Developing the New Interventions for independence in Dementia Study (NIDUS) theoretical model for supporting people to live well with dementia at home for longer: a systematic review of theoretical models and Randomised Controlled Trial evidence

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Abstract
Purpose To build an evidence-informed theoretical model describing how to support people with dementia to live well or for longer at home.
Methods We searched electronic databases to August 2018 for papers meeting predetermined inclusion criteria in two reviews that informed our model. We scoped literature for theoretical models of how to enable people with dementia to live at home independently, with good life quality or for longer. We systematically reviewed Randomised Controlled Trials (RCTs) reporting psychosocial intervention effects on time lived with dementia at home. Two researchers independently rated risk of bias. We developed our theoretical model through discussions with experts by personal, clinical and academic experiences, informed by this evidence base.
Results Our scoping review included 52 studies. We divided models identified into: values and approaches (relational and recovery models; optimising environment and activities; family carer skills and support); care strategies (family carer-focused; needs and goal-based; self-management); and service models (case management; integrated; consumer-directed). The 11 RCTs included in our systematic review, all judged at low risk of bias, described only two interventions that increased time people with dementia lived in their own homes. These collectively encompassed all these components except for consumer-directed and integrated care. We developed and revised our model, using review evidence and expert consultation to define the final model.
Conclusions Our theoretical model describes values, care strategies and service models that can be used in the design of interventions to enable people with dementia to live well and for longer at home.
Trial registration PROSPERO 2018 registration number: CRD42018099693 (scoping review).
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Keywords Dementia · Home care · Theoretical models

Introduction
Around 46.8 million people worldwide have dementia, and this is expected to increase to 131.5 million by 2050 [1]. Two-thirds of people diagnosed with dementia live in their own homes [2] and most want to continue to do so, as independently as possible [3]. Remaining at home benefits the individual with dementia, through greater quality of life, and society, by reducing costs of care [2]. It is unclear which care models enable this most effectively and equitably, and promote development of the “Dementia friendly, dementia capable, and dementia positive” services and communities, to which most developed countries aspire [4, 5]. Good quality community care should be accessible to all people living with dementia. Hospitalisation or nursing home admission of people with dementia may reflect inequities in availability of community care. Risks of care breakdown and hospitalisation are high in people living with dementia [6], especially
for people with greater cognitive, functioning and behavioural care needs; and who are cared for by family carers reporting high stress levels [7]. Living well with dementia has been conceptualised as living with quality of life, choice, autonomy, dignity and as independently as possible. There can be a tension between independence as an expression of full autonomy [8] and the interdependence that can enable people with dementia to live in their own homes for longer [9].

To inform future interventions and selection of outcome measures to evaluate them, we aimed to build a theory and evidence-based model to explain how people living with dementia can be supported to live as full a life as possible at home. To inform our model, we: (a) scoped literature for existing theoretical models of how to enable people with dementia to live at home more independently, with good life quality or for longer; and (b) systematically reviewed Randomised Controlled Trials (RCTs) to identify psycho-social interventions that effectively extended time lived with dementia outside 24 h care settings. Experts by experience, clinical or academic knowledge used this evidence to develop a new theoretical model.

Methods

Search strategies and selection criteria

We undertook searches in August 2018, without limits to language or publication date. We registered reviews (PROSPERO: CRD42018099693/9200).

Scoping review of theoretical models

We used standard scoping review methodology [10]. Inclusion criteria were broad, encompassing: studies, reviews, reports and chapters describing a theoretical or conceptual model, developed from expert consensus, sociological theory or primary research. We included models that explained how people can live well with dementia in their own homes, with greater independence, life quality or for longer. JBD searched Medline/PubMed and OVID. Search terms related to dementia (dementia, Alzheimer’s, memory loss, memory disorder, cognitive impairment), community (community care, community residing, home, private dwelling, sheltered housing), independence (autonomy, freedom, self determination, independent, living well, quality of life) and theories/models and concepts (theory, theor*, model, concept). CC removed duplicates, screened electronic search results, hand searched included papers’ references, and searched careinfo.org, and google scholar using similar terms. CC also search the journal Dementia: the international journal of social science research as a volume of particular relevance to the topic, that has published many papers describing theoretical models underpinning dementia care delivery.

KL and CC read papers independently to identify models. An expert reference group (comprising CC, AB, PR, IL, SB, MO, JJ, ML (authors), an occupational therapist and memory service manager) reviewed preliminary results and suggested areas for further scoping: compassion and empathy. A further PubMed search using these terms and dementia yielded two additional papers.

