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# Transition for people with dementia from day respite services to permanent residential care: a realist synthesis

Claudia Meyer<sup>1,2,3,4\*</sup>, Xanthe Golenko<sup>1,5</sup>, Ron Sinclair<sup>6</sup> and Judy Lowthian<sup>1,7,8</sup>

## Abstract

Respite and permanent transition to residential aged care are processes that are designed to support preferences and needs of people living with dementia and their carers as the disease progresses. These services are highly variable in acceptability, accessibility, and availability for the caregiving dyad, often not reflecting a person-centred, co-ordinated and cohesive approach. This study aimed to use a two-phase realist synthesis to explore how respite and permanent transition models of care work in different contexts, through different mechanisms to produce varying outcomes.

Phase 1 explored preliminary theories and assumptions of the respite care journey, including (a) identification of systematic reviews and innovative programs, and (b) semi-structured interviews sessions with key stakeholders. Phase 2 involved an iterative scoping review to identify and map the available evidence, with a synthesis designed to unpack underlying program theories of why, for whom and in what circumstances respite/transition models of care works.

Phase 1(a) identified ten citations from 126 systematic review abstracts. Fourteen residential care managers participated in a contextual scan – Phase 1(b). Phase 2 expanded this knowledge, identifying a further 13 studies. Three program theories, at the macro, meso and micro level, were elucidated: (1) system-level evidence-based integration, through collaboration and co-ordination; (2) inclusive, quality care, with supportive environmental design; and (3) trust, autonomy, and meaning-making.

A novel realist synthesis approach was used to explore respite and permanent transition models of care beyond ‘what works’. Importantly, findings at the macro, meso and micro level context, suggest nuance, with a shared decision-making approach, is needed to optimise the ever-changing dementia care journey.

**Keywords** Realist review, Dementia, Respite care, Caregivers, Residential care

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## Introduction

Approximately 50 million people globally are living with dementia with most care provided in the home by family and friends (informal caregivers rather than formal care workers) [1]. Worldwide, more than 50% of caregivers report physical and/or mental health concerns resulting from caring duties [2], with the caregiving dyad (i.e. the informal caregiver and person they are caring for) exposed to ongoing negative attitudes and stigma, related to dementia, even among health professionals [2]. Respite care is generally promoted as a means of providing a temporary break for a caregiver to reduce the stress associated with caregiving [3]; but respite care as a concept is more accurately defined as a mutually beneficial restoration of the dyad, through enhanced care partnerships [4]. Respite care can occur as a day program (in-home or in a community or residential facility), or as a temporary, or short stay, within a residential care home (often known internationally as nursing homes or long-term care facility).

Most traditional models of respite care do not meet the needs of the caregiving dyad (e.g., lack of accessibility, dissatisfaction with services), with improvement required in both policy and service provision [5–7]. Recent commissioned reports highlight the need for innovative day respite and residential models of care [8, 9], to relieve caregiver's often-intertwined feelings of guilt, relief, loss of identity, and, for the person with dementia, loss of dignity and control [10]. Transitions between home and respite services or transition to permanent residential care are complex emotional adjustments, with numerous systematic reviews highlighting the challenges and barriers of this journey [5, 11, 12].

Systematic reviews related to community-based day centre programs report mixed results, predominantly due to the variable characteristics of people living with dementia and their caregivers, program availability, staffing and structure [11, 13, 14]. Systematic reviews of transitions in care for people with dementia highlight the risk of adverse outcomes, the importance of the destination environment, and variable quality of relationships between key stakeholders [12, 15–18]. Taken together, these reviews highlight that the evidence is generally inconclusive, lacking depth in program description (and hence replicability), and lack of rigour in study designs and heterogeneity of outcome measurement. The complexity of respite and transition models of care, including highly variable social and environmental contexts, have not been well explored within these reviews, particularly when considering the non-linear progression of dementia.

Current systematic review evidence is often based upon individual studies that follow a more traditional data collection and collation approach, of outcome 'z' being the result of intervention 'x' applied to population 'y'. In the complex social system of health and aged care, understanding and implementing best practice evidence requires an approach accounting for the complexity of the research-practice ecosystem [19]. A realist synthesis generates ideas and assumptions about what works, for whom, under what circumstances, and how and why [20, 21]. Causal relationships are rarely clear or universal for social programs and, as such, the mechanism underpinning the program is critical to recognise, the link between the context of the program (including socio-cultural factors as well as geography) and the program outcomes for the people involved in the research (linked to their reasoning and resources available [22, 23]. This methodology is underpinned by the understanding that programs may or may not work depending on the macro, meso and micro context in which they occur, impacted by broader social and political structures, historical and organisational contexts, and individual factors (people involved in the research) at program level [23]. For the purposes of this study, macro level context was defined as the aged care system/industry, incorporating funding structures. It is acknowledged that there are younger people within residential care, but this study's scope was to inform the aged care sector. The meso level context relates to the service provider organisation, programs, and teams, while the micro level context refers to the individual person living with dementia, their informal caregivers and individual staff members.

The overarching aim of this study was to apply a realist synthesis approach to elucidate the complex nature of the experiences of a person living with dementia and their caregivers through day and short stay residential respite services, to transition to permanent residential care. This encompassed eliciting program theories at the macro, meso and micro levels that explain the mechanisms linking context to outcomes, designed to inform the development of a prototype model of care of embedding day respite within a residential care home.

The specific research questions were:

1. What current theories exist, and what assumptions are held, regarding respite care and transition to permanent care for people with dementia and their carers?

2. What new theories can be identified to understand the complex mechanism/s that underpin why, for whom and in what circumstance a respite care/transition care program (in day or short stay situations) works?

**Methods**

**Study design**

A realist synthesis was used to interpret evidence related to how the respite care experience could be understood within the residential care environment, generating desirable program outcomes [21]. Phase 1 explored preliminary theories and assumptions of the respite care experience, whether that be in the community or the residential care environment, including (a) identification of systematic reviews and innovative programs, and (b) preliminary co-design sessions with key stakeholders. Phase 2 involved an iterative scoping review to identify and map the available evidence, with a synthesis designed to unpack underlying program theories of why, for whom and in what circumstances a respite care/transition care program works, specifically in the context of day or short-stay respite embedded within residential care (see Fig. 1).

Within a realist synthesis, there are often many avenues to explore the involvement of non-research stakeholders is critical to bring an alternative perspective to the issue at hand [24]. Due to time and resource constraints: (a) rapid review methodology was used [25]; alongside (b) consultation with an expert advisory panel comprising of internal and external stakeholders with lived experience of dementia. This approach

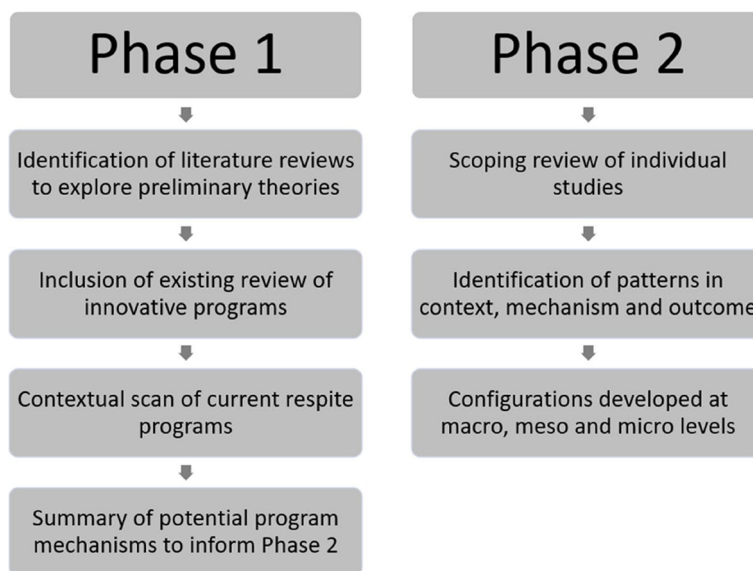
ensured that the research questions addressed gaps in the literature, and that the key findings would be useful and applicable [24].

**Phase 1: Exploration of preliminary theories and assumptions**

Exploration of preliminary theories and assumptions of the respite care experience was through the identification of published literature reviews (systematic, scoping and narrative reviews) and an existing review of innovative programs. In addition, a contextual scan of the current and perceived ideal model of respite care was undertaken with an expert advisory panel within a large aged and community care provider. This scan fits with the Bolton Clarke co-design framework [26], gathering information and insights as the first stage.

