

Abstract

Policy guidance promotes supporting people to live in their own homes for as long as possible with support from homecare services. People living with dementia who need such support can experience a range of physical and cognitive difficulties, which can increase the risks associated with homecare for this group. We aimed to examine risk and safety issues for people with dementia and their homecare workers and risk mitigation practices adopted by homecare workers to address identified risks. We searched MEDLINE, EMBASE, AMED, CINAHL, PsycINFO, ASSIA and Cochrane Central Register of Controlled Trials databases 5th March 2021. Included studies focussed on homecare for people with dementia and had a risk or safety feature reported. Risk of bias was assessed with the Joanna Briggs Institute Critical Appraisal tools. Two authors assessed articles for potential eligibility and quality. A narrative synthesis combines the findings. The search identified 2,259 records; 27 articles, relating to 21 studies, met the eligibility criteria. The review identified first order risks that homecare workers in the studies sought to address. Two types of risk mitigation actions were reported: harmful interventions and beneficial interventions. Actions adopted to reduce risks produced intended benefits but also unintended consequences, creating second order risks to both clients with dementia and homecare workers, placing them at greater risk. Risk mitigation interventions should be person-centred, the responsibility of all relevant professions, and planned to minimise the creation of unintended risks.

Key words (4-10): Dementia, Risk, Homecare, Safety, Social Care, Review, Domiciliary care

Contribution of paper:

What is already known about the topic?

Managing risks in dementia homecare

- Homecare is fundamental to enable people with dementia to stay in their own homes for longer.
- People with dementia can have a range of cognitive and physical difficulties which create specific risk management challenges.
- Risk management for people with dementia has traditionally focused on preventing physical harm.

What this paper adds

- Risks in homecare for people with dementia are varied (e.g., home environment and worker unmet training needs) and affect both clients with dementia and homecare workers.
- Risk mitigation strategies employed by homecare workers involved beneficial interventions and harmful interventions (e.g., restraint use).
- Risk mitigation strategies can lead to unintended further risks for the clients with dementia and their homecare workers.

INTRODUCTION

Dementia care is a growing challenge and has become one of the most important health and care issues facing the world, with over 50 million people living with the condition worldwide (Prince et al., 2015). Within the UK, more than 885,000 people are living with dementia and this is expected to rise to over a million by 2024 (Carter, 2016; Wittenberg et al., 2019). Dementia is a progressive condition, which can encompass a variety of cognitive and behavioural symptoms, which may be different for each person, and can involve difficulties with memory, reasoning, communication and carrying out daily activities of living, in addition to changes in personality (National Institute for Health and Care Excellence, 2018; Social Care Institute for Excellence, 2020).

Due to deinstitutionalisation, ageing populations, and preferences to live at home longer there is an increasing need for homecare across the world (WHO, 2008; Aged Care Financing Authority, 2018; Grabowski, 2021). Care at home is fundamental to community care policy and there is an ongoing policy drive to increase the number of people able to remain in their own homes (Carter, 2016; Taylor & Donnelly, 2007). In the UK, approximately sixty one percent of people with dementia over the age of sixty-five are living in their own or family homes (Prince et al., 2014). Whilst family carers may initially provide care for people with dementia, additional support is often provided by paid homecare workers who have a crucial role in enabling people with dementia to remain living as safely as possible in their own home (Polacsek et al., 2019). Homecare enables recipients with support needs to maintain their lives within their own homes by predominantly providing assistance with personal care. Homecare workers assist with activities such as washing, dressing, going to the toilet, eating, and medication, along with essential physical, social, and emotional support for older people

with dementia (Turner et al., 2018; Hayes & Moore, 2017). There are differences across countries, for example homecare in the United States includes the aforementioned activities provided by workers without healthcare qualifications, but also includes home healthcare provided by qualified practitioners or clinicians (MedlinePlus, 2021). For this review we included studies self-defining as concerning in-home support for people with dementia to maintain living in their own homes.

Sixty percent of homecare recipients in England are living with dementia (Carter, 2016). Providing care for people with dementia can involve particular challenges or risks associated with clients' cognitive and physical status which can create difficulties with understanding and communication, increasing complex care needs, and high dependency (Miller, Whitlatch, Lyons, 2016; O'Brien et al., 2019; Taylor and Donnelly, 2007). However, those homecare workers without healthcare qualifications who often provide most of the personal care support have limited skills, poor, non-accredited training, and inadequate supervision for their role. For example, of the estimated 520,000 homecare workers who provided personal care for people with dementia in England in 2016, over a third had not received any training for dementia (Carter, 2016). Homecare workers without healthcare qualifications also often work part-time and in isolation (Hussein and Manthorpe, 2012). Therefore, in dementia care, these homecare workers must manage complex situations in the context of limited training, and varied supervision and support (Polacsek et al., 2019; Leverton et al., 2021^b).

People with dementia are susceptible to a number of potential risks. These can be separated into two groups; 1) those first order risks from living with the condition itself, including poor hygiene, medication mismanagement (Dickins et al., 2018) and harm (for example, from fires, falls, or becoming lost) (Waugh, 2009; Dickins et al., 2018), and 2) risks as consequences that

result from attempts to intervene to reduce risks such as the use of restraints, or involuntary care (Scheepmans et al., 2019). In this review we are interested in risks that homecare workers identified as targets for intervention, their interventions, and the consequences of these (See Figure 1). Another related concept is that of risk factors, which are not risks in and of themselves, but social ecological factors (Golden and Earp, 2012), for example, personal characteristics, co-morbidities or conditions of living that can be associated with consequent or additional risks such as admission to long-term care or hospital (de Witt and Ploeg, 2016). Risk factors are not a focus of this review, rather the subsequent risks to people with dementia who are in receipt of homecare services and to homecare workers associated with these risk factors.

Figure 1: Types of risk

Risks are linked to two interrelated aspects of uncertainty: threats to individuals and the means employed to cope with those threats (Alaszewski and Coxon 2009). People with dementia often receive medical and/or social care assessments from a range of professionals and care providers who engage in a risk assessment process involving obtaining information, forming judgements, constructing recommendations and subsequently intervening (Firkins and Candlin 2006). Taylor and McKeown (2013) define risk as ‘a time-bounded decision-making situation where the outcomes are uncertain and where benefits are sought but undesirable outcomes are possible’ (Taylor and McKeown 2013, pg 163). Indeterminate outcomes from hasty decisions demonstrate the complexity of risk management situations. Risk management for people with dementia has traditionally focused on preventing physical harm (Clarke and Mantle, 2016) but recently there has been a recognition of the need to adopt positive risk management approaches in which the positive benefit from taking risks is

balanced against the negative effects (emotional, cognitive, physical) of avoiding risk altogether (Department of Health, 2010; Nuffield Council on Bioethics, 2009).

Learning about the complexities faced by, and viewpoints of, people living with dementia and their support networks can assist risk management at individual and service provision levels and may delay transitions to care institutions (Dickens et al., 2018). A recent qualitative research study (authors forthcoming) found that risk mitigation and safety for people with dementia and homecare workers were key areas of contention in homecare practice. Actions by homecare workers and services to mitigate risk could impact significantly on clients and result in different risks, for example by locking people with dementia into their homes (Scheepmans et al., 2018). The England National Institute for Health and Care Excellence's Guidance for Homecare (2015) recommends that research be conducted to examine specialist dementia support, and safety and wellbeing in homecare. Therefore, with this systematic review we aimed to explore the current knowledge about risk, safety and safeguarding issues, and risk mitigation practices in dementia homecare.

