difficult and not prioritised. Medication was perceived by clinicians and service users as the primary management tool, resulting in inappropriate or long-term prescription. Rigid nursing routines in care homes were reportedly not conducive to good quality sleep.

Conclusion

In primary care, SD among PLwD or MCI is not adequately addressed. Over-reliance on medication, under-utilisation of non-pharmacological strategies, and inflexible care home routines were reported due to low confidence and resource constraints. This does not constitute effective and person-centred care. Future work should consider ways to tailor the assessment and management of SD to the needs of individuals and their informal carers without overstretching services.

Keyword

Cognitive dysfunction, Sleep wake disorders, Primary health care, Family practice, Community health services, Caregivers

How this fits in

Existing literature reports that the management of SD among PLwD or MCI is a challenging problem. This realist review indicates why, how, and in which circumstances primary care is hindered when managing SD in this population. Medication is often considered the primary management option due a range of complex factors, despite limited efficacy and problematic side effects. Alternative management techniques, including evidence-based non-pharmacological strategies tailored to the individual and their carer/s, may improve SD within this population.

Introduction

Sleep disturbance (SD) can be defined as any condition that affects the quality, timing, or length of sleep so that a person's daily function is impacted (1). SD includes, but is not limited to insomnia, narcolepsy, obstructive sleep apnoea, restless leg syndrome, periodic limb movements, and REM sleep behavioural disorder (2, 3). SD, especially insomnia, is a common symptom of dementia and mild cognitive impairment (MCI), although as per people without dementia, factors such as pain, low mood, or a combination of causes may also disrupt sleep in this population (3). Some studies suggest that SD has a key role in the progression of dementia (4-6) or is associated with worsening symptoms (7).

In a meta-analysis of 11 studies to explore the prevalence of SD in people living with dementia (PLwD), 26% of the pooled population experienced SD symptoms, while 19% were clinically significant cases of SD (8). Another review of 55 studies estimated a 38% prevalence of SD among PLwD living in nursing homes based on symptoms, and 20% based on clinical measures (9). One literature review reported a 60% prevalence of any SD among the MCI population, although studies exploring the prevalence of SD among people with MCI are comparatively few (10-12).

In primary care, the assessment and management of SD among PLwD or MCI is complex due to a lack of clear diagnostic criteria and this population's characteristics, which typically comprises older people living with multiple co-morbidities, and polypharmacy (13). Although preliminary evidence suggests that non-pharmacological interventions are effective (14-16), these approaches are often not available, are not used or trusted by clinicians, and are not embedded within usual primary care practice (17).

The treatment of SD among PLwD or MCI is a challenging or "wicked" problem (18). Wicked problems originate from social planning and are defined as problems difficult or impossible to solve

because of incomplete, contradictory or changing requirements that are hard to define, and where solutions to one problem likely generate another problem (19). The assessment and management of SD in primary care may therefore benefit from being examined carefully by considering all potential solutions, contexts, and experiences. A realist approach was therefore used to explore how primary care clinicians assess, understand, and manage SD for PLwD or MCI; if and why such initiatives work; and how people and their carers experience SD and its treatment.

Method

This realist review is part of a larger NIHR funded research project (20). The review protocol is registered with PROSPERO (CRD42022304679) and published elsewhere (21).

The realist approach recognises that an intervention's impact is heavily dependent on its context and that a complex array of contextual factors therefore needs to be examined. Compared to other structured review approaches, the realist approach to review allows a wider array of search terms and broader inclusion criteria to be used, allowing for a more thorough identification and comparison of potential contextual factors (22).

The bibliographic database search strategy was developed in Ovid MEDLINE by an information specialist (SB) using a combination of free-text terms and controlled vocabulary (Supplementary Box S1). No date limit was applied. The MEDLINE search was translated for use in an appropriate selection of bibliographic databases in total comprising APA, PsycInfo, and HMIC, CINAHL, and ASSIA. The final searches were conducted on 4th July 2022. Forward citation searching and a reference list search of the included studies was also conducted. The retrieved documents were imported to an EndNote X9 file and were examined for inclusion and exclusion (Table 1) through title, abstract, and then full-text screening (AA, JB, MM). Fifteen percent of the papers were randomly cross-checked by two reviewers (AA, ZE) for consistency at the title, abstract and full-text screening stage. The recommended rate for cross-checking in realist reviews is 10%-20% (23). Discrepancies were discussed and screening strategies agreed upon.

Table 1. Inclusion and exclusion criteria

No. of the contract of the con		
Criteria	Include	Exclude
Population	PLwD and MCI, primary/community-based	
	clinicians, carers (family, friends, unpaid,	Trauma cases
	informal, or paid carers)	
Phenomenon	Assessment and management of sleep	End of life care (life expectancy <
of interest		three months)
Context and setting	Primary care centres, community in the	Hospital based/secondary/tertiary
	widest sense of the word (i.e. live at home,	care or interventions, hospice care,
	sheltered accommodation, care homes	non-Organisation for Economic

	including residential and nursing homes, or	Co-operation and Development
	supported/assisted living setting)	nations
Evaluation	Experience of SD, diagnosis, assessment, management, approaches, or interventions (what, how, why, by whom, for whom, what extent), experience with drug prescriptions, or medication usage	Quantitative findings from randomised controlled trials of effectiveness studies
Study design/type of document	Original research (published papers, conference abstracts, books, unpublished and grey literature), reviews, viewpoints, policy documents, websites of professional bodies, any relevant clinical or non-clinical guideline	
Other		Non-English language

The included papers were imported into NVivo 1.6.1.(QSR International). The content was initially coded by AA and JB into three broad areas; Assessment & Diagnosis, Management, Patient and Carer Experience and Influence. These categories were then refined into subcategories. Links between the data in each subcategory were discussed and arranged in an initial web of causation (Supplementary Figure S1) from which AA and JB began drafting initial context-mechanism-outcome configurations (CMOCs).