Systematic review of RCTs

KL searched PubMed, Embase and PsycINFO using keywords: Dementia OR cognitive impairment AND home or community AND time OR length; filtering results to include Randomised Controlled Trials (RCTs) only; hand searched included papers’ references and searched clinicaltrialsregister.eu. We included RCTs evaluating non-pharmacological interventions reporting time a person with dementia lived at home as a primary or secondary outcome. We excluded studies if any participants lived in 24-h care at baseline; and conference abstracts.

We resolved uncertainties regarding study inclusion through discussion. We contacted experts to enquire about additional published or unpublished work. A second author crosschecked one tenth of abstracts from the original searches, and did not identify any additional eligible papers. KL and CC extracted data. We narratively synthesised findings. We did not formally assess publication bias as our study aims did not warrant this.

Quality appraisal

In line with the selected methodological approach, we did not formally evaluate study quality in our scoping review; but we recorded level of evidence (Table 1) [10]. For our systematic review of RCTs, KL and CC appraised study risk of bias independently, using an operationalized checklist developed by our group [11, 12]. Each checklist item scored one point, so five was the highest possible quality score. KL and CC discussed discrepancies to reach consensus. The authors decided a priori the checklist items that should be endorsed to define a study as lower risk of bias (denoted by * below):

1. Were participants appropriately allocated to intervention and control groups? (Was randomisation independent?)*
2. Were patients and clinicians, as far as possible, ‘masked’ to treatment allocation?
3. Were patients who entered the trial accounted for and intention-to-treat analyses used?*
Table 1 Results of scoping review of publications proposing theoretical or conceptual models describing how people with dementia can be supported to live well or longer at home; showing model components identified and level of evidence

| Study | Country | Models proposed | Strategies | Service models | Level of evidence |
|-------|---------|-----------------|------------|----------------|------------------|
| Amella et al. [43] | USA | Values/approaches | 3P’s social ecological model |  | Case studies |
| Banerjee et al. [50, 51] | UK | Person-centred care | Identify needs, carer support, early intervention | Case management | Service evaluation |
| Beck et al. [44] | USA | Occupational therapy models |  |  | Expert opinion |
| Behuniak [21] | USA | Political model |  |  | Expert opinion |
| Brooker [16] | UK | VIPS framework |  |  | Expert opinion |
| Brodaty et al. [36] | Australia | Carer-focused strategies |  | Randomised controlled trial | |
| Bunn et al. [39] | UK | Carer-focused strategies |  | Systematic literature review | |
| Cabin [48] | USA | Rights-based care |  | Palliative care model | Expert opinion |
| Cahill [23] | UK | Person-centred care |  | Collaborative care | RCT and Implementation study |
| Callahan et al., Boustani et al., Callahan et al. [33, 67, 68] | USA | Person-centred care |  |  | Qualitative study |
| Caron et al. [34] | Canada | Carer proxy decisions |  |  | Qualitative study |
| Chang et al. [17] | UK | Agency and personhood |  |  | Qualitative study |
| Daley et al. [26] | UK | Recovery focused model |  |  | Qualitative study |
| Downs and Lord [13] | UK | Person-centred care | Increasing activities | Supporting people funding scheme | Expert opinion |
| Evans et al. [60] | UK | Person-centred care |  |  | Expert opinion |
| Gaugler et al. [40] | USA | Identify/prioritise unmet needs |  | Longitudinal quantitative study | |
| Goeman et al. [54] | Australia |  |  | Case management | Systematic literature review |
| Graff [45] | Netherlands | Optimising environment | Goal-setting, carer skills |  | Case study |
| Gresham et al. [37] | Australia | Ecological theory | Carer-focused strategies |  | Longitudinal quantitative study |
| Hoppes et al. [30] | USA | Home safety/Injury model |  | Pilot quantitative study | Qualitative study |
| Hurley et al. [35] | UK |  |  |  | |
| Khanassov et al. [55] | Canada | Person-centred care | Self-management, carer support, early intervention | Collaborative care | Randomised controlled trial |
| Kohler et al. [59] | Germany |  |  |  | |
| Kolanowski et al. [32] | USA | Theories of neuroplasticity |  | Evidence review | |
| Kontos [19] | Canada | Phenomenological model |  | Expert opinion | |
| Kovach [31] | USA | Sensoristasis & imbalance |  | Evidence review/expert opinion | |
| Laakkonen et al. [46] | Finland | Self-management |  | Randomised controlled trial | |
| Lin & Lewis [4] | USA | Dementia friendly communities |  | Narrative literature review | |
| Livingston [38] | UK | Carer-focused strategies |  | Randomised controlled trial | |
(4) Were all participants followed up and data collected in the same way?*

(5) Was there a power calculation, based on our outcome of interest?