Specific review questions:

- What are the risk, safety and safeguarding issues in dementia homecare?
- What strategies and interventions are currently used to manage risk and safety in dementia homecare?
- How do risk mitigation practices affect individuals (clients with dementia and homecare workers)?
- What are the factors associated with safety, safeguarding and risk mitigation practices in homecare provision for clients with dementia?

METHODS

The updated PRISMA Guidelines were drawn on to report this review (Page et al., 2020).

Protocol and registration

The protocol for this review is registered on PROSPERO (CRD42021246621) (Backhouse et al., 2021).

Eligibility criteria and Information sources

We searched MEDLINE, PsycINFO, EMBASE, CINAHL, AMED, ASSIA and the Cochrane Central Register of Controlled Trials databases for peer reviewed, primary research articles published from 01.01.2010 up to 05.03.2021. Articles were eligible if they included information on homecare for people with dementia and a risk or safety aspect.

Search strategy

The search strategy covered three domains: dementia, risk, and homecare. The search was piloted and refined. To maximize the findings, there were no limitations on the searches in relation to study design. Where possible, searches were limited to humans and English language. Reference lists of key articles and Google Scholar were searched for articles.

We searched from 2010 onwards. 2010 was chosen since in 2009 the World Alzheimer Report (2009) recommended planning for community-based social care and support for dementia and the World Health Organisation report in 2012 called for development in community services to help people with dementia to remain at home (Alzheimer's Disease International, 2009; World Health Organisation and Alzheimer's Disease International, 2012). At the same time the risk enablement movement was beginning in dementia care (Department of Health, 2010; Morgan and Williamson, 2014). Additionally, as an example, after the Health and Social Care Act 2008 came in to effect, the Care Quality Commission in England was established in

2009 (Parkin, 2020), and likewise the Care Inspectorate in Scotland was created in 2011 (Care Inspectorate, 2015), to regulate and inspect homecare providers. Taken together, these actions demonstrate a time of change for homecare around 2010, where practices became more regulated, and services were explicitly encouraged to provide for people with dementia.

Search terms

The search terms for MEDLINE, PsycINFO, EMBASE, CINAHL, AMED were (dementia or Alzheimer* or “cognitive impairment” or “memory loss” or “cognitive decline”) AND (risk or crisis or crises or danger or hazard or safety or protect* or safeguard* or “risk management” or “risk mitigation” or “preventing risk”) AND (“home care” or homecare or “care in the community” or “community care” or domiciliary or “home care services”). See Supplementary data 1 for ASSIA and Cochrane searches.

Study selection process

Titles were screened for eligibility and excluded if they were clearly not related to dementia, risk, or homecare such as those stating nursing homes. Abstracts of the remaining titles were then screened, and potentially relevant full texts were obtained to determine eligibility. Full text articles were read and assessed individually by both AR and TB regarding three questions for inclusion.

- 1) Population: *Does the article include or have a focus on people with dementia receiving homecare services?*
- 2) Condition: *Does the article focus on paid homecare and have a risk or safety feature reported?*

- 3) Intervention/outcomes: *Can we learn something about risk or safety issues in homecare and/or homecare worker practices to mitigate risk in paid homecare for people with dementia?*

Definitions of homecare varied and studies self-defined as concerning homecare (in-home support for people to maintain living in their own homes) in some way/s were included. Judgements were made individually by AR and TB about how the studies met the inclusion criteria, disagreements were discussed while reassessing full texts and resolved without the need to consult a third author. Articles where the answer to all three questions was 'yes' were included and those with one or more 'no' were excluded.

Data collection processes and Data items

A bespoke data extraction form was created and tested on two articles. The extraction form included information of the article reference, study design, method, country, participant type/s, setting, homecare staff, gender, age, dementia diagnosis, ethnicity, factors contributing to risk, type of risk or safety, risk to who, risk mitigation and results. After testing, this form was updated to include the nature of homecare. If only part of a study sample met the criteria of homecare or homecare workers (in-home support for people with dementia to maintain living in their own homes), only data relevant to our review were extracted. AR extracted the data, with TB duplicating extraction for two articles to check for consistency.

Risk of bias in individual studies

To assess risk of bias for each included full text article, critical appraisal tools from the Joanna Briggs Institute were employed (see Tables 5, 6 and 7 supplementary data 2) (Joanna Briggs Institute, 2017). Appraisal tools were matched to the appropriate study design (cohort,

qualitative and cross-sectional). Two authors (*AR and TB*) reviewed all articles independently against the relevant tool. Disagreements were resolved through discussion and then consensus, a third author was not required to adjudicate. We calculated a percentage index of the 'yes' scores against the number of applicable items for each article. This was to manage assessment items that were not applicable to some studies (for example loss to follow up was not applicable in retrospective cohort studies). Once not applicable scores were accounted for, articles with scores of 60% or below were rated as weak, between 61% and 79% rated as moderate, and 80% or over as strong. Bias levels were used to judge the quality of the studies included in the review, but not to exclude studies.

Synthesis of results

We conducted a narrative descriptive synthesis of the data using the 'Guidance on the Conduct of Narrative Synthesis in Systematic Reviews' (Popay et al., 2006) to frame our process. We used our review questions to guide analysis. We mapped risk/safety issues, strategies and factors in tables and examined how these affected individuals and which factors influenced these findings. We used groupings and clusters, thematic analysis, and concept mapping/conceptual triangulation (Popay et al., 2006). Authors AR and TB assessed tabulations for patterns, drawing out groupings, similarities and differences across data, revisiting source articles and having regular discussions about groupings, concepts and meanings. As data from cohort studies was at a different level and had a different focus, they were synthesised separately from qualitative and cross-sectional studies. Cohort studies were tabulated to show contextual factors associated with specific risks to homecare users.

Reporting bias

Reporting bias across studies was discussed between *AR* and *TB* to consider the impact of our search strategy on the included studies, selective reporting, and publication bias.

RESULTS

Study selection

The database search identified 2,259 records. After duplicates were removed, 1,282 records were assessed for eligibility. After title review, 78 full texts were retrieved for assessment. Twelve further records were found through the lateral search. Articles not meeting the eligibility criteria were removed. Final inclusion comprised 27 articles, relating to 21 different studies (see Figure 2).

Figure 2: Flow Diagram of Selection Process

Study characteristics

As shown in Table 1, studies came from a variety of countries: UK (n=6), Norway (n=4), USA (n=4), Australia (n=2), Canada (n=1), Korea (n=1), Belgium and Netherlands (n=1), Sweden (n=1), and Netherlands (n=1). Ten studies were qualitative, six were retrospective cohort, and five cross-sectional. All qualitative studies used interviews, with some also using focus groups and/or observations. Cross-sectional studies predominantly used surveys while retrospective cohort studies extracted data from observational and/or administrative datasets. Homecare was described differently across studies with terms including home healthcare, clinical care at home, and assistance with daily living/personal care. Sample sizes varied according to study design with qualitative studies having smaller sample sizes (range 7–82), cross-sectional larger (range 76–1,194), and retrospective cohort studies larger still (range 3,151–153,125).

Participant characteristics

Participants were people with dementia predominantly over the age of 80 and professional clinicians or care workers mostly aged in their 40s. Eighteen out of the twenty-one studies had a majority of female participants, two did not specify gender and one study had 50 percent female participants. Ethnicity, and dementia diagnostic criteria, type or severity were not stated in most studies.