CMOCs are the way that causal statements are expressed in realist reviews. Briefly, they set out how something that functions as context, is linked to an outcome, via a causal process called a mechanism. In other words, in a realist review, something that functions as context, 'triggers' a mechanism, which in turn causes an outcome (24).

The developed CMOCs were refined with thorough cross-checking and reference to the primary data by AA, JB and GW. Regular and substantial input was given throughout the process by GW, an expert in realist review methodology. The review followed RAMESES standards (24) (Supplementary Table S1).

Results

Study characteristics

Our screening process (Figure 1) ended with 60 included records (Supplementary Table S2). Most studies focussed on the challenges of providing effective care. Reported challenges included problems in care homes (25-39), limited awareness or knowledge among clinicians (39-46), inappropriate use of medication (16, 36, 44, 47-58), assessment and diagnosis difficulties (32, 39-41, 43-46, 59-62), and negative experiences reported by PLwD or MCI and their carers (31, 34, 41, 57, 63-79). Few studies explored tailored care as a management strategy (15, 78).

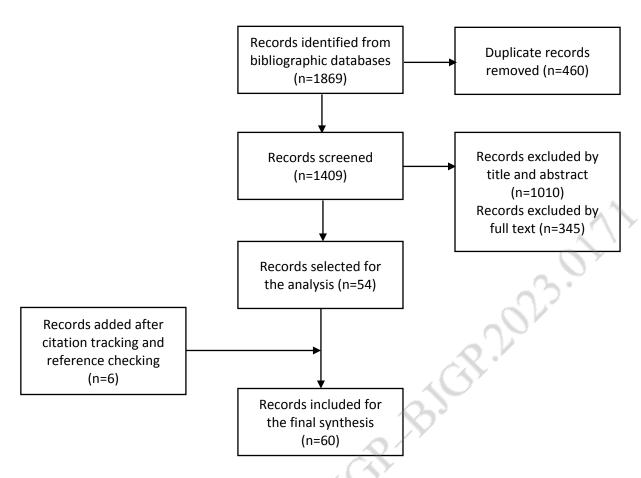


Figure 1. PRISMA flow diagram of screened documents

Publication dates ranged between 1995-2022, with 50% of the included studies published within the last decade. Among the documents included, 36 documents were primary research, 15 were review papers, 4 were commentaries, and 3 book chapters. Additionally, we incorporated one review protocol and one Ph.D. thesis, the latter of which had not been published in a peer-reviewed journal at the time of our review. Approximately one-third of the primary studies employed qualitative methodologies. Additionally, we incorporated qualitative data and information from the discussion and conclusion sections of the included studies.

In terms of geographical origin, most of the included papers were from the USA (25 papers), followed by the UK (9 papers). Australia and Belgium each accounted for 5 documents, while Germany and Norway contributed 3 documents each. Canada, Austria, Ireland, Japan, Netherlands, and New Zealand were each represented by 1 document and one document was developed through international collaboration (UK and Canada).

Context-Mechanism-Outcome Configurations

We developed 19 CMOCs (Supplementary Table S3), which are presented under four main themes.

Barriers to detection of SD

Multiple factors were found to limit discussion, investigation, detection, diagnoses, and management of SD within primary care. Most CMOCs explain the various reasons behind barriers or challenges and how they hinder appropriate intervention (Fig. 2). These challenges result in SD being unidentified or deprioritised as a health concern (32, 39-41, 43-46, 59-62). There was limited awareness of SD among clinicians, including its potential role in people's health, possible assessment techniques, and non-pharmacological interventions, which contributed to SD being unaddressed for many PLwD or MCI (39-46). Awareness of SD among PLwD or MCI and their informal carers also appeared to be limited (40, 63, 75). The symptoms were sometimes normalised and coped with by the patient-carer dyad (76, 80, 81), or went unrecognised by the PLwD due to cognitive or communication impairments (78). This overall lack of awareness of SD meant that discussions about sleep during primary care appointments did not frequently occur.

