How effective are models of post-diagnostic dementia care delivered by primary care?
A systematic review

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Figure 1. Flow chart of studies included in the review

Figure 2. Meta-analysis of PCP-case management partnership outcomes

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How this fits in:

- Global policy recommendations suggest moving to a primary care-led model of post diagnostic dementia care, but it is unclear how this should best be delivered
- Our review suggests that a primary care provider-case management partnership model currently offers the most promise.
- All models need further rigorous evaluation

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Abstract

Background: The World Alzheimer Report 2016 proposed a task-shifted model of post-diagnostic dementia care, moving towards primary and community-based care. It is unclear how this may best be delivered.

Aim: To assess the effectiveness and cost-effectiveness of primary care-based models of post-diagnostic dementia care.

Design and setting: Systematic review of trials and economic evaluations of post-diagnostic dementia care interventions where primary care was substantially involved in care plan decision making.

Method: Searches of MEDLINE, PsychINFO, EMBASE, Web of Science and CINAHL (inception-March 2019). Two authors independently critically appraised studies and inductively classified interventions into types of care models. Random effects meta-analysis or narrative synthesis was conducted for each model where appropriate.

Results: From 4506 unique references and 357 full texts, we included 23 papers from 10 trials of nine interventions, delivered in four countries. We identified four types of care models. Primary care provider (PCP)-led care (n=1) led to better caregiver mental health and reduced hospital and memory clinic costs compared to memory clinics. PCP-led care with specialist consulting support (n=2) did not have additional effects on clinical outcomes or costs over usual primary care. PCP-case management partnership models (n=6) offered the most promise, with impact on neuropsychiatric symptoms, caregiver burden, distress and mastery and healthcare costs. Integrated primary care memory clinics (n=1) had limited evidence for improved quality of life and cost-effectiveness compared to memory clinics.

Conclusion: Partnership models may impact on some clinical outcomes and healthcare costs. More rigorous evaluation of promising primary care-led care models is needed.

Introduction

Approximately 43.8 million people globally were living with dementia in 2016.[1] This is projected to almost double every 20 years, with the largest increase in low- and middle-income countries.[2] Dementia is a syndrome with a range of cognitive, psychological and behavioural symptoms which progressively impair activities of daily living.[3] Intensive health and social care support is often required. Globally, dementia is estimated to cost US$ 818billion, 20% of which arises from direct medical care and 40% each from social care and informal care.[2] Caregivers (unpaid family or other supports, also called carers) contribute a large amount of support but can experience substantial caregiving burden.[4]

With increasing prevalence and demand upon secondary care services, the World Alzheimer's Report (2016)5 recommended a global shift towards approaches where post-diagnostic dementia services are based within primary care. Primary care is defined as "first-contact, accessible, continued, comprehensive and coordinated care".6 Post-diagnostic dementia support includes initial treatment (e.g. caregiver wellbeing and support, post-diagnostic support package), ongoing and continuing care (e.g. comorbidities management, behavioural and psychological symptom management) and end-of-life care.5 We defined substantial involvement from primary care in dementia care as that in which care plan decision-making was either led by or substantially involved a member of the primary care team.

Little is known regarding the optimal way to deliver primary care post-diagnostic dementia care, with great variation within and between countries in service content, quality and providers. It is therefore of interest to compare both effects between primary and secondary care provision and different primary care models. Previous reviews have studied case management approaches,7 strategies used to deliver different models of primary care dementia care without a focus on effectiveness[8] and a scoping review of dementia interventions relevant to primary care.[5] These have found limited evidence, particularly regarding the costs of case management and its integration with primary care, the role of specialists and the potential range of outcomes that post-diagnostic support may impact upon.[5]

In light of this rapidly evolving field and the global policy recommendations, our review aims to assess the effectiveness and cost-effectiveness of models of post-diagnostic dementia care which have substantial involvement from primary care.

Methods

We undertook a systematic review following PRISMA reporting guidelines[9] (Prospero ID CRD42018104128).