Risk of bias in studies

Table 1 shows results of the quality assessments with included studies rated as strong, moderate, or weak. Quality assessments rated 19/27 articles as strong, 7 moderate and 1 weak. All 6 cohort studies were rated as strong, of the 5 cross-sectional studies 2 were rated as strong, and 3 as moderate, 6 qualitative studies were rated strong, 3 moderate and 1 weak. Quality assessments are available in Tables 5, 6 and 7 in supplementary data 2.

Results of individual studies

Table 2 shows individual results of the retrospective cohort studies and Table 3 shows the individual results of the cross-sectional and qualitative studies (see Supplementary data 3 for more information).

Results of syntheses

Results from the retrospective cohort studies: risk factors, protective factors and their associations to risks for homecare clients with dementia

Table 2 shows results from the retrospective cohort studies: these studies showed the associations of risk factors and protective factors leading to higher or lower association with potential risks for homecare clients with dementia (see Figure 3). These findings provide contextual information showing the key overarching risks to people with dementia receiving homecare. Potential risks for people with dementia receiving homecare were serious and potentially life changing including hip fractures and pressure ulcers (Kim et al., 2017; Kim et al., 2019), hospitalisation (Bick, 2018; Knox et al., 2020^a; Knox et al., 2020^b), and permanent transition to into long-term care (Young et al., 2020; Maxwell et al., 2019). Risk factors associated with these risks were predominantly related to the demographics and health status of the person with dementia receiving homecare and not to homecare practices directly, so are not easily modifiable. The main protective factor was homecare itself. People with dementia receiving homecare had a lower risk of hip fracture and pressure ulcers compared to those living in institutional care (Kim et al., 2017; Kim et al., 2019). Additionally, higher levels of homecare were associated with people with dementia entering institutional care later, so a lower risk of early institutionalisation (Welberry et al., 2020) - demonstrating the value of homecare for people with dementia.

Figure 3: Relationship of risk and protective factors to risks for homecare users with dementia

Results from the cross-sectional and qualitative studies: first and second order risks, risk mitigation interventional actions and resultant consequences

Figure 4 shows the results of the synthesis from the cross-sectional and qualitative studies.

These findings provide knowledge related to risk and safety, and risk mitigation in homecare.

We identified two types of risks: first and second order risks.

- **First order risks:** Potential risks homecare workers identified and acted to mitigate. As shown in Table 4, first order risks can be categorised into four types: 1) intrapersonal, 2) interpersonal, 3) environmental, and 4) institutional.
- **Second order risks:** Unintended consequences - new risks created by homecare worker risk mitigation interventional actions, such as client distress, transitions, involuntary care, ethical challenges for homecare workers, homecare worker fear, and reduced care provision. These were not acted on in the included studies but had potential to become future targets for risk mitigation (first order risks).

Interventional actions, their intended consequences and a range of unintended consequences/second order risks were identified. Interventional actions comprised of harmful interventions such as non-consensual care, and beneficial interventions such as relying on peer support or using different communication techniques. Intended consequences were the desired benefits from the interventional actions such as greater wellbeing for clients and collaborative working. Unintended consequences were new risks such as involuntary care, client distress, transition to alternative care or ethical challenges facing homecare workers.

First and second order risks could be to homecare clients with dementia and/or to homecare workers. Repeated pattern detection showed a process: first order risks leading to interventional actions, which then led to intended consequences (benefits) and/or

unintended consequences (second order risks). Second order risks had potential to perpetuate a cycle by creating a need for homecare workers to mitigate them.

Figure 4: First order risks – interventional actions – consequences cycle

What are the risk, safety and safeguarding issues in homecare for people with dementia?

As shown in Table 4, first order risks for clients with dementia included intrapersonal risks such as their own potential actions (Tudor Car et al., 2017; Leverton et al., 2021^b; Backhouse & Ruston 2021), becoming lost or injured (Sandberg et al., 2020), and care needs (Moermans et al., 2018; Hamers et al., 2016; Mengelers et al., 2020; Mengelers et al., 2018; Gjellestad et al., 2020; Evans et al., 2016). Environmental risks were the person with dementia's living situation (Hamers et al., 2016; Mengelers et al., 2020; Mengelers et al., 2018) and home environment (Tudor Car et al., 2017; Leverton et al., 2021^a).

Intrapersonal first order risks for homecare workers included unmet training needs (Backhouse & Ruston 2021) and perceived personal risk (Galinsky et al., 2010). Interpersonal risks were conflict with clients' family members (Smebye et al., 2016; Yeh et al., 2018), managing competing demands (Lundberg, 2017), and individual responsibility and isolation when lone working (Yeh et al., 2018; Abrams et al., 2019; Backhouse & Ruston, 2021; Leverton et al., 2021^b). Institutional risks included working conditions such as being short staffed (Leverton et al., 2021^b) and homecare workers lack of power (Leverton et al., 2021^a), constraints on care such as policies and procedures (Mole et al., 2019), shortage of time (Lundberg, 2017; Mole et al., 2019; Backhouse & Ruston 2021) and resources (Mole et al., 2019), and a lack of support or training (Backhouse & Ruston 2021).

What strategies and interventions were being used by homecare workers to manage first order risks?

To mitigate first order risks to people with dementia and homecare workers, homecare workers employed a range of interventional actions or strategies. These can be categorised into two groups: 1) harmful interventions, and 2) beneficial interventions.

- **Harmful interventions-** In order to mitigate first order risks such as level of care needed by the client, their home environment and behaviours, homecare workers' skill levels and working conditions a range of interventional actions were described that had the potential to result in adverse care. These were the use of physical and chemical restraints and non-consensual care (Moermans et al., 2018; Hamers et al., 2016; Mengelers et al., 2020; Mengelers et al., 2018; Leverton et al., 2021^b; Gjellestad et al., 2020); reduction of formal care provision, such as shorter visits when technology had been introduced or when homecare workers were fearful of violence (Fæø et al., 2020; Galinsky et al., 2010; Mole et al., 2019), and paternalism which was employed to manage conflict (Smebye et al., 2016).
- **Beneficial interventions-** Homecare workers adapted their approach to improve clients' wellbeing, reduce clients' anxiety, support them to feel safer and to work more effectively with family carers. Strategies included using distraction techniques; improving communication; using peer support/advice and improved time management (Backhouse and Ruston, 2021; Leverton et al., 2021^a; Leverton et al., 2021^b; Sandberg et al., 2020); providing end of life care provision (Yeh et al., 2018; Abrams et al., 2019); balancing risks against wellbeing and autonomy (Leverton et al., 2021^a; Sandberg et al., 2020), and developing risk management strategies such as

rearranging the home environment, hiding or making items prominent, and leaving notes for clients (Sandberg et al., 2020). To support clients with dementia to maintain their independence and improve safety assistive technology was used (Fæø et al., 2020). To overcome communication difficulties and the risk of distress and psychological harm to clients within homecare interactions person-centred communication was employed (Raichi, 2017).

How do risk mitigation practices have an impact on individuals (clients and homecare workers)?

The implementation of interventional actions to mitigate first order risks had consequences for people with dementia and/or homecare workers in the form of intended and unintended consequences. Intended consequences of interventional actions included reduced risks and less anxious behaviour amongst clients (Raichi, 2017), better tailored/improved care (Yeh et al 2018; Abrams et al 2019), feelings of safety (Fæø et al., 2020), greater wellbeing for clients (Leverton et al., 2021a; Raichi, 2017), maintenance of personhood (Raichi, 2017), and more support for clients (Mole *et al.*, 2019; Yeh et al., 2018; Abrams et al., 2019), homecare workers (Backhouse & Ruston 2021; Leverton et al., 2021^b), and family carers (Mole et al., 2019). Compared to other studies included in this review, the person-centred communication intervention (Specialised Early Care for Alzheimer's - SPECAL™) reported the most intended consequences and no unintended consequences (Raichi, 2017). However, risks targeted by this intervention were distress, psychological harm and communication difficulties, and different risks such as physical harm may be more difficult to address.