**Phase 1 (a): Identification of reviews and innovative programs**

A review of systematic, scoping, and narrative reviews was undertaken utilising Cochrane Database of Systematic Reviews; Database of Abstracts of Review of Effects; CINAHL; Medline; EBSCO Discovery Service; and the grey literature (via a Google search, and known government and peak body websites). For this preliminary exploration, the broad terms of ‘dementia’ with ‘transition’ and/or ‘respite’ were deemed appropriate for searching for titles, keywords, and abstracts, limited to the English language, and published from 2008 onwards. Quantitative, qualitative, and mixed methods reviews were included, with no limitation on the setting of the model of respite care/program. In line with rapid review



**Fig. 1** Outline of methodology

guidelines [25], one author (CM) reviewed titles and abstracts for inclusion. Full text articles were retrieved as relevant. Characteristics of included studies were extracted including author/s and year; aim/s; setting/context; and key features of the program or review. Each article was comprehensively reviewed and, similar to extracting high-level themes in thematic analysis, recurrent patterns were identified for potential mechanisms of why a program may work (or not). This analysis informed the program theories.

In addition, a summary of innovative models of respite care, identified as part of another project [8], was collated, as relevant to understanding respite care program theory.

#### ***Phase 1 (b): Contextual scan of current and perceived ideal respite models of care***

A contextual scan across Bolton Clarke, an aged and community care organisation was undertaken with residential care managers. Twenty managers of 25 care homes were approached to understand the current model of respite care for older people, whether or not they have cognitive impairment, and suggestions for an ideal model of care. Individual consent was not required, as the Bolton Clarke's Human Research Ethics Committee acknowledges this specific type of collection of information and insights aligns with the organisation's co-design framework. Individual discussions were facilitated using a structured interview guide via the online Microsoft Teams platform, and were recorded in lieu of note-taking (see supplementary file for interview questions). A constant comparative analysis method was used to categorise the data and reveal patterns, which were refined throughout the data collection and analysis process [27].

#### **Phase 2: Scoping review**

This phase was an iterative scoping review of individual studies. It built on the Phase 1 review of systematic reviews, with the objective of identifying and mapping available evidence. It was designed to unpack underlying program theories of why, for whom and in what circumstances a respite care/transition model of care works. Importantly, this phase focuses on respite care in the residential care environment NOT on respite models of care based solely in the community (i.e., day respite care provided in the person's home, or centre-based respite separate from a residential care community).

#### ***Data sources and search strategy***

The search was iterative, commencing with the academic database the EBSCO Discovery Service and expanding into CINAHL, Medline and Trip Medical using search terms of respite, day care, age specific care, transition

to (long term care, residential care, nursing homes), transitional programs and transitional care (including appropriate truncation and combination of keywords). Grey literature searching commenced with the advanced Google search function to identify relevant reports and policy papers nationally and internationally. This search strategy, rather than being exhaustive, aimed for a body of literature that would facilitate development of prototype testing and refinement.

#### ***Eligibility criteria***

All study types (including quantitative, qualitative, case studies and opinion pieces) were included to capture the breadth of data relevant to unpacking respite care contexts, the mechanisms by which they operate and the outcomes relevant to people living with dementia, their informal caregivers, organisational staff and management. For this phase, studies were excluded if they focused on community-based day respite programs, given that the emphasis of this review is respite care within the residential care environment (including day respite programs).

The search was restricted to 2008 – June 2020 due to changes within the residential aged care landscape over time. The search was restricted to the English language due to time and resource constraints related to translations. Limitations of age group were applied to eliminate day care related to children and transition care related to disability services. Hand searching of the reference lists was conducted to identify any further studies.

#### ***Selection and appraisal of documents***

One author (CM), in line with rapid review guidelines [25], reviewed the titles and abstracts for inclusion. A second author (XG) reviewed 10% of the titles/abstracts to corroborate inclusion of selected articles. Each study was preliminarily appraised for its contribution to understanding the context, mechanism and outcomes relevant to models of respite care. Relevant full text articles were retrieved.

#### ***Data extraction***

Data from included studies were extracted, including author/s; date; country; brief outline of the study, including the setting/context; contextual factors at the macro, meso and micro levels; and potential mechanisms at the macro, meso and micro levels.

#### ***Analysis and synthesis process***

Data from the included studies were comprehensively reviewed to identify recurrent patterns, in a manner similar to high-level thematic analysis, in the context, mechanisms, and outcomes. Outcomes focused on the

caregiving dyad – the person living with dementia and their caregiver/family member, clustered into negative and positive outcomes. Next, commonalities within context and mechanism were clustered at the macro-, meso- and micro-level, with patterns identified and configurations developed. For example, funding and staff availability are macro-level factors within health and aged care, while the environmental design of residential care homes is meso-level, and individual factors of shared decision-making is micro-level. Potential mechanisms were identified as how and why a program may work, according to resources available and how people act on, or with them. For example, flexibility in, and continuity of, care is a meso-level potential mechanism incorporating input of residential care home management to this principle of care and acting on it through subsequent processes. Data from the contextual scans was used to reinforce or dispute these configurations. This iterative process was led by the first author, with regular input from 2nd author.

**Results**

**Phase 1: Exploration of preliminary theories and assumptions**

**Phase 1 (a): Identification of systematic reviews and innovative programs**

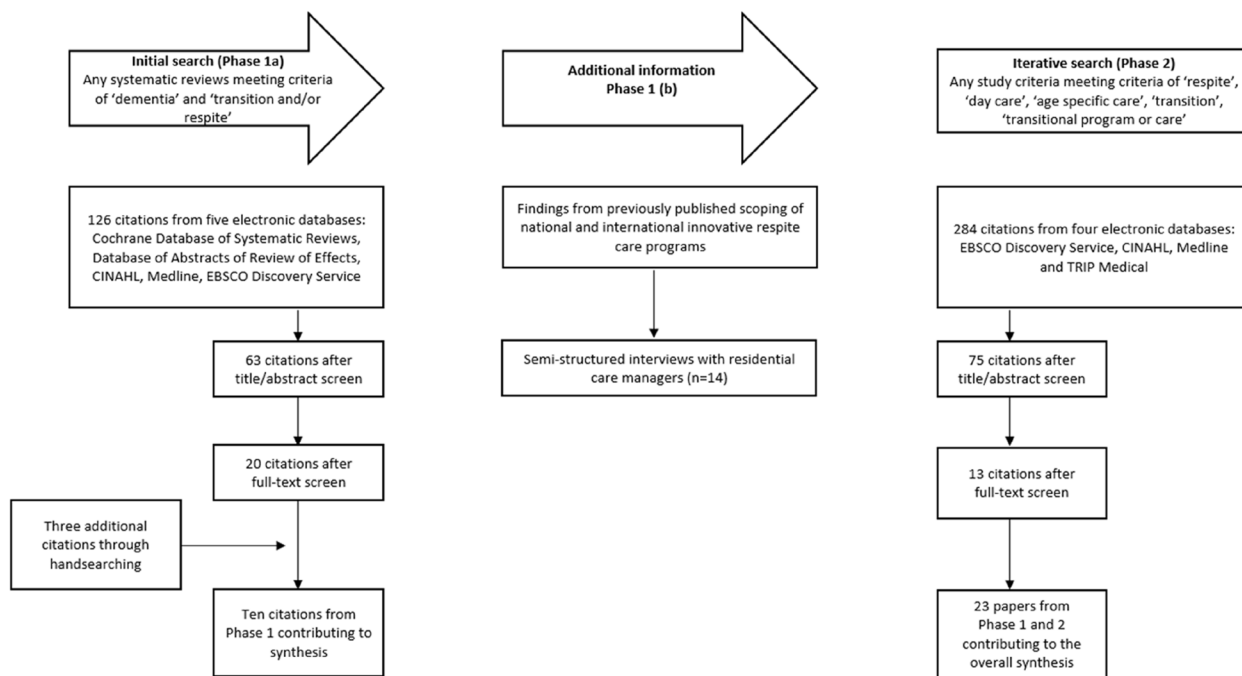
The initial review yielded 126 systematic reviews from the five databases. Sixty-three reviews were retained

after the first screen of title and abstract, with 20 reviews remaining after second screening of the full text article. Three additional reviews were found through handsearching of references. Thirteen reviews were excluded for reasons of: transition focused on residential care into hospital ( $n=2$ ); not dementia focused ( $n=3$ ); not focused on the care journey ( $n=7$ ); and focused on keeping people from transitioning rather than supporting transition ( $n=1$ ). Ten reviews were retained for analysis to elucidate an initial understanding of underlying theories and assumptions of respite care (as seen in Fig. 2). Potential mechanisms were identified (see below). The characteristics of the reviews and how they contributed to the initial prototype framework has been summarised in Table 1, with the above potential mechanisms noted. Figure 2 highlights the evolution of the search strategy between Phase 1 and 2, in line with RAMESES publication standards [21].