We followed PRISMA guidelines when reporting the review.

**Model development**

CC presented emerging evidence and an initial model draft to the expert reference group. The group considered evidence emerging from the two reviews to decide which components were included in the model. The group agreed the final model at a face to face meeting in September 2018, and although we held a subsequent period of consultation through email discussions, no further changes were suggested by the group or made after this meeting.

**Results**

**Theoretical models scoping review**

We included 52 studies (Fig. 1 shows search results). We list the models identified in Table 1 and described them below. We divided the identified models into (1) values and approaches; (2) strategies for delivering care, and (3) service models for delivering dementia care.
Values and approaches

These model components were reported in qualitative studies, evidence syntheses of predominantly qualitative studies, and expert opinion publications.

**Relational and recovery models** Kitwood is credited with introducing the biopsychosocial model of dementia care: now widely accepted, this posits that functioning in people living with dementia is not solely related to biological illness factors, but also their psychosocial environment [13]. His theory of person-centred care [14–16] argued that personhood, quality of life and well-being are a function of the quality of people’s interactions and relationships. He described malignant social psychology (also termed malignant positioning by others), to refer to interactions that diminish a person’s sense of belonging, personhood and self-worth. Person-centred care describes an individualised, humanistic care approach that promotes agency, choice and partnership in decision-making. Care consistent with this approach gives unconditional positive regard; facilitates a sense of worth; is risk tolerant; maintains the continuity of a person’s identity; and provides opportunity for meaningful engagement and occupation. It is operationalised in the VIPS Framework (absolute Value of human lives; Individualised care; understanding the world from the Perspective of service users; Social environment that supports psychological needs) [16, 17].

Relationship-focussed care extends personhood theory to include inter-relatedness in caring relationships: mutuality and reciprocity [18]. Kontos’ phenomenological model understands agency in people living with dementia as emanating from body (primordial and sociocultural characteristics residing below the threshold of cognition) as well as mind. It posits that people with dementia require respect as on-going although changed persons, who retain a sense of self and can form trusting relationships [19].

Rights-based models advocate for empowerment and engagement of people with dementia in dementia care [13]. Some political theories propose the need to accept the realities of interdependence in dementia care [20, 21], and balance rights to autonomy, protection and good care [22, 23]. There may be trade-offs, for example between reduced privacy from technological surveillance and its potential to enable continued relative autonomy and attenuate risks of harm [24]. Advocating the person with dementia’s autonomy

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**Fig. 1 PRISMA Flow Diagram** for literature review of theoretical and explanatory models of how people with dementia can be supported to live well independently

| Records identified through database searching (n = 703) | Additional records identified through other sources (n = 29) |
|-------------------------------------------------------|----------------------------------------------------------|
| Records after duplicates removed (n = 377)            | Records excluded and reasons (n = 328)                   |
|                                                       | • Not living in own home (n=137)                         |
|                                                       | • Not about dementia (n=61)                             |
|                                                       | • Not about living independently (n=59)                 |
|                                                       | • Model not proposed (n=49)                             |
|                                                       | • Model of family carer stress not directly related to PLWD (n=16) |
|                                                       | • Protocol with no extra information to trials included (n=4) |
|                                                       | • Not in humans (n=2)                                  |

| Full-text articles assessed for eligibility (n = 205) | Full-text articles included in narrative synthesis (n = 52) |
|------------------------------------------------------|------------------------------------------------------------|
|                                                      |                                                            |

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[13] Kitwood
[14] [16–16]
[17] [17]
[18] [18]
[19] [19]
[20] [20, 21]
[21] [22, 23]
[22] [24]
and integrity is described as the foundation of dignity-preserving dementia care [25].