Unintended consequences affected people with dementia adversely. These second order risks included malnutrition (Mole et al., 2019), distress (Leverton et al., 2021^b) depersonalising of the person's home (Leverton et al., 2021^a), reduction or loss of care provision (Fæø et al., 2020; Galinsky et al., 2010), loss in autonomy/independence (Smebye et al., 2016; Lundberg, 2017; Fæø et al., 2020), and risk of involuntary care (Moermans et al., 2018; Hamers et al., 2016; Mengelers et al., 2020; Mengelers et al., 2018).

Homecare workers were also affected by second order risks, for example, when regulatory codes constrained person-centred care (Lundberg, 2017) or ethical dilemmas became apparent (Gjellestad et al., 2020; Smebye *et al.*, 2016; Leverton et al., 2021^b). Homecare workers had to cope with fear of violence (Galinsky et al., 2010), exhaustion, isolation (Yeh et al., 2018), their own emotional responses (Yeh et al., 2018), losses to professional integrity (Abrams *et al.*, 2019), and/or loss of clients (Mole *et al.*, 2019).

What are the factors associated with safety and risk mitigating practices in homecare with clients with dementia?

Figure 5 draws on social ecological approaches (Golden and Earp, 2012) to categorise the factors associated with safety and risk mitigating processes. Many of the risk management strategies (interventional actions) employed relied on homecare worker intrapersonal factors, which were largely their emotional and energy resources and their knowledge and skills. Homecare workers had to rely on their own personal resources to make decisions in the moment, balancing risks with other factors (Backhouse and Ruston, 2021; Leverton et al., 2021^a; Sandberg et al., 2020). They did this in the context of interpersonal relations such as the presence of the person with dementia's family, the homecare environment such as the

living situation of person with dementia, and available technology, and institutional factors such as limited training and policies and procedures. The person with dementia's intrapersonal factors such as comorbidities could also provide different contextual factors for homecare workers to navigate. Institutional factors included constraints on care, such as working conditions, time resources, and lone working. All levels appeared to influenced homecare workers' actions.

Figure 5: Factors associated with safety and risk mitigation practices in homecare for people with dementia

Reporting biases

Included studies had a range of study designs, methods, sample sizes and findings, therefore, the risk of publication bias or selective reporting was thought to be low. However, it is worth noting that all studies came from developed, high income countries. The impact of the search strategy and varied terminology used in articles may have meant some eligible citations were not identified.

Certainty of evidence

Due to the disparate nature of the evidence involving different methods of investigation, there is low certainty of evidence for risk factors, mitigation actions and for intended and unintended outcomes. However, the synthesis has showed, through repeated pattern detection, a high level of certainty that mitigation actions to manage first order risks, such as client behaviours or lack of training for homecare workers, can lead to further second order risks, such as reduction of care provision or emotional toll on homecare workers for people with dementia and homecare workers.

DISCUSSION

Managing risks in dementia homecare

This review was undertaken to identify risk, safety, and safeguarding issues in homecare provision for people with dementia, to examine how risks are mitigated and how mitigating practices affect individuals with dementia and their homecare workers. The synthesis showed that actions taken by homecare workers to manage potential risks could create further risks for homecare clients with dementia and/or homecare workers.

Two main strands of evidence were identified: firstly, evidence from the cohort studies which focussed on risk protective factors and their associations to risks for homecare clients with dementia. The studies predominantly reported intrapersonal factors related to the person with dementia, as well as previous experiences of hospitalisation as increasing the likelihood of adverse events, hospitalisations, or permanent transition to nursing homes. Homecare was shown to be a protective factor itself, since when compared to institutional care risk of pressure ulcer and hip fracture was lower and receiving homecare enabled people with dementia to delay the risk of institutionalisation. These studies provided contextual information and set the scene by delineating prominent risks to people with dementia receiving homecare (adverse events and institutionalisation).

The second strand of evidence from the qualitative and cross-sectional studies identified first order risks as targets for interventional action by homecare workers and the intended (benefits) and unintended consequences (second order risks) of these interventional actions. Interventional actions adopted to manage first order risks included: harmful interventions such as non-consensual care, and beneficial interventions such as using assistive technology or alternative care. The resultant intended benefits included improved wellbeing and support. Unintended second order risks included reduced care provision, loss of autonomy,

involuntary care thereby creating new risk/s to clients with dementia and/or homecare workers that had the potential to become targets for interventional action.

The picture that emerges from this review is that in attempting to mitigate or manage first order risks, the interventional actions adopted or utilised by homecare workers had three potential negative outcomes. Firstly, subject the person with dementia to uncomfortable or harmful interventions. Secondly, result in a range of new second order risks for both clients with dementia and homecare workers. Thirdly, as part of this new second order risks, create emotional strains, fear, and ethical dilemmas for homecare workers due to engaging in risk reduction and safeguarding activities for their clients. Although positive consequences of interventional actions were demonstrated, multiple unintended consequences were identified through the synthesis.

Decision making in a situation of uncertainty is a central activity for all those who provide health or social care services for people with dementia (Firkins and Candlin, 2006; Taylor and McKeown, 2013). Managing risk in dementia can be a contested subject since people with dementia eventually lose their ability to care for themselves and become vulnerable in terms of increased risks to their safety (Clarke et al., 2009). Providing homecare for a person with dementia is both complex and challenging and the quality of the care received directly influences the person's capacity to remain in their own homes, their health and wellbeing, and their quality of life (Polacsek, 2019; Hallberg et al., 2016; Carter, 2016). Therefore, it is imperative that homecare provision addresses risks to all involved and meets the needs of clients with dementia.

This review makes an important contribution by identifying the possibility that the very interventional actions aimed at managing risks in dementia homecare have the potential not only to reduce risk, improve safety and increase wellbeing, but also to create additional risks for clients and homecare workers. The findings from this review provide evidence to support previously expressed views that programmes, designed to reduce risk or modify behaviour, which focus on immediate foreseen consequences or expected outcomes can create other unforeseen consequences, not considered, or planned for (Allen-Scott et al., 2014; Taylor and McKeown 2013).

In employing interventional actions, homecare workers may be balancing one risk against another - or transferring risk. For example, employing restraints or restrictive practices to reduce the level of risk due to a person having poor cognitive ability meaning they are unable to find their way or become confused, or due to them living alone. This may protect the homecare worker from other risks (physical such as being hurt and emotional such as the person going out and getting lost), and the organisation (reputational as they have kept the person safe) but potentially increases the risk (physical such as not moving about as much and emotional such as losing autonomy) for the person living with dementia. Facilitating positive risk taking can be seen as a legitimate part of a homecare workers role as it can be in a person's best interests and enhance their life, however data identified in this review did not cover this.

The care context for people with dementia is varied, complex and changes as the condition progresses. It is likely risks and consequences of risk mitigation are present in all care settings for people with dementia such as in nursing homes and acute hospital care. However, what sets homecare apart is the lone working nature of the role, where workers are making

decisions in isolation, often with little back up. Homecare workers, not providing healthcare, are often low paid and lack skills (Polacsek et al., 2019; Carter, 2016), and public finances constrain the range and type of support that can be provided, often resulting in planned interventions and support packages focusing only on immediate tasks. It is imperative that those implementing interventional actions also consider potential unintended consequences.