This initial understanding from Phase 1 has been summarised below, expanding the potential mechanisms and incorporating contextual factors and outcomes.

**Potential mechanisms**

- Collaborative care partnership, supporting shared decision-making [4, 12, 15–18, 28–30]. This has potential to alter negative beliefs about respite ser-



**Fig. 2** Evolution of Phase 1 and 2 search strategy and resultant studies

**Table 1** Characteristics of included reviews for Phase 1

Data provided by article to inform prototype by potential mechanism

| Author, year, country                 | Aim   | Environmental context  | Key features of the program/review   | Collaborative care partnerships | Responsive services | Meaningful activity | Adequate resourcing | Support for caregivers |
|---------------------------------------|---|--|--|---------------------------------|---------------------|---------------------|---------------------|------------------------|
| Chenoweth et al. (2015) Australia     | Examines the literature in relation to the impact of discharge procedures on patients with dementia and their continuity of care  | Transition (or discharge) from hospital                        | <p>Discharge processes and transitional care for people with dementia require higher levels of co-ordination, communication, and consultation</p> <p>Discharge protocols fall short due to lack of:</p> <ul style="list-style-type: none"> <li>• GP engagement/support</li> <li>• attention paid to handover</li> <li>• discharge planning at point of admission</li> <li>• team co-ordination</li> <li>• education and information for carers and families</li> <li>• comprehensive summaries including pending test results and changes to medication</li> </ul>   | X                               | X                   |                     | X                   | X                      |
| Ferrah et al. (2018) Australia        | To determine the impact of the transition process on nursing home residents following first admission   | Transition from home in the community to residential aged care | <p>Acknowledgement of the critical period of first 6 months after admission for early mortality, with risk factors of age, gender, functional impairment, and number of co-morbidities. Risk is also related to adverse events, hospitalisation and need for end-of-life care</p> <p>Pre and post admission processes were not clearly described, with transfer or changing conditions potentially impacting even in a high-quality environment</p>  | X                               | X                   |                     |                     |                        |
| Hirschman et al. (2018) United States | To provide an overview of available evidence-based interventions to improve transitions in care for persons living with dementia and their caregivers and to provide practice recommendations | Transition between hospital, community and residential care    | <p>Key delivery characteristics include:</p> <ul style="list-style-type: none"> <li>• interprofessional care team</li> <li>• prompt communication</li> <li>• caregiver education and support</li> <li>• establishment of goals of care</li> <li>• collaborative visits</li> <li>• planning for emergent needs</li> </ul> <p>Challenges arise through the need for:</p> <ul style="list-style-type: none"> <li>• care teams to have dementia expertise</li> <li>• informal caregivers to be an integral part of the team</li> <li>• caregiver education and preparation</li> <li>• behaviour symptom management when identifying goals of care</li> </ul> | X                               | X                   |                     | X                   | X                      |



**Table 1** (continued)

Data provided by article to inform prototype by potential mechanism

| Author, year, country               | Aim   | Environmental context                                       | Key features of the program/review  | Collaborative care partnerships | Responsive services | Meaningful activity | Adequate resourcing | Support for caregivers |
|-------------------------------------|---|---|---|---------------------------------|---------------------|---------------------|---------------------|------------------------|
| Maayan et al. (2014) United Kingdom | To assess the benefits and harms of respite care for people with dementia and their caregivers. In particular the effect of respite care on rates of institutionalisation | Community- and institution-based respite services           | This Cochrane review defined respite care as a blanket term for a very diverse range of services, with variable dimensions – place (in-home, day centre or residential care), provision of care (trained or untrained staff and volunteers), duration (couple of hours to a few weeks), and planned or unplanned. The included studies showed no effect on rate of institutionalisation and caregiver burden. This review highlights the difficulty with showing effect of a complex intervention   |                                 |                     |                     |                     | X                      |
| O'Shea et al. (2017) Ireland        | What are key stakeholder's experiences of respite services, and what are their perspectives on respite service development, in relation to dementia?                      | Community- and institution-based respite services           | Key stakeholder (people with dementia, carers, respite service staff and management, health professionals and policy makers) experience of respite services and perspectives on respite service development include: <ul style="list-style-type: none"> <li>• transitioning to service use</li> <li>• expanding organisational capacity</li> <li>• dementia care quality</li> <li>• building collaborative care partnerships</li> <li>• dyad restoration</li> </ul>   | X                               | X                   | X                   | X                   | X                      |
| O'Shea et al. (2019) Ireland        | To provide clarification on the use and meaning of the term 'respite' and to consider the concept in relation to the dominant care paradigm in dementia                   | Respite care in all settings – in-home and residential care | Characterisation of respite as a service often inconsistent with meaning for users – a physical break for carers does not always translate in reduction in carer burden<br>Several client factors impact a carer's ability to have a mental break <ul style="list-style-type: none"> <li>• dyadic relations</li> <li>• recognising and accepting need</li> <li>• carer psychosocial factors</li> <li>• restorative occupation</li> <li>• stigma</li> </ul> Several service-related factors were noted: <ul style="list-style-type: none"> <li>• service model and characteristics</li> <li>• care quality and staff expertise</li> <li>• meaningful occupation for the person with dementia</li> <li>• communication and support</li> </ul> | X                               | X                   | X                   | X                   | X                      |



**Table 1** (continued)

Data provided by article to inform prototype by potential mechanism

| Author, year, country                | Aim  | Environmental context                                     | Key features of the program/review   | Collaborative care partnerships | Responsive services | Meaningful activity | Adequate resourcing | Support for caregivers |
|--------------------------------------|--|---|--|---------------------------------|---------------------|---------------------|---------------------|------------------------|
| Ray et al. (2015) Canada             | To inform best practice for care transitions for people with dementia  | Transitions between hospital and home or residential care | Care transitions resulted in an increase in adverse outcomes related to early readmission to hospital, mortality, change in behaviour or function, and satisfaction<br>Factors affecting these outcomes included:<br>• transitioning as a group/with support<br>• caregiver involvement and pragmatic support<br>• level of BPSD<br>• health status  | X                               | X                   |                     | X                   | X                      |
| Sullivan et al. (2019) United States | To provide the state of the science on the experiences of older adults transitioning to long term care                         | Transition to residential care                            | Uses a framework to understand:<br>• relationships to nature of transition properties (e.g. time, process, critical points)<br>• transition conditions (e.g. personal, community)<br>• patterns of response (e.g. perceived wellbeing, engaging mastery)<br>Three themes emerged:<br>• painful loss that requires a mourning process<br>• seeking stability through gaining autonomy to sustain a new sense of self<br>• acceptance when a unique inner balance is reached | X                               |                     | X                   |                     | X                      |
| Vandepitte et al. (2016) Belgium     | To investigate the effectiveness of different types of respite care in supporting informal caregivers of persons with dementia | Community-based and institutional respite care services   | Day services resulted in:<br>• reduced carer burden and stress, especially when carer support is part of day program<br>• reduction in responsive behaviours<br>• acceleration of permanent care placement<br>Temporary residential admission has less favourable results than day services, likely related to the two transitions – the first adjustment into residential care and the second adjustment on returning home  | X                               |                     |                     |                     | X                      |

**Table 1** (continued)

Data provided by article to inform prototype by potential mechanism

| Author, year, country         | Aim  | Environmental context          | Key features of the program/review  | Collaborative care partnerships | Responsive services | Meaningful activity | Adequate resourcing | Support for caregivers |
|-------------------------------|--|--------------------------------|---|---------------------------------|---------------------|---------------------|---------------------|------------------------|
| Young et al. (2019) Australia | To explore the experiences of people with dementia of transition to long term care to establish principles of support, recommendations, and priorities for future research | Transition to residential care | <p>Five principles were identified:</p> <ul style="list-style-type: none"> <li>• persons living with dementia and their families should be supported with respect to their unique, individual context</li> <li>• both the positives and negatives of transitions to long term care should be acknowledged and validated</li> <li>• input should be sought from persons living with dementia regarding decisions to transition to long term care</li> <li>• persons living with dementia and their families should be encouraged to maintain regular social contact throughout all stages of the transition</li> <li>• once in the care home, persons with dementia should receive support to integrate socially in the new setting</li> </ul> | X                               | X                   | X                   |                     | X                      |

vice use and is underpinned by care quality and staff expertise.