Inclusion criteria

- Participants: People with dementia (post-diagnosis) and their caregivers, either community-dwelling or in care homes (no age limitations)
- Interventions: Post-diagnostic dementia care interventions substantially involving one or more members of a primary care team (as defined by the World Health Organisation[6]). For consistency the term 'primary care provider' (PCP) is used throughout this paper.
- Comparators: usual care, alternative care management models

- Outcomes: quality of life, functioning, cognition, depression, behavioural and psychological symptoms of dementia (BPSD), caregiver outcomes, costs, cost-effectiveness, service use (including hospital admissions), care and nursing home admission.
- Study type: randomised and non-randomised controlled trials (including cluster trials), economic evaluations

Exclusion criteria

- Interventions: Secondary care-led interventions; interventions with no or minimal primary care involvement; care home staff-led interventions; interventions focused on diagnosis or prevention; educational interventions focused on increasing professional knowledge, confidence or guideline adherence
- Comparator: no comparator
- Study type: intervention development studies, uncontrolled intervention studies, implementation studies, process evaluations, reviews, surveys, quality improvement initiatives.

Studies providing extra information on study methods but not outcomes (e.g. protocols) were included as supplementary papers, with relevant data extracted to inform quality assessment.

Searches

We searched MEDLINE, PsycINFO, EMBASE, Web of Science and CINAHL (inception to March 2019) and deduplicated studies using Mendeley and Excel functions (see Supplementary Figure S1 for search terms). One author (SA) screened titles and abstracts, with 10% checked independently by a second reviewer (RF). RF and GB/SA screened all full texts, with disagreements resolved through discussion with GR and KW. Full texts in another language were screened by a speaker of the language where possible.

RF screened reference lists, performed citation tracking of included papers and conducted searches of Ethos and trials registers. Protocols, trials register entries and conference abstracts were followed up through author and citation searches and author emails to locate full texts that had not already been found. We also screened reference lists of relevant reviews.[8,10]

Data extraction and quality assessment

Data were extracted on study characteristics using the TIDIER checklist[11]. Two authors (RF and GB) assessed study quality using the Cochrane Risk of Bias Tool[12] for RCTs; Risk of Bias in Non-Randomised Studies of Interventions (ROBINS-I) for non-randomised interventional studies[13]; and Consensus on Health Economic Criteria (CHEC) checklist for economic evaluations.[14] Disagreements were resolved through discussion between RF and GB.

Synthesis

As there is no established taxonomy of primary care-led models of care, two authors (RF and GB) inductively grouped study interventions, independently classifying these according to configuration of healthcare professionals involved. These models were refined with team members (GR, KW, KHD, SB, LR), then used as the basis for synthesis.

Functioning and quality of life were considered important outcomes. Where multiple studies were available for a model and an outcome with data suitable for aggregation (e.g. mean and SD), we carried out random-effects meta-analysis using Revman 5.3,[15] using mean difference, standardised mean difference (SMD) or odds ratios.[16] Non-normally distributed data (e.g. medians only reported) were not included in meta-analysis. If outcomes were measured using two or more scales, we used the measure most closely resembling others in the meta-analysis to minimise heterogeneity. Heterogeneity was measured using I^2. For cluster trial outcome data, we only included effect estimates adjusted for cluster (whether or not they were adjusted for additional variables), meta-analysed using Revman's generic inverse variance function (standard errors were calculated from reported confidence intervals). Where data were reported in a format that could not be included in meta-analysis (e.g. groupxtime interaction p value only), we approached the authors for further data (n=2) but did not receive a response. Where there were insufficient data for meta-analysis, we narratively synthesised outcomes, grouped by model.

Results

Out of 4506 deduplicated hits, we screened 357 full texts and included 23 papers of 10 studies relating to nine services/interventions (see Figure 1, Supplementary Figure S2). There were five RCTs and four controlled studies. Sample sizes ranged from 31 to 407, with two larger claims-based economic evaluations of 1756 and 3249. Studies were conducted in four countries: USA (n=5), Germany (n=3), Netherlands (n=1) and Singapore (n=1). Study quality is summarised in Supplementary File 3.

[Figure 1 about here]

Participant characteristics

The majority of trials included people diagnosed with dementia, with no severity restrictions.[17–23] Only three had new diagnosis or mild-moderate dementia as inclusion criteria.[24–26] Where reported, baseline Mini-Mental Status Examination (MMSE) scores ranged from 15 to 24.4 (mild to moderate dementia). All but one study limited inclusion to those living at home[17–19,21–26] with a family/friend caregiver.[18,19,21,22,24–26] One included those without caregivers, although 79% sample reported having a caregiver.[17] In another, presence of caregivers was not reported.[23]

Models of care

We grouped interventions into four models (see Table 1 for descriptions and associated studies).