Additionally, to support homecare workers, policies and guidance should be clear that risk assessment and mitigation needs to be a shared activity; everyone's business. Responsibility for judgements, which balance risks against each other should not fall solely on the shoulders of homecare workers but should be shared across professions. Vitally, specialist supporting services and homecare workers should understand the challenges that people living with dementia and their carers face on daily basis. Furthermore, support should utilise holistic, person-centred approaches, treating the person with dementia as the expert patient whose opinions and wishes matter.

Strengths and Limitations

The evidence gathered through this systematic review was based on studies using different methodologies and thereby generating differing types of data. Terminology used to refer to homecare, the definition of homecare, and homecare workers duties differed across countries with homecare including nursing or medical care in some countries as well as social care which may limit the applicability of some findings in all countries. Different terminology and service remits may have meant not all studies relating to this issue were identified.

Due to the exploratory nature of many of the included studies, the limited data available and the heterogeneity of the risks identified, there are still uncertainties about which risks are

perceived as the key risks in homecare for people with dementia and homecare workers. Our synthesis could only identify risks and the consequences of risk mitigation actions, but due to the nature of the data, not assess which risks have the most severe consequences nor recommend effective risk mitigation practices in homecare. Risks for people with dementia such as getting lost in the community (Bantry White and Montgomery, 2015; Emrich-Mills, Puthusserypady and Hornberger, 2021) or falls (Bansal et al., 2016) were not included in most of the eligible articles but can present significant risks to people living with dementia in their own homes and may need more examination in relation to homecare practices. Additionally, risks to family carers (Giebel et al., 2020) were beyond the scope of this review. More research is needed to determine the key risks as perceived by people with dementia and homecare workers and acceptable ways to mitigate these which do not lead to poor care provision and/or second order risks.

We took a broad approach to risk identification; therefore, the authors' categorisations of risks could be contested. For example, reduction of formal care provision, such as shorter visits occurred when homecare workers were fearful of violence (Galinsky et al., 2010). Shorter visits may not be classified by homecare services as risks, however if care provision was shortened from the original care assessment time allocation, the person with dementia is arguably more at risk.

Often people with dementia were not included in the cross-sectional and qualitative research as participants, therefore the perspectives of people with dementia themselves have not been adequately heard. Thus, we do not know how safe people with dementia feel when supported by homecare to continue living in their own homes, or if, or which risks are

tolerable to them. Future research should investigate the perspectives of people with dementia receiving homecare in relation to aspects of safety and risk.

CONCLUSIONS

The provision of safe, effective homecare is vital to ensure that people with dementia do not experience unnecessary risk, however, the findings of this review suggest that people with dementia may experience additional risks associated with the care they are given. It is important that care interventions are person-centred, the responsibility of all relevant professions, and address potential unforeseen risks for both clients with dementia and homecare workers. Future work should focus on delineating which risks are least tolerable for people living with dementia and homecare workers, and which parties have ownership of risks.

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FIGURE LEGENDS

Figure 1: Types of Risk

Figure 2: Flow Diagram of Selection Process

Figure 3: Relationship of risk and protective factors to risks for homecare users with dementia

Figure 4: First order risks – interventional actions – consequences cycle

Figure 5: Factors associated with safety / risk mitigation practices in homecare for people with dementia informed by Golden and Earp’s social ecological model