- Co-ordinated, tailored, and *responsive services* with transparent communication, enduring relationships, and timely access to services [4, 15–18, 28, 29].
- Engagement in *meaningful activity*, with a sense of belonging and social integration, promoting a mutually beneficial experience to restore the dyad [4, 12, 18, 28]. This also allows for contextualising current experiences and events through valued history.
- *Adequate resources*, infrastructure and clinical governance of destination environment and practices [4, 15, 17, 28, 29]. This includes dedicated personnel to adequately plan and manage transition, and a non-institutional design to enhance a sense of safety and wellbeing.
- Education and emotional *support for caregivers*, designed to reduce guilt and stress, and acknowledge grief and loss [3, 4, 12, 15, 17, 18, 28–30].

In addition to building on core principles of person-centred care, reablement/restorative care, ageing in place and integrated care, findings from the scoping of national and international innovative respite care programs (as per previously published work) [8] were:

- Community engaged scholarship, utilising an inter-generational approach with university students participating in structured aspects of the model of respite care;
- Social and community integration, by collaborating with existing services to combine resources and supplement programs; and
- Day care centre style models of respite care co-located in a care home, including for extended hours services and overnight care

#### **Phase 1 (b): Contextual scan of current and perceived ideal respite care programs**

Semi-structured interviews were held with fourteen residential care managers (70% participation rate). This contextual scan of current and perceived ideal (i.e., their views of an ideal program) models of respite care within Bolton Clarke care homes encompassed four key areas, with challenges and solutions/ideas to inform the evolving program theory (see Table 2).

As Phase 1 progressed, it became apparent that day models of respite care were often conducted in the community, separate from residential care services. However, the likelihood of a person living with dementia entering residential care at some stage, either for respite care services or transition to permanent care, is relatively high.

The apparent disconnect between community-based models of respite care and models of residential care highlighted the need for a deeper dive into the literature to understand the journey of respite care embedded within residential care homes ± transition into permanent care. This was explored in Phase 2, with community-based models of care excluded from this section.

#### **Phase 2: Scoping review**

The Phase 2 search resulted in 284 titles and abstracts from the four databases. Of these, 75 full text articles were retrieved, cross-referenced with articles included within the systematic reviews of Phase 1. A total of 62 articles were excluded for the following reasons: day respite not embedded within residential care ( $n=22$ ); not related to people living with dementia ( $n=24$ ); not related to respite/transition care ( $n=11$ ); transition from residential care to hospital ( $n=2$ ); study protocol ( $n=2$ ); and focus on caregiver education, not respite ( $n=1$ ). Thirteen studies contributed to the synthesis (Fig. 2). Of these, five studies met the criteria for short stay residential respite care [9, 31–34], and a further eight studies focused on transition into permanent residential care [35–42]. No studies met the criteria for day respite services embedded within residential care settings.

A program's impact (or outcomes) refers to the intended or unexpected intervention outcomes [21], typically as a result of the interaction between the context and the mechanism by which people involved in the research are encouraged or supported to change behaviour (and thus benefit from the program). Outcomes for respite care and transition to permanent care were identified for the caregiving dyad. These outcomes were clustered into: (1) positive outcomes including relief, increased quality of life, confidence, dignity, inclusion, and empowerment; and (2) negative outcomes including guilt, stress, anxiety and mortality.

There were several contextual factors and possible mechanisms identified within the studies at the macro, meso and micro levels as summarised in Table 3. Contextual factors at the macro level included systemic concerns and suitable staffing mix [9, 32, 38, 40, 42]; at the meso level, co-located services [31, 32], environmental design [32, 34–36, 38, 39, 42], and institutional practices [9, 33–39, 41–43]; and at the micro level, caregiving dynamics [9, 31, 33–42] and staff expertise and attitudes [9, 31–42, 44]. Potential mechanisms included: macro level factors of the need for robust and clear financial pathways [9] and clarity of service options and processes [9, 37, 38, 40, 42]; at the meso level, flexibility in, and continuity of, care [9, 31–36, 38, 39, 42] and equity and inclusion [9, 31, 32, 34–36, 38–42]; and at the micro level, shared narratives and decision making, for a common point of

**Table 2** Contextual scan of current and perceived ideal respite care programs – findings from interviews with current residential care managers

|                   | Current challenges   | Potential solutions/ideas  |
|-------------------|--|--|
| Admission process | Onerous documentation for the organisation<br>Inaccurate and incomplete handover information from hospital, making it difficult to match the resident with care home   | Life Story approach to gain an understanding of what is important to the individuals involved (dyad)<br>Good rapport with referrers<br>Family input for any behaviour management issues        |
| Resources         | Funding options/Financial implications<br>Workforce pressures related to sufficient numbers and quality for respite programs<br>Organisational targets for full bed occupancy versus availability of beds when respite is needed | Clear financial pathways for respite journey<br>Upskill of staff in dementia care<br>Transport support   |
| Environment       | Dedicated physical space issues<br>Appropriate access to the residential care home and internal access to toilets<br>Marketing limitations   | Shared environment between residential care and co-located retirement living communities<br>Homely and comfortable environment<br>Supporting diversity<br>Marketing to a care home's strengths |
| Engagement        | Staff attitudes related to residents in permanent care versus respite care<br>Stigma associated with residential care<br>Competition with other care providers in some areas   | Optimisation of social connection to decrease loneliness and isolation for both members of the dyad<br>Meaningful activity<br>Community connection   |

understanding between the person with dementia, and their informal and formal carers [9, 31–36, 38, 40–42], and meaningful activity [9, 31, 34–36, 38–41].

### Synthesis of findings

Evidence collation of ten reviews from Phase 1 and a further 13 studies from Phase 2, and input from the contextual scans of Phase 1 (b), allowed the configuration of emerging patterns in context, mechanisms, and outcomes. Mechanism components were differentiated into resources and reasoning, resulting in a deeper understanding of how program resources introduced into a particular context can elicit a change in reasoning (and behaviour), leading to outcomes [22].

From this synthesis, three program theories for dementia-specific models of respite care at the macro, meso and micro level, were elucidated (Fig. 3). The first program theory is macro-system-level evidence-based integration, through collaboration and co-ordination; the second at the meso-level is inclusive, quality care, with supportive environmental design; and the third program theory at the micro-level is trust, autonomy, and “meaning-making” (i.e. the restoration of meaning in the context of highly stressful situations) [45].

#### **Program theory (1): System-level evidence-based integration, through collaboration and co-ordination**

The program theory of system-level evidence-based integration, through collaboration and co-ordination for respite care ± transition to permanent care was supported by 13 studies (Phase 1 and 2) [4, 8, 9, 15–17, 28, 29, 32, 37, 38, 40, 42] and the contextual scans.

From a contextual perspective at the macro level, system-level concerns about funding, and institutional structures and practices were evident through Phase 1 and 2. Transition from hospital into residential care was considered an important component, given this is a common route to temporary respite or permanent care, with the demands on, and cultural norms of, hospitals being highly variable, often conflicting with the individual needs of people living with dementia [15, 29, 38]. Transition to residential care was impacted by these hospital processes, as elucidated through the contextual scan. Jurisdictional issues across municipalities can lead to unwanted delays in transition [40], while legalities, such as inability to access healthcare within the care home for the caregiver, also impact caregivers and people living with dementia who wish to transition together into residential care [42]. Further contextual issues arise for successful/effective transition into respite care services, with constraints noted on availability and accessibility of care due to the rigidity of respite care models (i.e. lack of flexibility and responsiveness) [4].