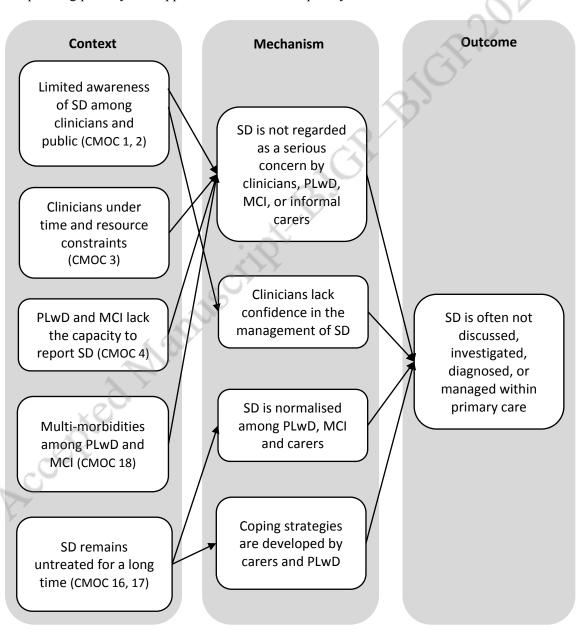


Figure 2. CMOCs that explain lack of SD diagnosis among PLwD or MCI

Long term or inappropriate medication use

In the instances where SD is addressed in primary care, CMOCs 5-8 and 10 reveal how and why, inappropriate prescription of sleep medication could manifest for PLwD or MCI (Figure 3). Clinicians' limited awareness or lack of confidence in non-pharmaceutical interventions (15, 16, 54) can result in medication being the preferred choice. Concerns about withdrawal effects if prescribed medications are ceased, from both clinicians and carers, also contributed to inappropriate long-term medication use (47, 50). Carers relied on medication to relieve the stress of sleep deprivation (25, 79), and prescribers reportedly felt compelled to prescribe medication to maintain positive relationships with their patients (41, 43). The side effects of some medications were sometimes less of a concern for prescribers if the PLwD or MCI had a short life expectancy (34, 44, 58).

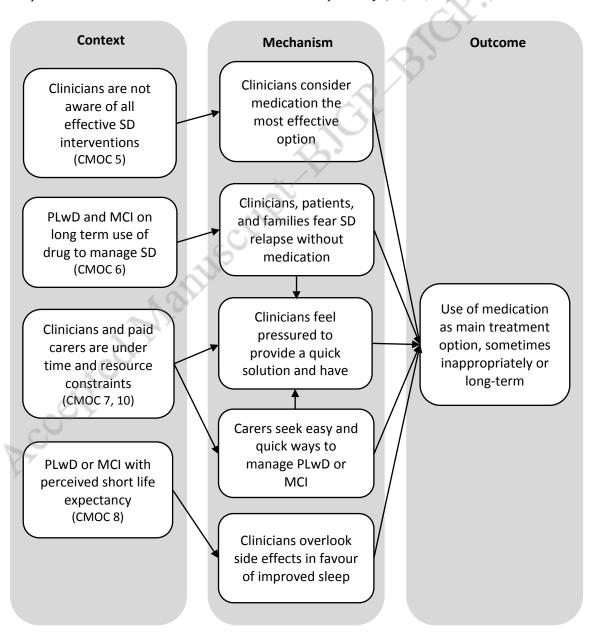


Figure 3. CMOCs that explain the causes for inappropriate or long-term use of medication

Care homes' role in the management of SD

Figure 4 demonstrates the relationships between CMOCs that explore care homes' role in the management of SD (CMOC 9, 11-14, 19). Some concerns from the themes above, such as limited awareness of SD, also apply to staff working in these settings (28, 29, 31, 32, 37). Care home staff were reluctant to implement sleep hygiene practices for PLwD or MCI for a range of reasons (64). As a result of environmental, resource and policy-driven challenges, care homes reportedly imposed rigid routines for residents regardless of their individual circumstances (33, 38). In some cases, night-time checks occurred without seeking consent, which was disruptive and anxiety-inducing for residents (31, 64).

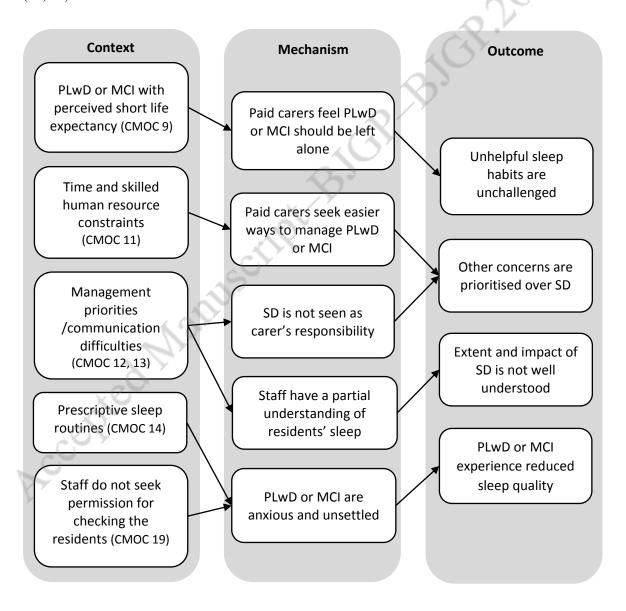


Figure 4. CMOCs explaining the role of care homes in the management of SD

Positive role of informal carers

When informal carers were supported by health systems with information and active assistance, they were able to follow recommended care plans for sleep management (Figure 5). Interventions for managing SD among PLwD or MCI appeared to be dependent on carers, either informal or formal (27, 34, 42, 53, 57, 61, 63, 67, 69-71, 74, 76, 79, 81). Informal carers who were supported with information and guidance reported feeling more able and motivated to implement sleep management strategies at home. Carers also implemented coping strategies for handling SD, which reportedly occurred independent of healthcare providers (72, 75, 76, 78, 80). However, the efficacy of these strategies was not explored in the literature.