Managing risks in dementia homecare

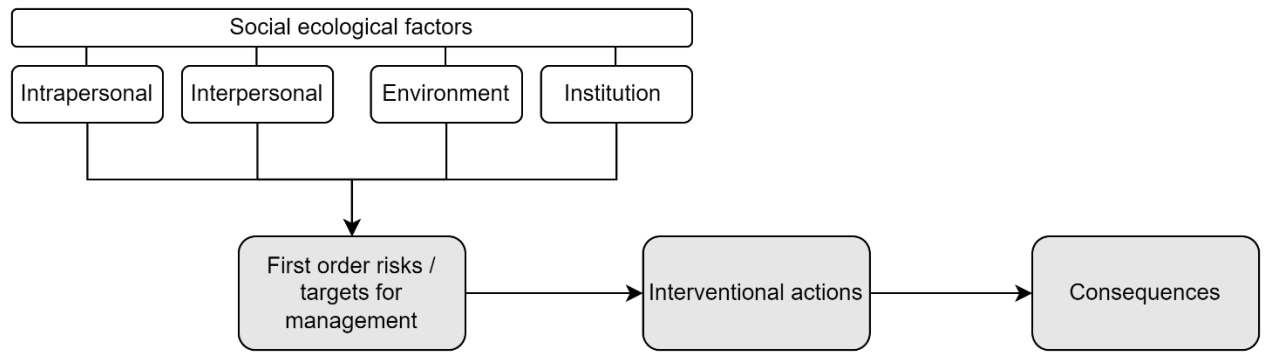


Figure 1: Types of risk

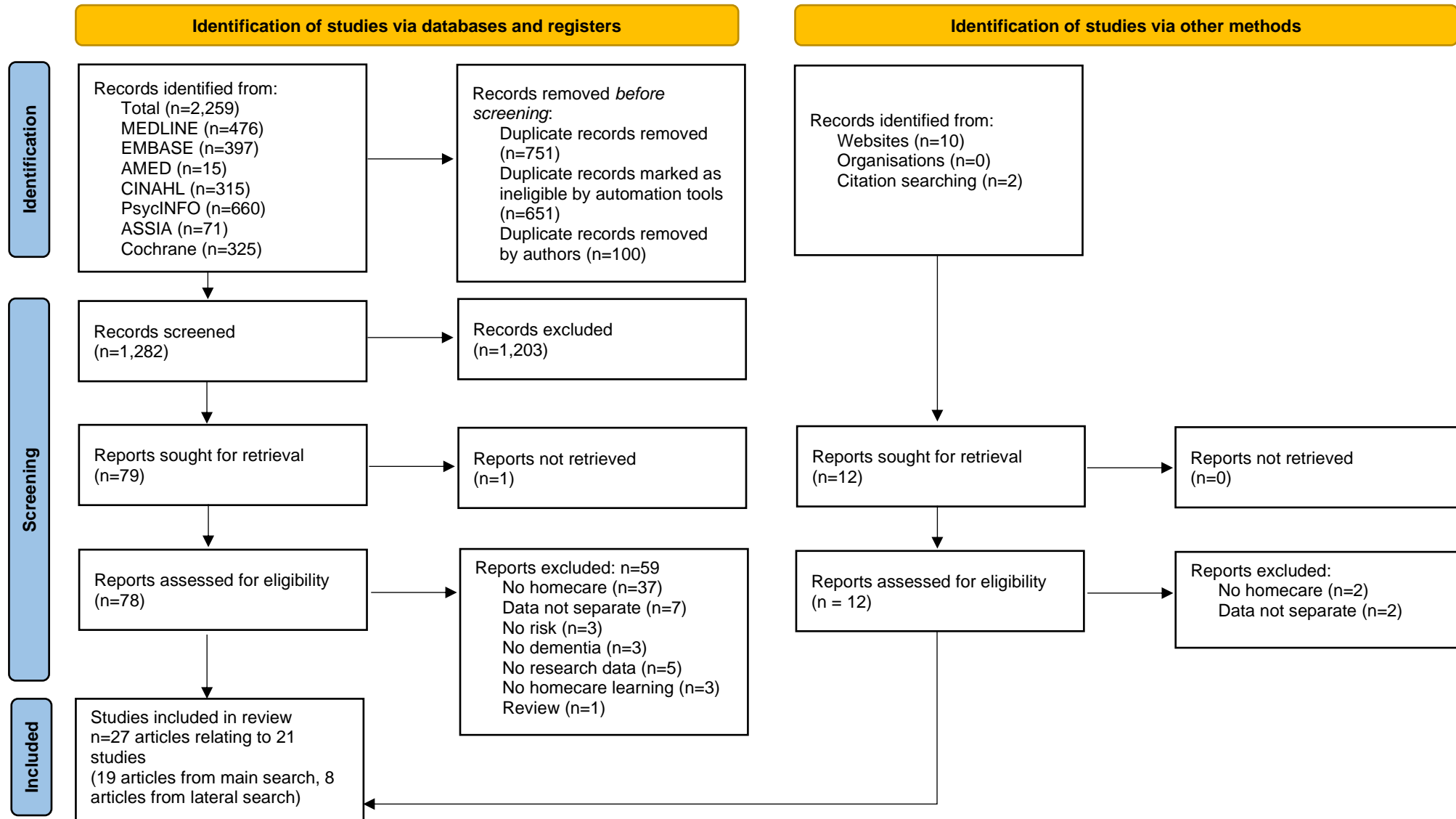


Figure 2: Flow Diagram of Selection Process

Managing risks in dementia homecare

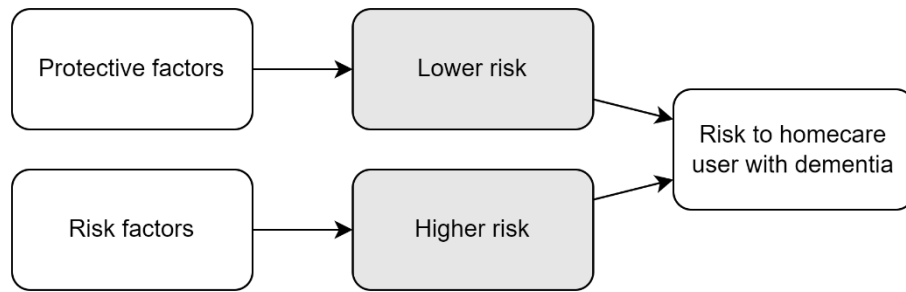


Figure 3: Relationship of risk and protective factors to risks for homecare users with dementia