The Phase 1(b) contextual scan identified that mechanisms including human and financial resourcing to support comprehensive discharge planning, including preparation of a detailed person history and behaviour support plan prior to transition from hospital to residential care, for respite care or permanent transition [15, 29, 38]. For respite care services, an adequate staffing mix to ensure suitably qualified personnel for service provision and supported transition was identified, including support for the less tangible aspects of care [9, 32, 38, 40]. Funding for innovative models of respite care is critical,

**Table 3** Individual studies, noting contextual factors and potential mechanisms

| Author, year, country   | Brief outline of study  | Contextual factors      |                                  |                     |                      |                         | Potential mechanisms |                            |                    |                                       |  |                    |                                      |   |   |  |
|---|---|-------------------------|----------------------------------|---------------------|----------------------|-------------------------|----------------------|----------------------------|--------------------|---------------------------------------|--|--------------------|--------------------------------------|---|---|--|
|   |   | Macro factors           |                                  | Meso factors        |                      | Micro factors           | Macro factors        |                            | Meso factors       |                                       | Micro factors                          |                    |                                      |   |   |  |
|   |   | Systemic funding issues | Staffing mix and task allocation | Co-located services | Environmental design | Institutional practices | Caregiving dynamics  | Staff expertise & attitude | Financial pathways | Clarity in service options/ processes | Flexibility in, and continuity of care | Equity & inclusion | Shared narrative and decision making | Meaningful activity, home-like routines |   |  |
| <b>Short term respite programs</b>                              |   |                         |                                  |                     |                      |                         |                      |                            |                    |                                       |  |                    |                                      |   |   |  |
| Harkin et al. (2020) Australia [31]                             | A comparison between 'cottage' model of respite, with no mandatory minimum stay, and traditional models within residential care homes   |                         |                                  | X                   |                      |                         | X                    |                            |                    |                                       |  | X                  |                                      |   | X |  |
| Mercieca et al. (2013) Australia [32]                           | An innovative 3-day person-centred respite program, providing a home-like experience  | X                       | X                                | X                   |                      |                         |                      |                            |                    |                                       |  | X                  |                                      |   | X |  |
| Older People's Commissioner for Wales (2018) United Kingdom [9] | There is a seamless transition between the day respite and short stay program   |                         |                                  |                     |                      |                         |                      |                            |                    |                                       |  |                    |                                      |   |   |  |
|   | A report commissioned by the Older People's Commissioner for Wales to give voice to the person with dementia and their caregivers, providers and healthcare professionals to rethink respite care | X                       | X                                |                     |                      | X                       |                      |                            |                    |                                       |  | X                  |                                      |   | X |  |

**Table 3** (continued)

| Author, year, country                           | Brief outline of study  | Contextual factors      |                                  |                     |                      |                         | Potential mechanisms |                            |                    |                                       |   |                    |                                      |   |   |
|---|---|-------------------------|----------------------------------|---------------------|----------------------|-------------------------|----------------------|----------------------------|--------------------|---------------------------------------|---|--------------------|--------------------------------------|---|---|
|   |   | Macro factors           |                                  | Meso factors        |                      | Micro factors           | Macro factors        |                            | Meso factors       |                                       | Micro factors                           |                    |                                      |   |   |
|   |   | Systemic funding issues | Staffing mix and task allocation | Co-located services | Environmental design | Institutional practices | Caregiving dynamics  | Staff expertise & attitude | Financial pathways | Clarity in service options/ processes | Flexibility in, and continuity of, care | Equity & inclusion | Shared narrative and decision making | Meaningful activity, home-like routines |   |
| Phillipson et al. (2011) Australia [33]         | Contrasting the views/ beliefs of non-users and users of residential respite care using the belief constructs of the Theory of Reasoned Action  |                         |                                  | X                   |                      | X                       |                      |                            |                    | X                                     |   |                    |                                      | X                                       |   |
| Riekkola et al. (2019) Sweden [34]              | Nurses, counselors, therapists, social workers and personal care workers provide insights on how participation was promoted during respite care |                         |                                  |                     | X                    |                         |                      | X                          |                    |                                       | X                                       |                    |                                      | X                                       | X |
| <b>Transition to permanent residential care</b> |   |                         |                                  |                     |                      |                         |                      |                            |                    |                                       |   |                    |                                      |   |   |
| Bramble et al. (2009) Australia [35]            | A qualitative study to outline the experiences of family caregivers who have placed a relative with dementia into long-term care                |                         |                                  |                     | X                    |                         |                      | X                          |                    |                                       | X                                       |                    |                                      | X                                       | X |

**Table 3** (continued)

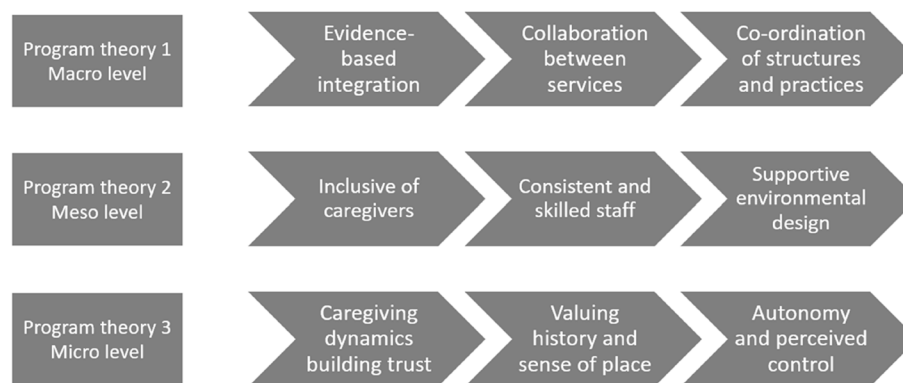
| Author, year, country                              | Brief outline of study  | Contextual factors      |                                  |                     |                      | Potential mechanisms    |                     |                            |                    |                                       |   |                    |                                      |   |  |   |
|--|---|-------------------------|----------------------------------|---------------------|----------------------|-------------------------|---------------------|----------------------------|--------------------|---------------------------------------|---|--------------------|--------------------------------------|---|--|---|
|  |   | Macro factors           |                                  | Meso factors        |                      | Micro factors           |                     | Macro factors              |                    | Meso factors                          |   | Micro factors      |                                      |   |  |   |
|  |   | Systemic funding issues | Staffing mix and task allocation | Co-located services | Environmental design | Institutional practices | Caregiving dynamics | Staff expertise & attitude | Financial pathways | Clarity in service options/ processes | Flexibility in, and continuity of, care | Equity & inclusion | Shared narrative and decision making | Meaningful activity, home-like routines |  |   |
| Davison et al. (2019) Australia [36]               | The perspectives of residents with dementia, their family members and care home staff were sought on factors that facilitate or impede adjustment on transition to permanent residential care |                         |                                  | X                   |                      | X                       |                     |                            |                    | X                                     |   |                    | X                                    |   |  | X |
| Gaugler et al. (2015) United States [37]           | A multiple-methods study evaluating the effectiveness of a psychosocial intervention to help families manage distress following long-term care placement of a relative with dementia          |                         |                                  |                     |                      |                         | X                   |                            |                    | X                                     |   |                    | X                                    |   |  |   |
| Gilmore-Bykovskiy et al. (2017) United States [38] | Describing and identifying factors related to the quality of transition from hospital to long-term care, from the perspective of skilled nursing staff  | X                       |                                  |                     | X                    |                         |                     |                            |                    | X                                     |   |                    | X                                    |   |  | X |



**Table 3** (continued)

| Author, year, country                 | Brief outline of study  | Contextual factors      |                                  |                     |                      | Potential mechanisms    |                     |                            |                    |                                       |   |                    |                                      |   |   |
|---------------------------------------|---|-------------------------|----------------------------------|---------------------|----------------------|-------------------------|---------------------|----------------------------|--------------------|---------------------------------------|---|--------------------|--------------------------------------|---|---|
|                                       |   | Macro factors           |                                  | Meso factors        |                      | Micro factors           |                     | Macro factors              |                    | Meso factors                          |   | Micro factors      |                                      |   |   |
|                                       |   | Systemic funding issues | Staffing mix and task allocation | Co-located services | Environmental design | Institutional practices | Caregiving dynamics | Staff expertise & attitude | Financial pathways | Clarity in service options/ processes | Flexibility in, and continuity of, care | Equity & inclusion | Shared narrative and decision making | Meaningful activity, home-like routines |   |
| Henkus-ens et al. (2014) Canada [39]  | Secondary analysis of longitudinal qualitative data exploring the experiences of food and mealtimes after relocating to long-term care                        |                         |                                  | X                   |                      | X                       |                     |                            |                    | X                                     |   |                    |                                      |   | X |
| Kiwi et al. (2018) Sweden [40]        | Exploring cultural adaptation and changing family values for carers of people with dementia from Iranian backgrounds living in Sweden                         | X                       |                                  |                     |                      |                         | X                   |                            | X                  |                                       |   |                    |                                      |   | X |
| Lee et al. (2013) United Kingdom [41] | A qualitative study exploring older person's experiences of transition to residential care, including how relocation is reflected in their personal narrative |                         |                                  |                     |                      | X                       |                     |                            |                    |                                       | X                                       |                    |                                      |   | X |