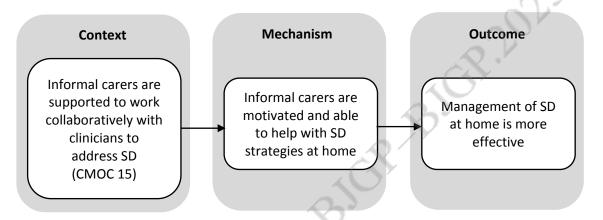


Figure 5. Role of informal carers in caring for a PLwD or MCI with SD

Discussion

Summary

Our findings highlight numerous challenges and barriers that impair effective assessment, diagnosis and clinical management of SD for PLWD or MCI. The diagnosis of SD among this population is hindered by limited awareness of the issue among primary care clinicians and care home staff, compounded by time and resource constraints. PLwD or MCI who are unable to accurately report SD can further challenge its identification. Long-term and inappropriate prescribing practices result from clinicians and service users' beliefs that medication is the most effective and easiest 'quick-fix' management option. This is exacerbated by clinicians' lack of confidence in the effectiveness or availability of evidence-based alternative, non-pharmacological interventions such as light-therapy, cognitive behavioural therapy, physical activities, social relations, or sleep hygiene (15, 36, 62, 71, 77, 82). In care homes, a lack of sufficiently trained staff and other resources, communication challenges, and conflicting organisational priorities resulted in rigid routines that negatively impact residents'

sleep. For those living in their own homes, informal carers play a significant role in the implementation of sleep management interventions.

Strengths and limitations

This realist review was a detailed account of current literature on this topic. The review was led by a leading expert in realist review (GW), and input was received throughout from those with expertise in the subject area. Arguably, the breadth of the inclusion criteria was also a limitation, as the large number of papers included from outside the UK made it difficult to ascertain whether the findings are wholly relevant to UK health provision. For example, there were some discrepancies between countries when reporting prescribing practices (47, 48, 52). However, many identified themes, such as low levels of awareness of SD and the use of medication as the primary treatment method were common across countries and healthcare systems.

Whilst including papers without a limit on date of publication allowed for a more comprehensive search, we cannot be sure that the findings detailed are entirely contemporary to current practice. Attitudes towards certain practices, such as the prescription of antipsychotic medications to treat SD, have changed in recent years, with the UK government pledging to reduce the prescription of antipsychotic medications for PLwD by two-thirds (83). Earlier UK-based research may not reflect this policy initiative and inappropriate use of this medication may no longer be contemporaneous with UK practice. However, there is evidence to suggest that whilst GPs are now aware of the negative consequences of sleep medication, there is a variable attitude to their use due to a perceived lack of alternatives and time constraints (84). Further, whilst many papers gave detailed insight into sleep management practices in care homes, few studies explored current practices within GP surgeries and few primary care professionals, excluding care home staff, were included as participants within the reviewed studies. More work is therefore required to accurately determine clinicians' perspectives, and how current practice within primary care operates outside care homes, including general practice. A detailed exploration of current practice in the UK, including GP surgeries, is currently being conducted as the second phase of the TIMES project.

Comparison with existing literature

Research exploring the general management of SD in primary care identifies similar concerns regarding the inappropriate prescription of sleep medication and under-utilisation of more tailored non-pharmacological solutions (85-87). Although practitioners may perceive a pressure to prescribe, this practice may actually deter patients with SD from seeking further help (88). The use of sleep medication for PLwD or MCI can cause unintended consequences such as the progression of dementia, falls, and loss of functional abilities (13, 89). Management of comorbidities, due to issues

such as polypharmacy or use of medications for more than one condition, may further hinder deprescribing for different conditions (90). Like our findings, other studies indicate that when GPs work under time pressures, they are prone to suboptimal prescribing practices (90, 91). Resource pressures in care home, such as understaffing and poor communication was also linked to long-term medication use to manage SD (92, 93).

Implications for research and practice

We identified significant gaps within the literature. Further research is therefore needed to explore how SD is assessed and managed for people attending GP surgeries and living in their own homes. Little information was available on how SD is managed among people with MCI, and the literature did not readily distinguish between people with a dementia or MCI diagnosis. Future research could investigate SD in the MCI population and focus on whether approaches do or should differ between PLwD and those with MCI. Lastly, whilst much of the literature focussed on the barriers to effective sleep management, few explored current and effective community-based sleep management practices. We would recommend that the perspectives of those implementing any SD intervention, such as clinicians or, more likely, carers, are explored prior to any intervention being developed and more widely implemented. An understanding of carer perspectives is key to developing any effective sleep management tool within primary care.

The deprioritisation of SD and lack of confidence in effective assessment and management strategies highlight the need to increase awareness of this area. This awareness should include instilling confidence in evidence-based non-pharmacological interventions, such as light-therapy, cognitive behavioural therapy, physical activities, social engagement, and sleep hygiene (15, 36, 62, 71, 77, 82). Integrating these components as part of a tailored approach to care may enable more effective interventions for SD that are sensitive to the person's unique circumstances and goals. It is essential, however, that any proposal for a new approach to care is implemented with due consideration for the time and resource constraints faced by healthcare and social service providers. We believe that patient care should include timely assessments of PLwD and MCI for possible sleep disturbances, a holistic approach to addressing sleep issues alongside various health conditions in this population, and the provision of continuous and context-specific care.

For PLwD or MCI with SD living in care homes, a flexible and context-sensitive approach to managing SD may help mitigate some of the negative experiences reported by care home residents at night. This might include adjusting sleep routines, limiting the number of night-time checks and interventions relevant to residents' preferences. Night-time care in care homes should be considered no less important than care during the day, and support and training for night staff to recognise, manage and communicate SD should be readily available.

PLwD or MCI, informal carers and family members may also benefit from a greater awareness and understanding of the impact of poor sleep, good sleep hygiene practices, and advice on the potential side effects of sleep medication, including potentially severe adverse events (13). This could enable some elements of SD to be effectively self-managed and alter the expectation or concern that doctors will prescribe as a first port of call. Notably, the current assessment and management of SD for PLwD or MCI living at home is often dependent on the input of informal carers and families. Informal carers often experience high levels of burden associated with caring for a PLwD (80, 94, 95). Any intervention package involving informal carers should therefore be formulated collaboratively and with consideration as to how any proposed intervention can be feasibly implemented given their available means.