Managing risks in dementia homecare

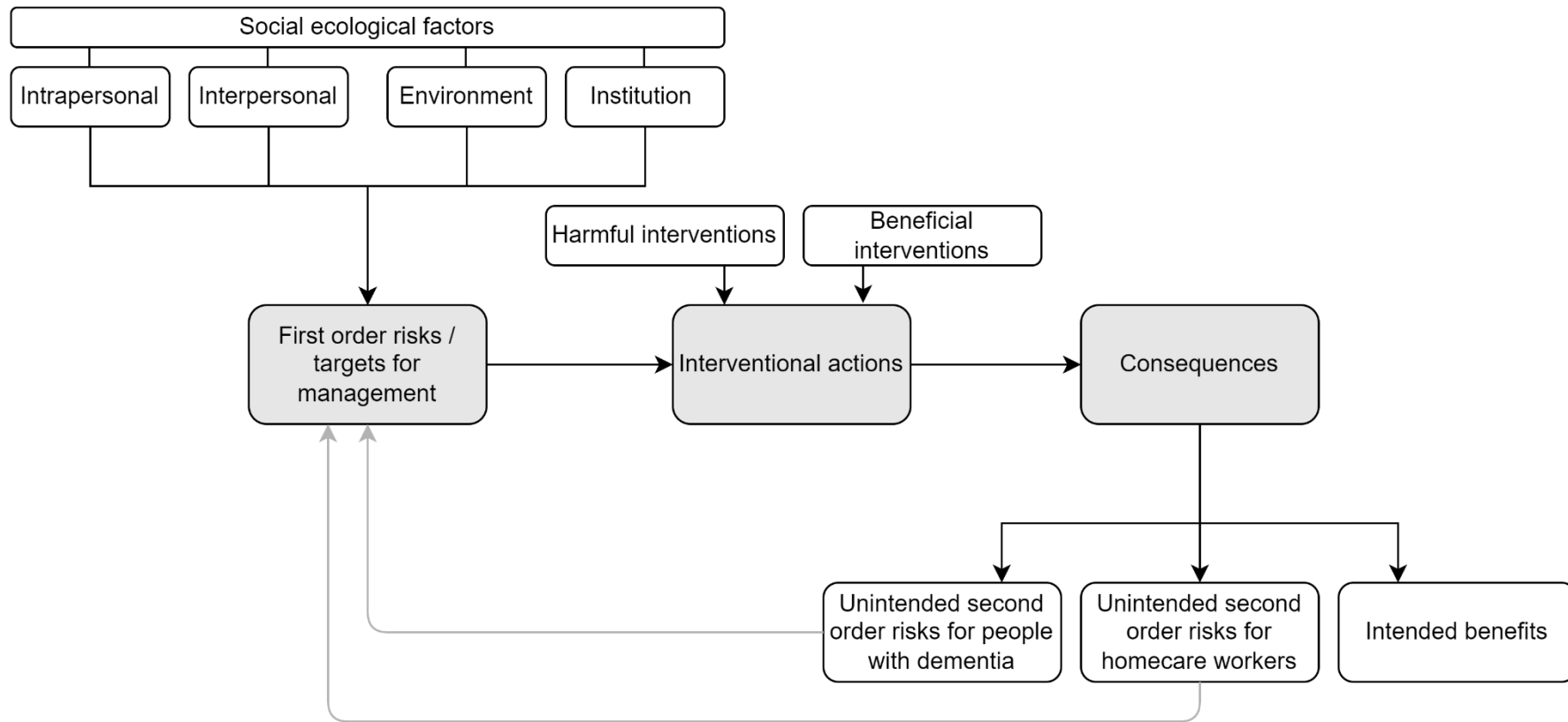


Figure 4: First order risks – interventional actions – consequences cycle

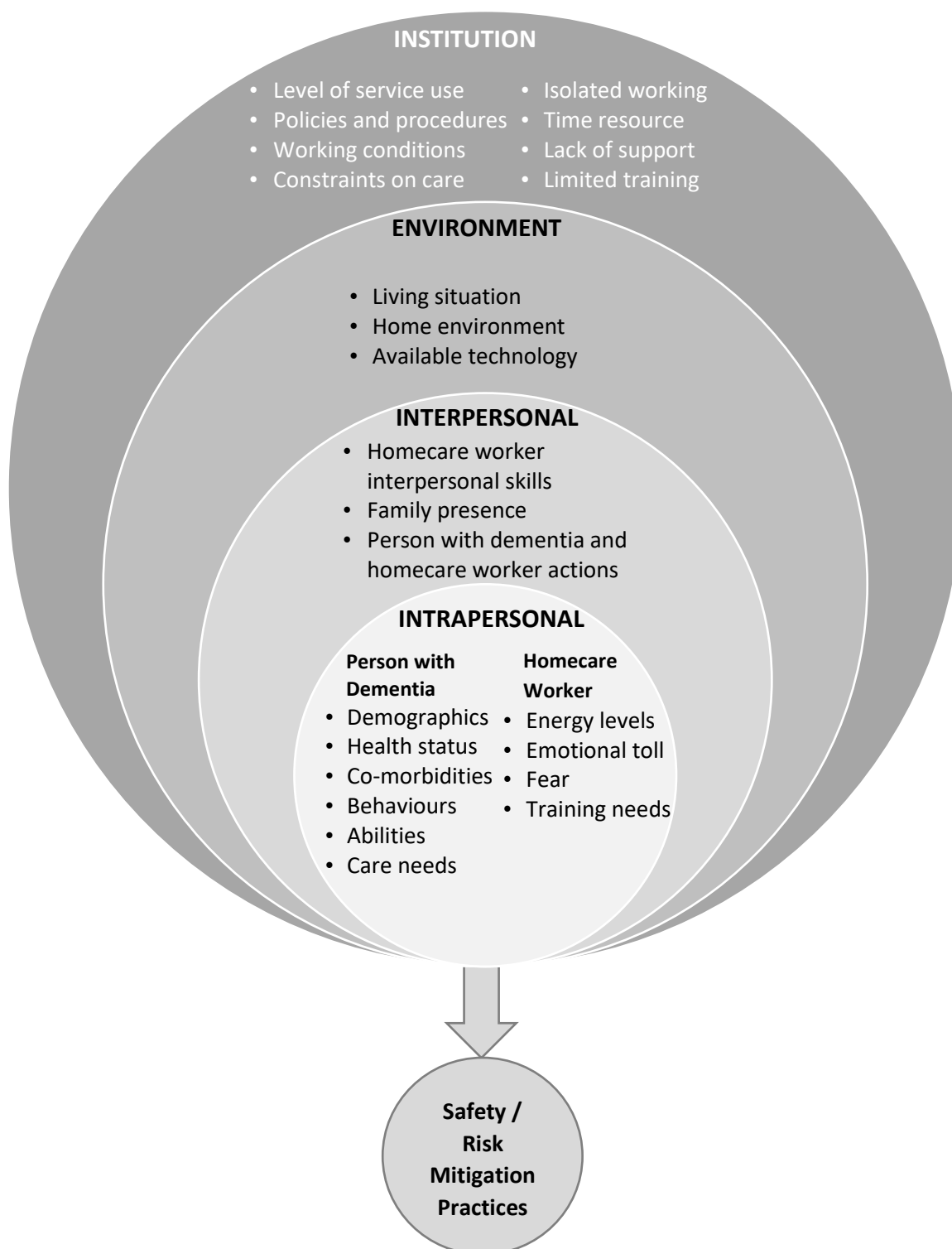


Figure 5: Factors associated with safety / risk mitigation practices in homecare for people with dementia informed by Golden and Earp’s social ecological model

Table 1: Study Characteristics

| Study Reference/s | Country | Study Design | Method/s | Homecare | Sample size n/ Participant type/s | Age mean (range) | Gender Female % | Quality score |
|--|-----------|----------------------------|--|--|--|---|-----------------|---------------|
| Young <i>et al.</i> , 2020 | USA | Retrospective cohort study | Homecare outcome and assessment dataset | Home health agencies - to manage the impact of illness and disability | 48,338 PwD receiving home health care | 83 (65-111) | 68.25 | Strong |
| Bick, 2018 | USA | Retrospective cohort study | Homecare outcome and assessment dataset | Home health care - skilled nursing, physical, occupational and speech therapy, aide services and medical social work | 57,88 People 65 or above admitted to visiting nurse service | 80.1 | 63.7 | Strong |
| Kim <i>et al.</i> , 2019 | Korea | Retrospective cohort study | Observational data: health insurance and long-term care data | Homecare - home bathing, home help, adult day and night care | 7,112 | Mode: 81-85 | 72.4 | Strong |
| Kim <i>et al.</i> , 2017 | | | | centres, skilled nursing services, and medical equipment rental | 7,841 Older adults with dementia receiving long-term care | Mode: 81-85 | 72.6 | Strong |
| ^a Knox <i>et al.</i> , 2020 | USA | Retrospective cohort study | Administrative and clinical assessment data | Home health agencies - for homebound patients who temporarily need skilled nursing and rehabilitation services | 126,292 | Mode: 81+ | 61.4 | Strong |
| ^b Knox <i>et al.</i> , 2020 | | | | PwD receiving home health care | 118,171 | Mode: 81+ | 61.6 | Strong |
| Welberry <i>et al.</i> , 2020 | Australia | Retrospective cohort study | Survey and observational data linkage study | Homecare - domestic and personal care, respite for carers, home maintenance, as well as nursing and allied health | 3,151 PwD who had taken part in the 45 and up study and who had entered residential care July 2010 - June 2014 | Homecare low: 85.78; Homecare high: 83.72 | 51.5 | Strong |
| Maxwell <i>et al.</i> , 2019 | Canada | Retrospective cohort study | Resident assessment instrument for homecare | Long-stay homecare - homemaking, transport, personal, nursing, end of life care, physiotherapy, | 153,125 long-stay homecare recipients with and without dementia | 80.08 | 64.7 | Strong |

Managing risks in dementia homecare

| | | | assessment data | occupational and speech and language therapy | | | | |
|---------------------------------|----------------------|-----------------|--|---|---|-----------------|---------------|----------|
| Galinsky <i>et al.</i> , 2010 | USA | Cross-sectional | Survey | Homecare: manual handling - bathing, dressing, turning, and lifting | 677 nurses, nurse aides and assistants | 48 (20-80) | 92 | Moderate |
| Mengelters <i>et al.</i> , 2020 | Netherlands, Belgium | Cross-sectional | Secondary data analysis | Professional nursing care at home / professional homecare | 844 PwD; 627 in the Netherlands; 217 in Belgium | PwD 82 (51-102) | 60.1 | Strong |
| Hamers <i>et al.</i> , 2016 | Netherlands | | Questionnaire survey | | 837 people with cognitive impairment | 81.6 | 60 | Strong |
| Moermans <i>et al.</i> , 2018 | Belgium | | Online questionnaire | | 1194 older adults with cognitive impairment | 82.5 | 67 | Strong |
| Mengelters <i>et al.</i> , 2018 | Netherlands | Cross-sectional | Questionnaire survey | Professional and informal care of PwD at home | 228 professionals, 77 family caregivers | 49.7 (19-92) | 76 | Strong |
| Tudor-Car <i>et al.</i> , 2017 | UK | Cross-sectional | Questionnaire, then priority scoring | Homecare for people with dementia | 76 clinicians | Not specified | Not specified | Moderate |
| Gjellestad <i>et al.</i> , 2020 | Norway | Cross-sectional | Data extraction from case management systems | Somatic healthcare for home dwelling PwD | 108 separate decisions to use forced treatment and care for PwD | 77.5 (34-99) | 69 | Moderate |