**Fig. 3** Three program theories at macro, meso and micro level

moving away from a one-size-fits-all approach [9], to social and community integration [8], leveraging a range of sectors (i.e. hospitality, arts, the environment) [9]. Sharing and supplementing service resources [8, 28], plus collaborative inter-professional teams are key for success [15, 17, 28, 29]. Mechanisms also include a reasoning perspective (i.e. behavioural and cognitive changes), such as innovations that allow creative partnerships to flourish [9] and respite care to be sufficiently acceptable to the care recipient to allow caregivers to experience the mental, physical, emotional and spiritual break they desire [4]. Fostering system and organisational change is crucial to support outcomes of flexible and responsive services [9, 28, 38], with clear financial transaction pathways, as identified by residential care managers, to allow different sectors of aged care to ‘marry up’ for seamless transitions [9, 37].

**Program theory (2): Inclusive, quality care, with supportive environmental design**

The second program theory at the meso-level, encompassed inclusive, quality care, with supportive environmental design, emerging from 21 studies (Phase 1 and 2) [4, 9, 15–18, 28–42] and the contextual scans.

From a contextual perspective, adequate infrastructure and clinical governance of destination environment and practices emerged as key factors during transition to respite or permanent care. Ray et al. [29] identified the risk of mortality for people living with dementia should they transition to an environment with high anti-psychotic use or lack of access to end-of-life care, acknowledging that outcomes may differ according to care home characteristics. Organisational structures that support the establishment of care goals and forward planning for emergent care needs are key [17], including advance care planning, while practices to support shared decision-making ease negative emotions associated with transition [18]. The

contextual scans of Phase 1 (b) revealed the benefit of co-located services such as retirement living with residential care services and/or community-based activities within the residential care home, to support familiarity, acclimatisation and seamless transition, as supported by Harkin et al. [31].

Contextual factors also include environmental design, capturing architecture, physical layout and the less tangible aspects that make the environment home-like and dementia-enabling. The physical environment supports engagement and participation, whether this be group participation or space for quiet and calm, a non-institutional design tailored for individual preferences and needs [28, 34, 38]. Appropriate orientation to the care home environment, both physical and social, promotes feelings of inclusion and reduces grief for families [35], with positive mealtime environments highlighted as an area for necessary adaptation [39]. Positively, accommodating the needs of both the person living with dementia and their caregiver through co-habitation options was occasionally provided [42].

Resource-oriented mechanisms to support program theory 2 included consistent and skilled residential care staff, and dedicated roles to support transition. An inclusive environment is fostered through appropriately trained care staff, ensuring high quality person-centred dementia care [17, 28]. This is particularly relevant for the management of atypical behaviours associated with dementia [17, 29], impacting a caregiver’s willingness to take up respite care for the care recipient for fear of emotional and physical care needs not being met [33]. Formal qualifications are perceived as being important, as is care delivery centred around empathy and respect [32]. Remaining cognisant that the person living with dementia continues to be a person with diverse needs and preferences, will ease the emotional stress of transition and promote inclusion [18], with resourcing for flexibility,

meaningful participation and choice in care critical [9, 35].

Residential care homes rely on comprehensive and accurate admission information to ensure a smooth transition into respite or permanent care [15], which is supported by dedicated inter-professional personnel to plan and manage these transitions [17, 29]. Consistency in staffing encourages a 'getting to know you' culture, with information technology aiding ongoing connection with family throughout this challenging time [29]. From a practical perspective, clarity around user costs, and safe and reliable transport for day respite services ease the burden for informal caregivers [28].

From a reasoning perspective of mechanisms, informal caregivers are integral to the care team [17], with preparation for temporary or permanent transition being beneficial [15, 17]. With appropriately trained staff assisting transition, a gradual settling in period to residential care home structures and routines enhance feelings of safety and security [28], as does striving to understand individual dyad preferences so that respite provides the necessary restorative break [4].

#### **Program theory [3]: Trust, autonomy and meaning-making**

The third program theory at the micro, or individual, level of trust, autonomy and meaning-making, was identified through 22 studies in Phase 1 and 2 [3, 4, 9, 12, 15, 17, 18, 28–36, 38–42, 46], plus the contextual scans.

From the perspective of social context, caregiving dynamics, between the person living with dementia, their informal caregiver, and individual staff was core to the culture of meaningful respite care and acceptable transition to permanent care programs. Trustworthy relationships were built around a reciprocal exchange of knowledge and information [34] alongside open and honest communication with familiar staff [46]. Fostering social connection between new and existing residents promoted inclusion in the new environment [18], identifying commonalities between those having respite at the same time [32]. Establishing a culture of valuing the person living with dementia's history and sense of place, promoted feelings of belonging and security [46]. Family involvement at the time of transition to permanent care sometimes created tension such as when a family member was blamed for the decision [36], but family visitation in the early days of transition was generally promoted as a guiding principle of care [18].

From a structural context perspective, traditional models of respite care (of time away from each other) were not necessarily restorative nor resilience building [9], with non-institutional environments promoting connection to more homely, familiar settings [31, 32] and dyad restoration [4]. The contextual scans highlighted the

benefits of co-located retirement living and residential care programs through promoting comfort and familiarity with staff and residents.

Resource-oriented mechanisms incorporated education and support for caregivers. This may have been part of a day respite program designed to reduce stress [30], or as comprehensive information on the options of transition to permanent care [46]. Importantly, education and support included acknowledging and validating both positive and negative aspects of respite care and transition to permanent care, plus guidance on shared decision-making with the person living with dementia to build a common point of understanding between informal and formal carers [18]. Resources that contextualise current experiences and events through valued history, promoting dignity and autonomy are critical to ensuring meaningful activity for the person with dementia [31, 38].

From a reasoning perspective, successful respite experiences for caregivers including the perceived utility of the service and addressing normative beliefs about caring responsibilities [33], reducing feelings of guilt and inadequacy [28] and having confidence in the staff that it would be a positive experience for the care recipient [34]. Autonomy and perceived control in negotiating and facilitating transition through shared decision making was valued [29, 33, 41, 46], but at times the focus on quality of life for caregivers meant the opinion of the person living with dementia went unheard [3, 40]. A fear of being socially evaluated, or the stigma and perceived image of residential care, was a deterrent to the use of respite care [28], with a wide range of dementia-friendly initiatives encouraged [9]. Over time, on moving through aspects of the grief process, transition to permanent care is usually accepted [12].

#### **Discussion**

Models of respite care are considered an integral part of best practice dementia care, with O'Shea et al. [4] conceptualising them as "a psychological outcome of a mental break for caregivers, which can be facilitated by the use of formal health and social care services under certain conditions, when the caregiver perceives that service use is necessary and mutually beneficial for the dyad" (4, pg 1458). The realist synthesis of the international literature exploring models of respite and transition to permanent care beyond 'what works', has expanded our understanding that models of care or programs operating in different contexts with different mechanisms produce different patterns of outcomes [21]. The international review has been supplemented with material from the Australian context. Three program theories were synthesised at the macro, meso and micro level: (1) System-level evidence-based integration, through collaboration and

co-ordination; (2) Inclusive, quality care, with supportive environmental design; and (3) Trust, autonomy, and meaning-making. These findings suggest how Australian service providers (and perhaps beyond) can work more closely, with a shared decision-making approach, with people living with dementia and their informal caregivers to optimise dementia care, whilst accounting for the macro, meso and micro level context.