Funding

This study is funded by the National Institute for Health and Care Research (NIHR) under its Programme Grants for Applied Research (PGfAR), Grant Reference Number NIHR202345. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Ethical approval

Not applicable

Competing interests

None declared.

Acknowledgements

We would like to acknowledge the support of the following research networks: NIHR Applied Research Collaboration South West Peninsula (PenARC) and East of England (ARC EoE), the NIHR Exeter Biomedical Research Centre (BRC), and the Exeter Clinical Trials Unit. We gratefully acknowledge the local principal investigators and researchers involved in participant recruitment, assessment, and intervention. We are grateful to the TIMES study participants for their participation in the study and to members of the patient and public involvement and engagement group for their support and contribution throughout the study.

References

- 1. Sleep Foundation. Sleep disorders 2022 [Available from: https://www.sleepfoundation.org/sleep-disorders.] Accessed 02.12.2022
- 2. Alzheimer's Society. Sleep problems and treatments for people with dementia 2022 [Available from: https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/sleep-problems-treatments-dementia.] Accessed 02.12.2022
- 3. Mayo Clinic. Sleep disorders 2022 [Available from: https://www.mayoclinic.org/diseases-conditions/sleep-disorders/symptoms-causes/syc-20354018.] Accessed 02.12.2022
- 4. Caputo M, Monastero R, Mariani E, et al. Neuropsychiatric symptoms in 921 elderly subjects with dementia: a comparison between vascular and neurodegenerative types. Acta Psychiatr Scand. 2008;117(6):455-64
- 5. Huang S-S, Wang W-F, Liao Y-C. Severity and prevalence of behavioral and psychological symptoms among patients of different dementia stages in Taiwan. Rev Psiquiatr Clín. 2017;44:89-93
- 6. Shi L, Chen S-J, Ma M-Y, et al. Sleep disturbances increase the risk of dementia: a systematic review and meta-analysis. Sleep Med Rev. 2018;40:4-16
- 7. Bubu OM, Andrade AG, Umasabor-Bubu OQ, et al. Obstructive sleep apnea, cognition and Alzheimer's disease: a systematic review integrating three decades of multidisciplinary research. Sleep Med Rev. 2020;50:101250
- 8. Koren T, Fisher E, Webster L, et al. Prevalence of sleep disturbances in people with dementia living in the community: A systematic review and meta-analysis. Ageing Res Rev. 2022:101782
- 9. Webster L, Costafreda Gonzalez S, Stringer A, et al. Measuring the prevalence of sleep disturbances in people with dementia living in care homes: a systematic review and meta-analysis. Sleep. 2020;43(4):zsz251
- 10. Guarnieri B, Adorni F, Musicco M, et al. Prevalence of sleep disturbances in mild cognitive impairment and dementing disorders: a multicenter Italian clinical cross-sectional study on 431 patients. Dement Geriatr Cogn Disord. 2012;33(1):50-8.10.1159/000335363
- 11. McKinnon A, Terpening Z, Hickie IB, et al. Prevalence and predictors of poor sleep quality in mild cognitive impairment. J Geriatr Psychiatry Neurol. 2014;27(3):204-11.10.1177/0891988714527516
- 12. Mubashir T, Abrahamyan L, Niazi A, et al. The prevalence of obstructive sleep apnea in mild cognitive impairment: a systematic review. BMC Neurol. 2019;19(1):195.10.1186/s12883-019-1422-3
- 13. Richardson K, Loke YK, Fox C, et al. Adverse effects of Z-drugs for sleep disturbance in people living with dementia: a population-based cohort study. BMC Med. 2020;18(1):351.https://dx.doi.org/10.1186/s12916-020-01821-5
- 14. Gibson R, Dowell A, Jones L, Gander P. Non-pharmacological interventions a feasible option for addressing dementia-related sleep problems in the context of family care. Pilot Feasibility Stud. 2021;7(1):114.https://dx.doi.org/10.1186/s40814-021-00851-x
- 15. Livingston G, Barber JA, Kinnunen KM, et al. DREAMS-START (Dementia RElAted Manual for Sleep; STrAtegies for RelaTives) for people with dementia and sleep disturbances: a single-blind feasibility and acceptability randomized controlled trial. Int Psychogeriatr. 2019;31(2):251-65.https://dx.doi.org/10.1017/S1041610218000753
- 16. O'Caoimh R, Mannion H, Sezgin D, et al. Non-pharmacological treatments for sleep disturbance in mild cognitive impairment and dementia: A systematic review and meta-analysis. Maturitas. 2019;127:82-94. https://dx.doi.org/10.1016/j.maturitas.2019.06.007
- 17. Kinnunen KM, Vikhanova A, Livingston G. The management of sleep disorders in dementia: an update. Curr Opin Psychiatry. 2017;30(6):491-
- 7.https://dx.doi.org/10.1097/YCO.000000000000370
- 18. Burns D, Hyde P, Killett A. Wicked problems or wicked people? Reconceptualising institutional abuse. Sociol Health Illn. 2013;35(4):514-28