PCP-led models

One RCT found that PCP-led care did not lead to significantly different outcomes compared to memory clinics in functioning (Interview for Deterioration in Daily Living Activities in Dementia scale), quality of life (Quality of Life in Alzheimer's Disease (QOL-AD)), behavioural and psychological symptoms of dementia (BPSD, Neuropsychiatric Inventory (NPI)) or depression care over 6 or 12 months.[25] There were lower caregiver anxiety (State-Trait Anxiety Inventory) and depression scores (Centre for Epidemiological Studies Depression scale (CES-D)) at follow up, but this may be due to dropouts as it was not sustained after a sensitivity analysis imputing missing values.[25] There were no differences in burden, mastery and quality of life at 6 or 12 months.[25]

The associated economic evaluation found similar use of health and social care services to memory clinics. There were greater PCP contact costs but lower hospital admission and memory clinic contact costs.[27] When a societal perspective was taken (including informal and formal care, productivity loss, community and health service use) there were no significant differences in overall costs (€23 059 vs €22035, €1024 (95% CI -€7723 to €5674)) or quality-adjusted life year (QALY) gains, although QALYs favoured the PCP-led group.

PCP-led with specialist consulting support

Compared to usual primary care, one moderate quality three-arm RCT and one low quality controlled clinical trial (CCT) found no significant effects upon functioning (Barthel Index,[24] Nuremberg Alters-Alltags-Skala[17]), quality of life (EQ-5D,[17,24] QOL-AD and Short Form-36[17]), cognition (MMSE),[17,24] caregiver mastery and burden,[17,24] caregiver health-related quality of life or caregiver EQ-5D scores.[17] There were no differences in moves to care homes or use of other home care or health care services,[17,24] apart from higher neurologist contacts than usual care (18.6% vs 2.8%, $p<0.002$, not adjusted for baseline differences),[17] and greater caregiver counsellor and support group uptake.[28] The economic evaluation associated with the RCT was high quality, and found no differences in social care, healthcare or overall costs between groups (Group A €82,745, Group B €80,361 and Group C €75,754, $p=0.64$), apart higher outpatient costs than usual PCP care.[24]

PCP-case management partnership models

This model had sufficient studies to conduct a meta-analysis (Figure 2). There were significant effects from two RCTs (n=414) at 12 months upon NPI scores (mean difference -6.68 (95%CI -9.45 to -3.91), Figure 2A).[19,21] Two further studies reporting medians or group x time interaction data only found no effects over six[18] or 12 months,[26] although one had a much shorter intervention period[18] and the other a small sample size.[26] No studies found effects upon functioning (Alzheimer Disease Cooperative Study Group ADLs,[19] Bayer ADL scale[21]), quality of life (QOL-AD[21,26]), cognition (MMSE)[19,21] or depression (Cornell Scale for Depression in Dementia (CSDD)).[19]

[Figure 2 about here]

Three RCTs found moderate effects upon caregiver burden (NPI) at 12 months[18,19,21] (SMD = -0.43 (-0.83 to -0.04), N=3, n=469, Figure 2B), although in one study these effects were not sustained at 18 months.[19] For other burden measures not included in meta-analysis, there were significant effects when measured by the Revised Memory and Behavioural Problems Checklist,[18] but not the Zarit Burden Index (ZBI).[18,26] Effects upon caregiver self-efficacy and coping were mixed,[18,26] although significant in one study with extra caregiver education content.[18] No study found effects upon caregiver depression (CES-D,[26] CSDD[19]), but there were lower 9-item Patient Health Questionnaire (-1.6 (-3.0 to -0.2) p =0.02, 18 months) and caregiver stress (2.2 (-4.2 to -0.2) p=0.03, 12 months) scores.[19]