The right of people living with dementia and their caregivers to live life with dignity, autonomy and equality is the World Health Organisation's vision for the global action plan on the public health response to dementia [47]. For this to be fulfilled, it must be manifested at the macro, meso and micro levels, including a focus on respite and permanent transition models of care. Multi-sectoral collaboration, with a comprehensive and coordinated response [47], is vital to connect acute care, community health and social care, and residential care. In Australia, the introduction of the Aged Care Act 1997 and subsequent Productivity Commission report 'Caring for Older Australians' reframed residential care from being institutional care to that underpinned by person-centred care principles, offering greater choice and flexibility of services for older people [48, 49]. It is perhaps understandable that institutions have individual policies and processes in place, but seamless person-centred transition appears predicated on sufficient human and financial resourcing [28, 37, 38]. Several studies in this review also highlighted the need for innovative models of care, to share resources across services and to encourage choice and flexibility. Interestingly, this extended to several industries beyond health and social care such as the arts, education, and the environment [8, 9, 28], providing linkage opportunities for meaningful intergenerational and multisector engagement.

At the organisational, or meso level, shared decision-making between people living with dementia, caregivers and staff was central to effective respite and permanent transition models of care. Shared decision-making depends on the nature and complexity of the decision, and the level of cognitive impairment, with a spectrum approach of benefit – from independent to joint, supported and then substitute decision-making [50]. This approach becomes intertwined with the need for consistent and skilled staffing, and promotion of feelings of safety and security as highlighted by this review. The decision to transition to permanent care is a major life event, often undertaken at a time of crisis [51], with both psychological and physical aspects of the transition to be considered [52]. Alongside, at this level, is conducive environmental design, moving beyond static design principles to dementia-related design which promotes dignity first and foremost [53].

The design of the built environment, and how that environment is activated by people, enhances person-centred practice [54, 55]. Innovative models of care that integrate the wider community with residential care homes, including day and short stay respite services, expand on this concept. Kate Swaffer, an Australian dementia advocate, points out that community integration, rather than setting people living with dementia apart, includes them as a valued member of the community [56]. Weaving together these elements is not straightforward for organisations; however, striving for truly person-centred practice with an integrated skilled care team will provide the restorative break and/or supported transition to permanent care required.

The core of the third program theory is trust, autonomy and meaning-making, aimed firmly at the individual level. Placing value on the history of a person living with dementia and their sense of self was identified critical in this review. Instrumental work by Tom Kitwood [57] connected the neurobiology of dementia with the social world, and that trustworthy relationships support personhood and the rights and values of the person living with dementia. Nolan et al. [58] extended this thinking with the six senses of wellbeing – security, belonging, continuity, purpose, achievement, and significance – all of which were variously highlighted in this review. Authentic partnerships between care providers, people living with dementia and their caregivers were flagged as important for this program theory, with genuine respect, collective wisdom and mutual benefit creating the environment in which these partnerships can flourish [4, 43]. Culturally safe care, designed specifically for improving Indigenous health inequities, adds to this body of work, providing a constructive reflective framework to disentangle inherent power imbalances that may exist in care homes [59]. Dignity in Care Australia provides a voice for people receiving care, informal caregivers, professionals and service providers, with guiding principles including engaging caregivers as care partners and supporting people to express their needs and wants [60]. Doing *with* rather than doing *to* or *for*, guiding and supporting people living with dementia and their caregivers exploring respite and transition to permanent care has the potential to make an emotionally challenging experience less traumatic.

A limitation of this review is its focus on relevance for an Australian audience. The review identified international literature through a comprehensive search strategy and has been contextualised for the Australian service provider landscape by drawing on local expertise. The realist synthesis has defined three program theories generalisable to international settings, but

each local jurisdiction will need to establish contextual relevance and acceptability. A further limitation is the iterative process for developing theories being predominantly conducted by the first author, with regular input from the 2nd author, due to time and resource constraints.

## Conclusion

The three identified program theories provide a foundation for understanding how a model of respite and permanent transition to care within a residential care home can be altered by contextual factors that trigger various mechanisms, both resources and reasoning to produce intended and unintended outcomes. The findings from this study informs how service providers can work more closely with people living with dementia and their caregivers to optimise ever-changing dementia care, supported through respite and transition to permanent care services. This work leads on to the next component of this research program, a realist evaluation, of testing and refining a prototype model of care within a care home of a large Australian aged care provider.

## Supplementary Information

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Supplementary Material 1.

## Authors' contributions

Claudia Meyer, Xanthe Golenko, Ron Sinclair and Judy Lowthian have contributed to the conception or design of the work and/or the acquisition, analysis, and interpretation of data for the work. Claudia Meyer, Xanthe Golenko, Ron Sinclair and Judy Lowthian have assisted in drafting the work or revising it critically for important intellectual content. Claudia Meyer, Xanthe Golenko, Ron Sinclair and Judy Lowthian have provided final approval of the version to be published.

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## Availability of data and materials

The data that support the findings of this study are not publicly available due to privacy restrictions but are available from the corresponding author upon reasonable request.

## Declarations

### Ethics approval and consent to participate

This entire project has been approved by the Bolton Clarke Human Research Ethics Committee (project no. 215), with individual consent not required.

### Consent for publication

Not applicable as there is no individual person-level data.

### Competing interests

The authors declare no competing interests.

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## References

- World Health Organization. Dementia key facts. Health topics. Geneva: World Health Organization; 2020.
- Alzheimer's Disease International. World Alzheimer Report 2019: Attitudes to dementia. London: Alzheimer's Disease International; 2020.
- Maayan N, Soares-Weiser K, Lee H. Respite care for people with dementia and their carers. *Cochrane Database Syst Rev*. 2014;2014(1):CD004396. <https://doi.org/10.1002/14651858.CD004396.pub3>.
- O'Shea E, Timmons S, O'Shea E, Fox S, Irving K. Respite in Dementia: An Evolutionary Concept Analysis. *Dementia*. 2019;18(4):1446–65.
- McCabe M, You E, Tatangelo G. Hearing their voice: A systematic review of dementia family caregivers' needs. *Gerontologist*. 2016;56(5):e70–88.
- Phillipson L, Jones S, Magee C. A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. *Health Soc Care Community*. 2014;22(1):1–12.
- Shaw C, McNamara R, Abrams K, Cannings-John R, Hood K, Longo M, Myles S, O'Mahony S, Roe B, Williams K. Systematic review of respite care in the frail elderly. *Health Technol Assess*. 2009;13(20):1–224. <https://doi.org/10.3310/hta13200>.
- Dyer S, van den Berg M, Barnett K, Brown A, Johnstone G, Laver K, et al. Review of innovative models of aged care. Adelaide, Australia: Flinders University; 2019.
- Rochira S. Rethinking respite for people affected by dementia. Wales, United Kingdom: Older People's Commissioner for Wales; 2018.
- Hainstock T, Cloutier D, Penning M. From home to "home": Mapping the caregiver journey in the transition from home care into residential care. *Journal of Aging Studies*. 2017;43:32–9.
- Neville C, Beattie E, Fielding E, MacAndrew M. Literature review: use of respite by carers of people with dementia. *Health Soc Care Community*. 2015;23(1):51–63.
- Sullivan G, Hain D, Williams C, Newman D. Story-Sharing Intervention to Improve Depression and Well-Being in Older Adults Transitioning to Long-Term Care. *Res Gerontol Nurs*. 2019;12(2):81–90.
- Ellen M, Demaio P, Lange A, Wilson M. Adult Day Center Programs and Their Associated Outcomes on Clients, Caregivers, and the Health System: A Scoping Review. *Gerontologist*. 2017;57(6):e85–94.
- Orellana K, Manthorpe J, Tinker A. Day centres for older people: a systematically conducted scoping review of literature about their benefits, purposes and how they are perceived. *Ageing Soc*. 2020;40(1):73–104.
- Chenoweth L, Kable A, Pond D. Research in hospital discharge procedures addresses gaps in care continuity in the community, but leaves gaping holes for people with dementia: a review of the literature. *Australas J Ageing*. 2015;34(1):9–14. <https://doi.org/10.1111/ajag.12205>.
- Ferrah N, Ibrahim J, Kipsaina C, Bugeja L. Death Following Recent Admission Into Nursing Home From Community Living: A Systematic Review Into the Transition Process. *J Aging Health*. 2018;30(4):584–604.
- Hirschman K, Hodgson N. Evidence-based interventions for transitions in care for individuals living with dementia. *Gerontologist*. 2018;58(S1):S129–40.
- Young JA, Lind C, Orange JB. A qualitative systematic review of experiences of persons with dementia regarding transition to long-term care. *Dementia (London)*. 2021;20(1):5–27. <https://doi.org/10.1177/1471301219862439>. Epub 2019 July 23.
- Braithwaite J, Churrua K, Long JC, Ellis LA, Herkes J. When complexity science meets implementation science: a theoretical and empirical analysis of systems change. *BMC Med*. 2018;16(1):63. <https://doi.org/10.1186/s12916-018-1057-z>.
- Pawson R, Tilley N. Realistic evaluation. Thousand Oaks, CA, US: Sage Publications, Inc; 1997. p. 235–xvii.
- Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMESES publication standards: realist syntheses. *BMC Med*. 2013;11:21. <https://doi.org/10.1186/1741-7015-11-21>.