- 19. Rittel HW, Webber MM. Dilemmas in a general theory of planning. Policy Sci. 1973;4(2):155-69
- 20. Fox C. The clinical, social and cost effectiveness of a decision support tool to optimise community-based tailored management of sleep (TIMES) for people living with dementia or mild cognitive impairment and sleep disturbanceTIMES Tallored Management of Sleep. UK: National Institute for Health and Care research; 2022.
- 21. Greene L, Aryankhesal A, Megson M, et al. Understanding primary care diagnosis and management of sleep disturbance for people with dementia or mild cognitive impairment: a realist review protocol. BMJ Open. 2022;12(11):e067424
- 22. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review-a new method of systematic review designed for complex policy interventions. J Health Serv Res Policy. 2005;10(1_suppl):21-34
- 23. Hunter R, Gorely T, Beattie M, Harris K. Realist review. Int Rev Sport Exerc Psychol. 2022;15(1):242-65
- 24. Wong G, Greenhalgh T, Westhorp G, et al. RAMESES publication standards: realist syntheses. BMC Med. 2013;11:1-14
- 25. Webster L, Powell K, Costafreda SG, Livingston G. The impact of sleep disturbances on care home residents with dementia: the SIESTA qualitative study. Int Psychogeriatr. 2020;32(7):839-47.https://dx.doi.org/10.1017/S1041610220000642
- 26. Agnew T. Common sense solutions for sleepless nights. Nurs Older People. 2008;20(5):7-8
- 27. Alessi CA, Schnelle JF. Approach to sleep disorders in the nursing home setting. Review article. Sleep Med Rev. 2000;4(1):45-56
- 28. Blytt KM, Bjorvatn B, Husebo B, Flo E. Clinically significant discrepancies between sleep problems assessed by standard clinical tools and actigraphy. BMC Geriatr. 2017;17(1):253.https://dx.doi.org/10.1186/s12877-017-0653-7
- 29. Blytt KM, Flo-Groeneboom E. New knowledge on the impact of sleep disturbances illustrates the urgent need to address sleep problems in nursing home residents. Int Psychogeriatr. 2020;32(7):795-7. https://dx.doi.org/10.1017/S1041610220001106
- 30. Janus SI, Kosters J, van den Bosch KA, et al. Sounds in nursing homes and their effect on health in dementia: a systematic review. Int Psychogeriatr. 2021;33(6):627-44
- 31. Kerr D. Supporting older people in care homes at night2008.
- 32. Kontos P, Martin W. Embodiment and dementia: exploring critical narratives of selfhood, surveillance, and dementia care. Dementia (London). 2013;12(3):288-302.https://dx.doi.org/10.1177/1471301213479787
- 33. Nunez KM, Khan Z, Testad I, et al. Current practice and challenges in night-time care for people with dementia living in care homes: a qualitative study. Int J Geriatr Psychiatry. 2018;33(1):e140-e9.https://dx.doi.org/10.1002/gps.4737
- 34. Nygaard A, Halvorsrud L, Grov EK, Bergland A. 'What matters to you?'—a qualitative study on the views of nursing home residents with dementia regarding the health care they receive. J Clin Nurs. 2022;31(1-2):262-74
- 35. Snow AL, Loup J, Morgan RO, et al. Enhancing sleep quality for nursing home residents with dementia: a pragmatic randomized controlled trial of an evidence-based frontline huddling program. BMC Geriatr. 2021;21(1):281.https://dx.doi.org/10.1186/s12877-021-02189-8
- 36. Song Y, Dowling GA, Wallhagen MI, et al. Sleep in older adults with Alzheimer's disease. J Neurosci Nurs. 2010;42(4):190-200
- 37. The Lamp Group. Nurses impress at royal commission: Evidence from nurses was well received at the inquiry into Australia's aged care system. Lamp. 2019;76(5):8-9
- 38. Webster L, Costafreda SG, Powell K, Livingston G. How do care home staff use non-pharmacological strategies to manage sleep disturbances in residents with dementia: The SIESTA qualitative study. PLoS One. 2022;17(8):e0272814