Recovery-focused models in dementia conceptualise recovery as a journey that involves accommodating to diagnosis [26, 27]. Continuity with pre-existing identity, networks, roles and activities can enable recovery. Taking personal responsibility is helpful to people living with dementia where possible; as dementia severity increases, there is a greater role for carers in supporting continuity with pre-existing identity. Menne et al. [28], in reporting findings from qualitative interviews with people living with early dementia, found that a desire to maintain continuity with previous ways of life emerged from narratives. They situated their findings in continuity theory.

Environmental and activity models Functional decline is influenced by the social and caregiving environment, which can induce or maintain “excess disability”: for example, inactivity, boredom, and social withdrawal can compromise functioning [9]. Modifying the home environment can help maintain an individual’s “maximum performance potential” [29, 30]. Modifying the wider environment can promote Dementia-friendly communities [4]. Pacing activities optimally and matching sensory-stimulating and sensory-calm activities to the person with dementia’s needs may prevent intrapsychic discomfort, agitation, and associated functional decline [31]. Physical activity and exercise may also stimulate neuroplasticity and increase cognitive reserve [32]. Callahan suggests these mechanisms are important in a restorative model of care [33].

Family carer-focused models Family carer proxy decision-making regarding place of residence directly influences how long people live with dementia at home. Care recipient factors (degree of autonomy, dementia severity and capacity), context and care (support, environment and crises); family carer factors (other obligations, health, role meaning, emotions and help-seeking attitudes) determine their perceived ability to provide care, which they balance against anticipated consequences of moves to long-term care [34]. Carer self-efficacy, practical ability, values, traditions and resources will also influence their decisions that balance risks and benefits of people with dementia staying at home for longer [35].

Strategies for delivering care

There is at least one Randomised Controlled Trial (RCT) supporting efficacy of each of these broad categories.

Family carer-focused interventions Have reduced carer burden and increased time lived at home by care recipients [36–38], probably because carers who are less stressed and burdened are more able to continue in supporting roles. UK Admiral Nursing Services work specifically with dementia family carers in some localities, but service content depends on local requirements and commissioning [39].

Needs and goals-based care Numerous models focus on identifying and prioritising needs, and/or setting goals to address them. People with dementia with fewer unmet needs live longer at home [40]. The Need-driven, Dementia-compromised Behaviour theory describes how unmet needs can lead to behaviours that challenge, increase carer burden, decrease life quality, and care breakdown. Scholzel-Dorenbos considered how needs might be prioritised, based on their likely impact on quality of life [41]. Goal Attainment Scaling is a method for identifying the unmet need with highest priority and setting goals to address it [42].

Other models guide responses to behavioural or functional needs, e.g. the 3P’s model to change behaviour by considering “the Person, People (who are caring) and Place (environment)” [43]; and a framework to address functional needs, through strategies including stimulus control, verbal and physical prompts, modelling, and physical guidance [44]. In a case study, Graff described an Occupational Therapy (OT) treatment model in dementia combining education, goal-setting, environment adaptation, skills training for people with dementia or family carers, and addressing dysfunctional cognitions about patient behaviour and carer role [45].

Self-management models Position professionals as partners rather than experts and seek to enable self-efficacy in problem-solving [46, 47]. Beneficial effects on spousal quality of life and cognitive function of people with dementia have been reported [46].

Dementia care service models

Cabin contrasted medical and palliative care models that assume treatment is not curative. These include respite care, pastoral care, and volunteer services. Focus is on symptom management and quality of life [48].

Dementia care service models (collaborative care/care coordination) In this service model, people living with dementia are allocated a care manager to coordinate care, facilitate collaboration between services and usually deliver care [49–53]. Dementia case management interventions have been associated with greater benefits for patient and carers if they are: for 6 months or more; multi-disciplinary, interprofessional, and delivered by a case worker with a skilled background (e.g. clinical or trained in dementia care) [54]. It may be more successful when more intensive (up to 50 clients per fulltime worker), with proactive and timely follow-
up [55, 56]. It should deliver relationship-based, holistic, enabling and accessible care [57]. The UK memory service model has a particular focus on early diagnosis and intervention; some memory services deliver case management, while many offer assessment and medication review [50, 51].

**Integrated care models** Aim to create connectivity, alignment and collaboration within services at funding, administrative or provider levels. This is different to, but may facilitate, case management approaches, where a case manager seeks to provide clients with integrated care by liaising with different services on their behalf. These approaches have been associated with fewer hospital days, and increased service use, but not life quality [58, 59]. The UK Supporting People programme funded local authority-employed activity coordinators to support people with dementia living in their own homes to increase pleasant activities. By working across extra-care sheltered and private accommodation, that sought to promote community integration [60].