22. Dalkin SM, Greenhalgh J, Jones D, Cunningham B, Lhussier M. What's in a mechanism? Development of a key concept in realist evaluation. *Implement Sci.* 2015;10:49. <https://doi.org/10.1186/s13012-015-0237-x>.
23. Wong G, Westhorp G, Greenhalgh J, Manzano A, Jagosh J, Greenhalgh T. Quality and reporting standards, resources, training materials and information for realist evaluation: the RAMESES II project. Southampton (UK): NIHR Journals Library; 2017.
24. Abrahms R, Park S, Wong G, Rastogi J, Boylan A, Tierney S, et al. Lost in reviews: Looking for the involvement of stakeholders, patients, public and other non-researcher contributors in realist reviews. *Research Synthesis Methods.* 2020;12:239–47.
25. Tricco A, Langlois E, Straus S. Rapid reviews to strengthen health policy and systems: A practical guide. Geneva, Switzerland: World Health Organisation; 2017.
26. Meyer C, Ogrin R, Golenko X, Cyarto E, Paine K, Walsh W, et al. A code-signed fit-for-purpose implementation framework for aged care. *J Eval Clin Pract.* 2022;28(3):421–35.
27. Dye J, Schatz I, Rosenberg B, Coleman S. Constant comparison method: A kaleidoscope of data. *The Qualitative Report.* 2000;4(1/2):1–9.
28. O'Shea E, Timmons S, O'Shea E, Fox S, Irving K. Key stakeholders' experiences of respite services for people with dementia and their perspectives on respite service development: a qualitative systematic review. *BMC Geriatr.* 2017;17:282.
29. Ray C, Ingram V, Cohen-Mansfield J. Systematic review of planned care transitions for persons with dementia. *Neurogenerative Disease Management.* 2015;5(4):317–31.
30. Vandepitte S, Van Den Noortgate N, Putman K, Verhaeghe S, Verdonck C, Annemans L. Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review. *Int J Geriatr Psychiatry.* 2016;31(12):1277–88.
31. Harkin D, O'Connor C, Birch M, Poulos C. Perspectives of Australian family carers of people with dementia on the "cottage" model of respite: Compared to traditional models of residential respite provided in aged care facilities. *Health Soc Care Community.* 2019;28:850–61.
32. Mercieca M, Kimberley H. A preliminary evaluation of the Short Break Stay Program: Respite care for people with dementia. Melbourne, Australia: Brotherhood of St Laurence; 2013.
33. Phillipson L, Jones S. Residential respite care: The caregiver's last resort. *J Gerontol Soc Work.* 2011;54(7):691–711.
34. Riekkola J, Rutberg S, Lilja M, Isaksson G. Healthcare professionals' perspective on how to promote older couples' participation in everyday life when using respite care. *Scand J Caring Sci.* 2019;33(2):427–35.
35. Bramble M, Moyle W, McAllister M. Seeking connection: family care experiences following long-term dementia care placement. *J Clin Nurs.* 2009;18:3118–25.
36. Davison T, Camoes-Costa V, Clark A. Adjusting to life in a residential aged care facility: Perspectives of people with dementia, family members and facility care staff. *J Clin Nurs.* 2019;28(21–22):3901–13.
37. Gaugler J, Reese M, Sauld J. A pilot evaluation of psychosocial support for family caregivers of relatives with dementia in long-term care. *Res Gerontol Nurs.* 2015;8(4):161–72.
38. Gilmore-Bykovskiy A, Roberts T, King B, Kennelty K, Kind A. Transitions from hospitals to skilled nursing facilities for persons with dementia: A challenging convergence of patient and system-level needs. *Gerontologist.* 2017;57(5):867–79.
39. Henkusens C, Keller H, Dupuis S, Schindel M. Transitions to long-term care: how do families living with dementia experience mealtimes after relocating? *J Appl Gerontol.* 2014;33(5):541–63.
40. Kiwi M, Hyden L, Antelius E. Deciding upon transition to residential care for persons living with dementia: why do Iranian family caregivers living in Sweden cease caregiving at home? *Journal of Cross Cultural Gerontology.* 2018;33:21–42.
41. Lee V, Simpson J, Froggett K. A narrative exploration of older people's transition into residential care. *Aging Ment Health.* 2013;17(1):48–56.
42. Torge C. "Being in-Between": Spouses That Cohabit With and Provide Care for Their Partners in Nursing Homes. *J Appl Gerontol.* 2020;39(4):377–84.
43. Dupuis S, Gillies J, Carson J, Whyte C, Genoe R, Loisel L, et al. Moving beyond patient and client approaches: mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia.* 2012;11:427–52.
44. Cary M, Hall R, Anderson A, Burd A, McConnell E, Anderson R, et al. Management Team Perceptions of Risks and Strategies for Preventing Falls Among Short-Stay Patients in Nursing Homes. *Health Care Manager.* 2018;37(1):76–85.
45. Park C. Making sense of the meaning literature: an integrative review of meaning making and its effects on adjustment to stressful life events. *Psychol Bull.* 2010;136(2):257.
46. Kokonya A, Fitzsimmons V. Transition to Long-Term Care: Preparing Older Adults and their Families. *Med Surg Nurs.* 2018;27(3):143–8.
47. World Health Organization. Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017.
48. Eager K, Westera A, Snoek M, Kobel C, Loggie C, Gordon R. How Australian residential aged care staffing levels compare with international and national benchmarks. Sydney, Australia: Australian Health Services Research Institute; 2019.
49. Productivity Commission. Caring for Older Australians: Overview, Report No. 53. Canberra: Final Inquiry Report; 2011.
50. Sinclair C, Gersbach K, Hogan M, Blake M, Bucks R, Auret K, et al. "A Real Bucket of Worms": Views of people living with dementia and family members on supported decision-making. *Bioethical Inquiry.* 2019;16:587–608.
51. Gravalin M, Rowell K, de Groot J. Interventions to support the decision-making process for older people facing the possibility of long-term residential care. *Cochrane Database Syst Rev.* 2007;(3):CD005213. <https://doi.org/10.1002/14651858.CD005213.pub2>.
52. Ellis J. Psychological transition into a residential care facility: older people's experiences. *J Adv Nurs.* 2010;66(5):1159–68.
53. Fleming R, Zeisel J, Bennett K. World Alzheimer Report 2020: Design Dignity Dementia: dementia-related design and the built environment Volume 1. London, England: Alzheimer's Disease International; 2020.
54. Calkins M. From research to application: Supportive and therapeutic environments for people living with dementia. *Gerontologist.* 2018;58(5):S114–28.
55. Chaudhury H, Cooke H, Razaghi L. The influence of the physical environment on residents with dementia in long-term care settings: A review of the empirical literature *The Gerontologist.* 2018;58(5):e325–37.
56. Swaffer K. What the hell happened to my brain: Living beyond dementia. London, England: Jessica Kingsley Publishers; 2016.
57. Kitwood T. Dementia reconsidered: The person comes first. Buckingham, England: Open University Press; 1997.
58. Nolan M, Brown J, Davies S, Nolan J, Keedy J. The Senses Framework: improving care for older people through a relationship-centred approach - Getting research into practice. United Kingdom: University of Sheffield; 2006.
59. Laverty M, McDermott D, Calma T. Embedding cultural safety in Australia's main health care standards. *Medical Journal of Australia.* 2017;207(1):15.
60. Dignity in Care Australia. 10 Dignity in Care principles Australia 2016 [Available from: <http://www.dignityincare.com.au/>].

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