- 39. Yesavage JA, Friedman L, Ancoli-Israel S, et al. Development of Diagnostic Criteria for Defining Sleep Disturbance in Alzheimer's Disease. J Geriatr Psychiatry Neurol. 2003;16(3):131-9.https://dx.doi.org/10.1177/0891988703255684
- 40. Brown CA, Wielandt P, Wilson D, et al. Healthcare providers' knowledge of disordered sleep, sleep assessment tools, and nonpharmacological sleep interventions for persons living with dementia: a national survey. Sleep Disord. 2014;2014:286274. https://dx.doi.org/10.1155/2014/286274
- 41. Flick U, Garms-Homolová V, Röhnsch G. "And mostly they have a need for sleeping pills": Physicians' views on treatment of sleep disorders with drugs in nursing homes. J Aging Stud. 2012;26(4):484-94
- 42. Kales HC, Gitlin LN, Lyketsos CG. Assessment and management of behavioral and psychological symptoms of dementia. BMJ. 2015;350:h369.https://dx.doi.org/10.1136/bmj.h369
- 43. Lee DR, Thomas AJ. Sleep in dementia a caregiving-Assessment and treatment implications: A review. Int Psychogeriatr. 2011;23(2):190-201. https://dx.doi.org/10.1017/S1041610210001894
- 44. Lichstein KL, Morin CM. Treatment of late-life insomnia: SAGE; 2000.
- 45. Papp KK, Penrod CE, Strohl KP. Knowledge and attitudes of primary care physicians toward sleep and sleep disorders. Sleep Breath. 2002;6(3):103-9
- 46. Stoppe G, Sandholzer H, Staedt J, et al. Sleep disturbances in the demented elderly: Treatment in ambulatory care. Sleep. 1995;18(10):844-8. https://dx.doi.org/10.1093/sleep/18.10.844
- 47. Azermai M, Elseviers M, Petrovic M, et al. Assessment of antipsychotic prescribing in Belgian nursing homes. Int psychogeriatr. 2011;23(8):1240-8.https://dx.doi.org/10.1017/S104161021100024X
- 48. Azermai M, Elseviers M, Petrovic M, et al. Geriatric drug utilisation of psychotropics in Belgian nursing homes. Hum Psychopharmacol. 2011;26(1):12-20
- 49. Borson S, Scanlan JM, Doane K, Gray S. Antidepressant prescribing in nursing homes: is there a place for tricyclics? Int J Geriatr Psychiatry. 2002;17(12):1140-5
- 50. Bourgeois J, Elseviers M, Azermai M, et al. Benzodiazepine use in Belgian nursing homes: a closer look into indications and dosages. Eur J Clin Pharmacol. 2012;68(5):833-44.10.1007/s00228-011-1188-z
- 51. Bourgeois J, Elseviers MM, Van Bortel L, et al. The use of antidepressants in Belgian nursing homes: focus on indications and dosages in the PHEBE study. Drugs Aging. 2012;29(9):759-69
- 52. Brimelow RE, Wollin JA, Byrne GJ, Dissanayaka NN. Prescribing of psychotropic drugs and indicators for use in residential aged care and residents with dementia. Int Psychogeriatr. 2019;31(6):837-47.https://dx.doi.org/10.1017/S1041610218001229
- 53. Class CA, Schneider L, Farlow MR. Optimal management of behavioural disorders associated with dementia. Drugs Aging. 1997;10(2):95-106
- 54. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 2020;396(10248):413-46
- 55. Mann E, Köpke S, Haastert B, et al. Psychotropic medication use among nursing home residents in Austria: a cross-sectional study. BMC Geriatr. 2009;9(1):1-8
- 56. McGee N, Hart AM, Burman M. Reconsidering benzodiazepines and z-drug prescriptions: responsible prescribing and deprescribing. J Nurse Pract. 2021;17(1):76-83
- 57. Polenick CA, Leggett AN, Maust DT, Kales HC. Medical Care Tasks among Spousal Dementia Caregivers: Links to Care-Related Sleep Disturbances. Am J Geriatr Psychiatry. 2018;26(5):589-97. https://dx.doi.org/10.1016/j.jagp.2018.01.206
- 58. Shuster JL. Palliative care for advanced dementia. Clin Geriatr Med. 2000;16(2):373-86
- 59. Anderson KN, Catt M, Collerton J, et al. Assessment of sleep and circadian rhythm disorders in the very old: the Newcastle 85+ Cohort Study. Age Ageing. 2014;43(1):57-63.https://doi.org/10.1093/ageing/aft153
- 60. Benca RM. Diagnosis and treatment of chronic insomnia: a review. Psychiatr Serv. 2005;56(3):332-43

- 61. Jan DL, Delfine D, Eileen VDP, et al. The management of dementia by flemish GPs: it remains a difficult job. Acta Clin Belg. 2021;76(4):264-
- 71.https://dx.doi.org/10.1080/17843286.2020.1716462
- 62. McCrae CS, Dzierzewski JM, Kay DB. Treatment of late-life insomnia. Sleep Med Clin. 2009;4(4):593-604
- 63. Corey KL, McCurry MK. When Caregiving Ends: The Experiences of Former Family Caregivers of People With Dementia. Gerontologist. 2018;58(2):e87-
- e96.https://dx.doi.org/10.1093/geront/gnw205
- 64. Flick U, Garms-Homolova V, Rohnsch G. 'When they sleep, they sleep': daytime activities and sleep disorders in nursing homes. J Health Psychol. 2010;15(5):755-
- 64.https://dx.doi.org/10.1177/1359105310368182
- 65. Hoekert M, der Lek RFR-v, Swaab DF, et al. Comparison between informant-observed and actigraphic assessments of sleep-wake rhythm disturbances in demented residents of homes for the elderly. Am J Geriatr Psychiatry. 2006;14(2):104-11
- 66. Koch S, Haesler E, Tiziani A, Wilson J. Effectiveness of sleep management strategies for residents of aged care facilities: findings of a systematic review. J Clin Nurs. 2006;15(10):1267-75
- 67. Kotronoulas G, Wengstrom Y, Kearney N. Sleep and sleep-wake disturbances in care recipient-caregiver dyads in the context of a chronic illness: a critical review of the literature. J Pain Symptom Manage. 2013;45(3):579-94.https://dx.doi.org/10.1016/j.jpainsymman.2012.03.013
- 68. Liu Y, Leggett AN, Kim K, et al. Daily sleep, well-being, and adult day services use among dementia care dyads. Aging Ment Health. 2021:1-
- 9.https://dx.doi.org/10.1080/13607863.2021.1998354
- 69. Logsdon RG, McCurry SM, Teri L. Behavioral treatment of affective disorders and associated symptoms: Guilfrd Press; 2006.
- 70. Matsuda O, Hasebe N, Ikehara K, et al. Longitudinal study of the mental health of caregivers caring for elderly patients with dementia: effect of institutional placement on mental health. Psychiatry Clin Neurosci. 1997;51(5):289-93
- 71. McCurry SM, Gibbons LE, Logsdon RG, et al. Training caregivers to change the sleep hygiene practices of patients with dementia: the NITE-AD Project. J Am Geriatr Soc. 2003;51(10):1455-60.10.1046/j.1532-5415.2003.51466.x
- 72. McCurry SM, LaFazia DM, Pike KC, et al. Managing sleep disturbances in adult family homes: recruitment and implementation of a behavioral treatment program. Geriatr Nurs. 2009;30(1):36-44. https://dx.doi.org/10.1016/j.gerinurse.2008.05.001
- 73. McCurry SM, LaFazia DM, Pike KC, et al. Development and evaluation of a sleep education program for older adults with dementia living in adult family homes. Am J Geriatr Psychiatry. 2012;20(6):494-504.https://dx.doi.org/10.1097/JGP.0b013e318248ae79
- 74. McCurry SM, Pike KC, Vitiello MV, et al. Factors associated with concordance and variability of sleep quality in persons with Alzheimer's disease and their caregivers. Sleep. 2008;31(5):741-8
- 75. Moore RC, Harmell AL, Chattillion E, et al. PEAR model and sleep outcomes in dementia caregivers: influence of activity restriction and pleasant events on sleep disturbances. Int Psychogeriatr. 2011;23(9):1462-9.https://dx.doi.org/10.1017/S1041610211000512
- 76. Rapaport P, Webster L, Horsley R, et al. An intervention to improve sleep for people living with dementia: Reflections on the development and co-production of DREAMS:START (Dementia REIAted Manual for Sleep: STrAtegies for RelaTives). Dementia (London). 2018;17(8):976-89.https://dx.doi.org/10.1177/1471301218789559
- 77. Richards KC, Beck C, O'Sullivan PS, Shue VM. Effect of individualized social activity on sleep in nursing home residents with dementia. J Am Geriatr Soc. 2005;53(9):1510-7
- 78. Svendsboe EJ. Carers to people with Lewy body dementia and Alzheimer's disease: Experiences and coping strategies [Developmental Psychology 2800]2022.