One RCT found higher physician and nurse visits at 12 and 18 months,[19] but mean hospital days,[19] mean hospitalisations, readmissions and emergency department visits[23] were not different to usual PCP care. Evidence for effects upon moving to residential care was mixed: our meta-analysis found no effects on odds of moving to residential care at 12 months (Figure 2C; OR 1.37 [0.28, 6.66], N=2, n=560),[19,21] maintained at 18 months in one study.[19] One large economic evaluation found significant reductions over three years (HR 0.60 (95% CI 0.59 to 0.61), n=3249),[23] but this was not adjusted for baseline functioning or caregiver support. There were no cost-effectiveness analyses for this model, but US claims-based analyses found medical cost savings of $601 (2013$) per patient per quarter[23] or $3474 (2012$) per year,[20] and one study concluded the programme was cost-neutral.[23]

Integrated models

One CCT found no differences between integrated models, usual primary care and usual memory clinics at 12 months in quality of life (QoL-AD), caregiver burden (ZBI), emergency department attendance or hospital admission.[22] Costs did not differ between integrated models and memory clinics (S$13275 vs $15308, p=0.40) or usual PCP care (S$13275 vs $15766, p=0.38) from a societal perspective. Direct medical costs were lower at six months compared to usual primary care. Integrated models were considered cost-effective as they had higher QALYs at 12 months than memory clinics (0.07, 95% CI 0.12 to 0.018), leading to a cost per QALY gained of S$29 042.[22]

Discussion

Summary

We systematically reviewed 23 papers, including 10 studies of nine interventions. There was little good quality evidence for post-diagnostic dementia care led by or substantially involving primary care. We classified interventions into four primary care models. We found that PCP-led care showed effects upon caregiver anxiety and depression in one study from the Netherlands, but no significant differences in depression, neuropsychiatric symptoms, quality of life or functioning. There were lower hospital and memory clinic costs, but no overall cost savings. A PCP-led with specialist consulting support model added little value over usual PCP care for clinical, cost and service use outcomes in two German studies of mixed quality. PCP-case management partnership models showed evidence of effects upon neuropsychiatric symptoms and caregiver burden, distress, coping and mastery, although not upon functioning, quality of life, depression or cognition across one German and four US studies of mixed quality. Evidence for the impact upon moves to residential care was mixed, but claims-based economic analyses indicated this model may be cost-neutral or cost-saving regarding healthcare costs. Finally, integrated memory clinics had limited quality evidence from one Singaporean trial of improved quality of life and cost-effectiveness compared to memory clinics, but no effects upon caregiver burden.

Strengths and limitations

The strengths of this review include the rigorous review process, although we relied upon the quality of the paper's intervention reporting for inclusion decisions and classification decisions regarding primary care involvement. It is therefore possible a small number of studies were excluded or misclassified. Interventions were also heterogeneous even within similar models, limiting conclusions that can be drawn about what works within models. Previous methods of classifying interventions (e.g. carved out, co-managed and integrative hubs[8]) have led to few recommendations, and grouping services in this way allowed us to draw clearer conclusions. Additionally, many studies compared interventions to 'usual care', which is not always well defined or consistent across control services. Most trials were carried out with people with mild-to-moderate dementia and few included key dementia subpopulations such as care home residents, those without a caregiver, or with learning disabilities. Interventions were reported in varying levels of detail and the full range of components covered was difficult to determine in some studies, limiting the conclusions that can be drawn. Although we used quality assessment tools specific to study type, these tools contain items that are difficult to meet in trials which involve substantial service changes (e.g. participant blinding) and often rely on how well a study is reported. Finally, the relatively small number of studies found means our review conclusions may change substantially as future evidence emerges.

Comparison with existing literature

Our review focussed solely on interventions involving shared decisions with a PCP and found primary care provider-case management partnership models offered the most promising evidence. This is similar to reviews of dementia case management alone, both within and outside of primary care, where there is evidence of meeting people's needs, improving quality of life and reducing moves to residential care.[7,10,29] NICE (2018) recommends a named health care professional to coordinate care for people with dementia in England and Wales,[3] although the best professional for this role is still under debate.[30] Our review still found a lack of rigorous cost-effectiveness evidence on PCP-case management partnership models; although recent studies in this review suggested reduced or neutral healthcare costs. Many outcomes were heterogeneous across studies, limiting the opportunity for meta-analysis except for PCP partnership models (and even within this model studies were fairly heterogeneous), but this may improve with increasing core outcome sets.