**Consumer-directed care models** Also termed personal budgets or direct payments in the English context, in these models the person living with dementia, or their proxy, decides which services or support to purchase. They increase service usage, satisfaction and costs in certain circumstances [58].

**Systematic review of RCTs**

Figure 2 shows our search results. We included 11 studies, all of which were rated as higher quality. Table 2 describes study characteristics and findings for included studies. We describe below the three studies (describing two interventions) that significantly increased time for people with dementia living at home.

The Maximizing Independence at Home (MIND) intervention delivers person-centred care with elements from all the “values and approaches” domains in our draft model: there is a focus on optimising environment and supporting family carers. Care is needs- and goal-based; needs are identified and mapped to a menu of care strategies including self-management strategies, carer-focussed...
| Author, (Country) | Participants | N | Intervention | Effect on institutionalisation | Quality rating |
|------------------|--------------|---|--------------|------------------------------|---------------|
| Eloniemi-Sulkava et al. [70] (Finland) | Person with dementia: Family carer dyads | 53 | 47 | Family care coordinator | After 2 years, 17 intervention patients (32%) and 14 control patients (30%) were in care home ($P = 0.80$). | ✓ X ✓ X |
| Eloniemi-Sulkava et al. [71] (Finland) | Person with dementia: spouse dyads | 63 | 62 | Family care coordinator, a geriatrician, carer support groups and individualized services | 2-year adjusted hazard ratio for admission to care home in intervention group was 0.53 ($P = 0.12$). | ✓ X ✓ X |
| Gaugler et al., [72] (USA) | Adult–child carers | 54 | 53 | Carer and Family counselling (see text) | Intervention participants were significantly less likely ($P < 0.05$) to admit their parents to a residential care setting and delayed their parents’ time to admission significantly longer (228.36 days longer on average) than those in the control group. | ✓ ✓ ✓ X |
| Joling et al., [73] (Netherlands) | Person with dementia: Family carer dyads | 96 | 96 | Family counselling | No sig difference in time until institutionalisation (23/96 intervention vs 18/96 usual care). | ✓ ✓ ✓ ✓ |
| Kurz et al., [74] (Germany, Austria, Switzerland) | Family carers | 156 | 136 | Educational, family carer intervention | No significant difference between groups in rates of institutionalisation to nursing home (34 intervention vs 23 control permanent institutionalisations) | ✓ ✓ ✓ ✓ |
| Menn et al., [75] (Germany) | Person with dementia: Family carer dyads | 109 | 110 | 171 | general practitioners' training in dementia care and (1) recommendation of support groups and (2) actively approaching caregiver counseling | No differences between the three study groups (associated $P$ value based on a log-rank test of 0.31 after 2 years and 0.74 after 4 years). | ✓ X ✓ X |
| Mittelman et al., [61] (USA) | Person with dementia: spousal dyads | 103 | 103 | Carer and Family counselling (see text) | Median time from baseline to NH placement of AD patients was 329 days longer in treatment vs control. | ✓ X ✓ X |
| Mittelman et al., [62] (USA) | Person with dementia: spousal dyads | 203 | 203 | Family carers as primary focus of intervention; Family counselling | Patients whose spouses received the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with usual care controls; difference in model-predicted median time to placement was 557 days. | ✓ X ✓ ✓ |
An interventionist takes a coordination role consistent with dementia case management. Relative to participants receiving the control intervention, intervention participants were less likely to permanently leave their home or die over 18 months and remained at home for longer (mean difference: 51 days) [49]. Benefits were sustained over 26 months: intervention participants were less likely to transition from home and remained at home longer than control participants (median difference: 288 days).

The New York University Spouse Caregiver Intervention (NYUCI) comprises two individual and four family counselling sessions tailored to each carer’s specific situation, encouragement of weekly support group participation and ad hoc telephone counselling. Counselling session content was determined by the needs of each caregiver and their family and could include behavioural management and improving family communication. The person with dementia did not attend sessions [61, 62]. Intervention content maps to relational and recovery and family carer-focussed approaches and, because content was flexible, it was possible that other domains were covered.