- 79. Wade R, Pachana NA, Dissanayaka N. Factors Related to Sleep Disturbances for Informal Carers of Individuals With PD and Dyadic Relationship: A Rural Perspective. J Geriatr Psychiatry Neurol. 2021;34(5):389-96.https://dx.doi.org/10.1177/0891988720944250
- 80. Gibson RH, Gander PH, Jones LM. Understanding the sleep problems of people with dementia and their family caregivers. Dementia (London). 2014;13(3):350-65
- 81. Kaskie B, Bobitt J, Herrera J, et al. Cannabis use among persons with dementia and their caregivers: Lighting up an emerging issue for clinical gerontologists. Clin Gerontol. 2020:No-Specified.https://dx.doi.org/10.1080/07317115.2020.1852465
- 82. Jin JW, Nowakowski S, Taylor A, et al. Cognitive behavioral therapy for mood and insomnia in persons with dementia: A systematic review. Alzheimer Dis Assoc Disord. 2021;35(4):366-73
- 83. Medicines and Healthcare products Regulatory Agency. Antipsychotics: initiative to reduce prescribing to older people with dementia. In: H1 DSU, editor. 2012.
- 84. Sirdifield C, Anthierens S, Creupelandt H, et al. General practitioners' experiences and perceptions of benzodiazepine prescribing: systematic review and meta-synthesis. BMC Fam Pract. 2013;14:1-13
- 85. Doherty AJ, Boland P, Reed J, et al. Barriers and facilitators to deprescribing in primary care: a systematic review. BJGP Open. 2020;4(3)
- 86. Wallis KA, Andrews A, Henderson M. Swimming against the tide: primary care physicians' views on deprescribing in everyday practice. Ann Fam Med. 2017;15(4):341-6
- 87. Sirdifield C, Chipchase SY, Owen S, Siriwardena AN. A systematic review and meta-synthesis of patients' experiences and perceptions of seeking and using benzodiazepines and Z-drugs: towards safer prescribing. Patient. 2017;10:1-15
- 88. Cheung JM, Bartlett DJ, Armour CL, Saini B. The insomnia patient perspective, a narrative review. Behav Sleep Med. 2013;11(5):369-89
- 89. Schroeck JL, Ford J, Conway EL, et al. Review of safety and efficacy of sleep medicines in older adults. Clin Ther. 2016;38(11):2340-72
- 90. Cadogan CA, Ryan C, Francis JJ, et al. Improving appropriate polypharmacy for older people in primary care: selecting components of an evidence-based intervention to target prescribing and dispensing. Implement Sci. 2015;10(1):1-14
- 91. Luijks HD, Loeffen MJ, Lagro-Janssen AL, et al. GPs' considerations in multimorbidity management: a qualitative study. Br J Gen Pract. 2012;62(600):e503-e10
- 92. Bell HT, Granas A, Enmarker I, et al. Nurses' and pharmacists' learning experiences from participating in interprofessional medication reviews for elderly in primary health care-a qualitative study. BMC Fam Pract. 2017;18(1):1-9
- 93. Palagyi A, Keay L, Harper J, et al. Barricades and brickwalls—a qualitative study exploring perceptions of medication use and deprescribing in long-term care. BMC Geriatr. 2016;16:1-11
- 94. Lawson S, Mullan J, Wong G, et al. Family carers' experiences of managing older relative's medications: Insights from the MEMORABLE study. Patient Educ Couns. 2022;105(7):2573-80
- 95. Parkinson M, Carr SM, Rushmer R, Abley C. Investigating what works to support family carers of people with dementia: a rapid realist review. J Public Health (Oxf). 2017;39(4):e290-e301