Implications for research and practice

Our review found that specialists providing consulting advice to primary care providers added little over usual primary care. Better evidence was found for integrated models and for incorporating specialist support into PCP-case management partnership models, but the quality of evidence was still mixed. Further rigorous evidence is needed for other models of care; for example, whilst evidence such as service evaluations suggest integrated memory clinics are received positively by stakeholders, are implementable and may reduce costs,[31,32] there is currently only one non-randomised trial of this approach. Further rigorous evaluation is needed for models that show promising effects, taking country and resources into account to avoid placing an undue burden on primary care services, particularly in low- and middle-income countries.

Conclusion

Primary care offers the potential benefits of care closer to home, closer links to community services and better management of other long-term conditions. Our review suggested primary care-led models produced similar outcomes to memory clinics. Adding specialist consulting support did not appear to improve outcomes or cost-effectiveness, but adding a case manager closely collaborating with a primary care provider showed promise as a care model. Integrated memory clinics may also offer promise in terms of costs.

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Author contributions

RF, GR and KW conceptualised the review as part of a larger grant programme designed by the Pridem research team. SA ran initial searches and RF updated these to 2019. RF, SA and/or GB screened titles, abstracts and full texts. RF and GB assessed study quality. RF led the synthesis with input from GR, KW and JW. RF drafted the manuscript and all authors read and provided feedback on manuscript drafts.

The PriDem research team includes co-authors LR, GR, KW, JW, MK, JM, LA and KHD; and Claire Bamford, Sube Banerjee, Doug Lewins, Lynne Corner, Raphael Wittenberg, Joy Adamson, Sally-Marie Bamford, Sue Tucker and Alistair Burns.

Supplementary figures

1. S1 List of search terms
2. S2 Table of included studies
3. S3 Study quality

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Table 1. Description of model classifications used in review

Model name	Studies	Model description	Comparator	Quality of evidence
PCP-led	n=1 RCT with economic evaluation, Netherlands	Post-diagnosis care is provided and coordinated by the primary care provider (PCP). In the single study available (AD-EURO), management was based on Dutch general practice dementia guidelines and provided over 12 months.[25]	Memory clinics	RCT had low risk of bias in five domains, high risk for participant blinding. EE met the majority of CHEC criteria.
PCP-led with specialist consulting support	n=1 RCT (three arm) with economic evaluation, n=1 CCT, Germany	The PCP leads post-diagnostic care, with specialist support for complex or crisis cases,[17,24] in the form of an interdisciplinary dementia support network[17] or specialists (neurologists or psychiatrists).[24] One also recommended a family caregiver support and psychoeducational group and optional family caregiver counselling (after 12 months in one group).[24]	Usual primary care	RCT moderate quality. EE met all but one CHEC criteria. CCT critical risk of bias due to difference in outcome follow timepoints.
PCP-case management partnership models	n=3 RCTs, n=1 CCT, n=2 economic evaluations (5 USA, 1 Germany)	Post-diagnostic care is led by a case manager (usually a nurse), with a structured needs assessment. A care plan is formed with input from a PCP either on specific aspects of care (e.g. medication, urgent symptoms)[18,19,23,26] or the whole care plan.[21] All were delivered face-to-face over 12 months[19,21,26] except one delivered entirely by phone for 3 months[18] and one unclear.[20] Contacts varied bimonthly to three monthly, with contacts usually becoming less frequent over time. Additional components in some studies included a telephone caregiver education programme[18] and a chair-based exercise group (people with dementia) and support group (caregiver).[19] Four services had specialist input, such as out-of-hours geriatrician support for the person with dementia and caregiver[23] or interdisciplinary case conferences to support the case manager[21] and/or PCP.[19]	Usual primary care	RCTs mixed quality (2-3 domains at high risk of bias and 3-5 domains at low risk). CCT at serious risk of bias. EEs were mixed quality (meeting less than two thirds of the quality criteria).
Integrated memory clinic	n=1 CCT (three arm) with economic evaluation, Singapore	Consultations with the primary care physician and nurse were co-run with a memory clinic geriatrician and nurse, with fortnightly case conference discussions to address concerns or challenges in dementia care and referrals to other allied professionals as necessary, delivered over 12 months.[22]	Usual primary care Usual memory clinic	CCT at serious risk of bias. EE met most CHEC criteria.