Expert consultation and Model development

CC synthesised evidence from reviews and the expert reference group to develop a theoretical model of independence at home for people living with dementia, which was then agreed and finalised in consultation with co-authors. Figure 3 shows the final model. This includes the ten values and approaches that should underpin support for people living with dementia: (1) Care should be compassionate and be centred around the person living with dementia, their important relationships and family carers. (2) Care decisions and strategies should balance often conflicting needs to consider both the autonomy and the safety of the person living...
with dementia. Calculated risks can allow more freedom and independence. [3] A focus on continued connections with earlier social networks and roles is important, as these are part of a person’s identity. (4) The home and wider environment should be as dementia-friendly as possible. (5) Activities and plans should be tailored to the individual.

The care strategies that these values and approaches inform should be: [6] developed around the needs and goals of the person living with dementia and their family carers. [7] Psychological and occupational therapy strategies used to reduce disability from behavioural or functional impairments as far as possible and [8] self-management should be supported and. These care strategies should be delivered within a service: [9] for which family carers and people with dementia have a single point of contact. This could, for example be a case manager or General Practitioner; and that provides consistent, joined up care.

**Fig. 3** NIDUS theoretical model of independence at home

**Discussion**

The new model is theoretically informed, aligned with RCT evidence, and has been shaped by personal, clinical and academic perspectives. It incorporates the values and approaches integral to good quality dementia care as well as care strategies and service models likely to deliver these. People living with dementia and family carers are at the centre of our model. Their wellbeing, rights, dignity, needs and goals should inform what care is delivered and how. Care needs to be accessible; family carers and people with dementia need a clear point of contact to support them in managing needs as they arise. This point of contact can monitor the care delivered, ensuring it conforms to the values and approaches that support people to live well with dementia. Our model proposes that the home and wider community should be dementia friendly, and thus extends beyond the realm of clinical to social and community interventions.

Two interventions successfully increased time people with dementia lived at home: the Maximizing Independence at Home (MIND) and New York University Spouse Caregiver Interventions. We explored how the components of these interventions mapped onto our emerging theoretical model. These collectively encompassed the core values included in our final model. The similarities between findings from our theory-based and RCT-based review, and expert opinion supports face validity to our model.

Our model focuses on how people are supported to live well with dementia in their own homes. Essentially, we have developed a model of quality of care at home, though findings resonate with literature on quality of life in dementia and of the subjective experience of living well with dementia. Models of quality of life additionally include life events and challenges. Interestingly, in the IDEAL study, the largest study to date of living well with dementia, domains of psychological
characteristics and psychological health (e.g., personality, optimism, loneliness, depression) most strongly predicted measures of living well.

Limitations

Our model was developed from a synthesis of theoretical models with a range of foci often with poorly defined constructs: living well, with life quality, with better functioning or longer at home. Our scoping review was deliberately broad and not all components included have a strong evidence base. For some model components, such as person-centred care, we find it hard to envisage how their efficacy in improving the lives of people living at home with dementia could be directly, ethically and empirically tested. For others there was equivocal evidence. A Cochrane review of care management interventions in dementia found heterogeneity in interventions and equivocal results, with some indication of delay to care home placement over 18 months [52]. Two care models (consumer-led and integrated-care models) that we identified in our theoretical review were not included in the final model because there was a lack of evidence that they were directly associated with good quality care, though they may facilitate it.

We did not include models explaining how family carers of people with dementia cope and can be supported, for example the stress health process framework [64], unless they directly addressed how and whether people with dementia were able to live well and for longer at home. Other work was excluded because it did not specifically consider dementia. For example, we reported limited evidence for restorative models of home care in dementia as most trials exclude people living with dementia [65].

We only systematically reviewed RCTs regarding the outcome of time lived at home. This is an indicator of living well at home, but quality of the lived experience is important too. We did not meta-analyse outcomes due to heterogeneity of populations and outcomes and because our purpose was to identify effective interventions to inform development of our model. Of all the included studies in our RCT systematic review, only the MIND RCT included a racially diverse population (29% non-white). People from Black and minority ethnic backgrounds tend to access services less and are less likely to move to a care home [66], so there may be cultural differences in optimal models of home support.

Conclusions

Our theoretical model describes values, care strategies and service models that can be used in the design of future interventions to enable people with dementia to live well and for longer at home.

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This work forms the first phase of the NIDUS (New Interventions in Dementia Study), which is hosted within the Alzheimer’s Society Centre of Excellence for Independence at home (Centre of Excellence grant 330).

Compliance with ethical standards

Conflict of interest

On behalf of all authors, the corresponding author states that there is no conflict of interest.

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