Managing risks in dementia homecare

| | | | | | | | | |
|-------------------------------|--------|-------------|---|---|---|---|---|----------------------|
| Abrams <i>et al.</i> , 2019 | UK | Qualitative | Semi-structured interviews | Managers organising care, homecare workers all aspects of homecare/end of life services | 13 homecare managers; 29 homecare workers | Homecare managers mode: 41-50; Homecare workers mode: 41-50 | Homecare managers 84.6; Homecare workers 93.1 | Moderate Moderate |
| Yeh <i>et al.</i> , 2018 | | | | | | | | |
| Lundberg, 2017 | Norway | Qualitative | Interviews | Daily living tasks in homecare and nursing homes | 31 care workers and licenced vocational nurses | Mode: 50-59 (20–50) | Homecare workers 93.3; Nursing homes 80 | Weak |
| Mole <i>et al.</i> , 2019 | UK | Qualitative | Interpretative phenomenological study: semi-structured interviews | Provision of professional care in clients' homes | 1 GP; 1 community social worker; 1 community occupational therapist; 1 community dietician; 1 Community nurse; 2 homecare workers | Not specified | 85.7 | Strong |
| Sandberg <i>et al.</i> , 2020 | Sweden | Qualitative | Semi-structured interviews and focus groups | Homecare supporting day-to-day existence | 11 nurse assistants; 12 care assistants | Not specified | 74 | Strong |
| Fæø <i>et al.</i> , 2020 | Norway | Qualitative | Hermeneutic approach using semi-structured interviews | Homecare/day care for people with dementia | 12 PwD | Not specified (69-89) | 50 | Strong |

Managing risks in dementia homecare

| | | | | | | | | |
|--|-----------|-------------|--|---------------------------------------|---|--|--|----------|
| Smebye <i>et al.</i> , 2016 | Norway | Qualitative | Hermeneutic approach using cases: interviews, observations, fieldnotes | Homecare: daily living tasks | 27 participants - 9 triads: PwD, informal and formal caregivers | 83 (82-88) | PwD 77.7; informal caregivers 66.6; formal caregivers 100 | Strong |
| Riachi, 2017 | UK | Qualitative | Semi-structured interviews | Live in care, care co-ordination | 7 homecare workers | Not specified | 100 | Moderate |
| Evans <i>et al.</i> , 2016 | Australia | Qualitative | Interviews and focus groups | Home based support | 21 community health and social care clinicians | Not specified | Not specified | Moderate |
| Leverton <i>et al.</i> , 2021 ^a | UK | Qualitative | Interviews and participant observation | Provision of formal homecare services | 82 participants: 19 homecare workers; 22 family carers; 11 homecare managers; 11 PwD; 19 health and social care professionals | Homecare workers 48.9; family carers 57.7; homecare managers 47.3; PwD 78.6; health and social care professionals 41.4 | Homecare workers 84.2; family carers 54.5; homecare managers 81.8; PwD 45.5; health and social care professionals 68.4 | Strong |
| Leverton <i>et al.</i> , 2021 ^b | | | | | | | | Strong |
| Backhouse & Ruston, 2021 | UK | Qualitative | Semi-structured interviews | Provision of formal homecare services | 17 homecare workers | 38 (21-65) | 94.1 | Strong |

PwD: People with dementia; GP: General Practitioner

Table 2: Risk factors and protective factors associated with risks to people with dementia receiving homecare: cohort studies

| Reference | Risk factors (in bold) | Associations | Risk to homecare users |
|--|---|---|--|
| Young <i>et al.</i> , 2020 | Increasing age | OR 1.1, 95% CI 1.03 - 1.18 | HIGHER risk of Permanent transition to nursing home |
| | White compared to black | OR 1.25, 95% CI 0.83 - 0.94 | |
| | Urinary and bowel incontinence vs continence | OR 1.46, 95% CI 1.37 - 1.56 | |
| | Depression vs no depression | OR 1.2, 95% CI 1.11 - 1.25 | |
| | Hip fracture vs no hip fracture | OR 2.63, 95% CI 2.27 - 3.05 | |
| | 3+ hospitalisations vs no hospitalisations | OR 3.02, 95% CI 2.77 - 3.29 | |
| ^a Knox <i>et al.</i> , 2020 | Severe dementia | dementia severity 6 OR 1.37, 95% CI 1.29 - 1.46 | HIGHER risk of potentially preventable readmissions to hospital |
| ^b Knox <i>et al.</i> , 2020 | Cognitive impairment | dementia severity 7 OR 1.94, 95% CI 1.64 - 2.31 | |
| | Dependence in mobility | OR 1.23, 95% CI 1.16 - 1.30 | |
| | Dependence in self-care | OR 1.59, 95% CI 1.47 - 1.71 | |
| | Unmet caregiving needs | OR 1.73, 95% CI 1.61 - 1.87 | |
| Maxwell <i>et al.</i> , 2019 | Dementia | sHR 2.60, 95% CI 2.53 - 2.67 | HIGHER entry into long-term care |
| | Frailty | Frailty index (p<0.001 interaction terms) | Frailty modified risk |
| Bick, 2018 | Male | Female: OR 0.87, 95% CI 0.80 to 0.95 | HIGHER risk of Hospitalisation within 30-days of admission to home health care |
| | Black | OR 1.21, 95% CI 1.09 to 1.35 | |
| | Medicaid eligibility | OR 1.27, 95% CI 1.04 to 1.54 | |
| | Number of co-morbidities | OR 1.05, 95% CI 1.00 to 1.09 | |
| | Cancer | OR 1.67, 95% CI 1.40 to 1.99 | |
| | Diabetes | OR 1.18, 95% CI 1.08 to 1.28 | |
| | Congestive heart failure | OR 1.25, 95% CI 1.12 to 1.38 | |
| | Renal disease | OR 1.52, 95% CI 1.34 to 1.72 | |
| | Skin ulcers | OR 1.35, 95% CI 1.20 to 1.52 | |
| | Cardiovascular conditions | OR 1.27, 95% CI 1.03 to 1.55 | |
| | Dyspnea: shortness of breath | OR 1.33, 95% CI 1.14 to 1.56 | |
| | ADL severity | OR 1.05, 95% CI 1.04 to 1.05 | |
| | Prior hospital stays 2+ | OR 1.28, 95% CI 1.17 to 1.39 | |
| | Number of therapy visits | OR 1.02, 95% CI 1.01 to 1.03 | |
| | Number of medications | OR 1.12, 95% CI 1.01 to 1.24 | |

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| Reference | Protective factors (in bold) | Associations | Risk to homecare users |
|-------------------------------------|--|---|--|
| Welberry <i>et al.</i> , 2020 | <p>Prior high-level homecare vs no homecare:</p> <p>Prior low-level homecare vs no homecare:</p> | <p>OR 3.41, 95% CI 2.14 - 5.44</p> <p>OR 2.61, 95% CI 1.69 - 4.03</p> <p>OR 2.02, 95% CI 1.06 - 3.84</p> <p><2 years after entry: HR 1.12, 95% CI 0.89 - 1.42</p> <p>2-4 years after entry: HR 1.49; 95% CI 1.01 - 2.21</p> <p>OR 0.61, 95% CI 0.45 - 0.81</p> <p>OR 0.72, 95% CI 0.54 - 0.95</p> <p>OR 0.51, 95% CI 0.33 - 0.77</p> | <p>LOWER risk of entering residential care (early).Entered residential care with:</p> <p>HIGHER ADL assistance needs HIGHER behaviour assistance needs</p> <p>HIGHER complex health needs HIGHER death rate (shorter length-of-stay in residential care)</p> <p>Entered residential care with:</p> <p>LOWER ADL assistance needs</p> <p>LOWER behaviour assistance needs</p> <p>LOWER complex health needs</p> |
| Maxwell <i>et al.</i> , 2019 | Dementia | <p>sHR 0.84, 95% CI 0.83 - 0.86</p> <p>HR 0.87, 95% CI 0.84 - 0.89</p> | <p>LOWER urgent hospitalisation</p> <p>LOWER mortality</p> |
| Kim <i>et al.</i> , 2017 | Institutional care vs homecare | HR 6.48, 95% CI 3.38 - 10.86 | HIGHER risk of pressure ulcer in institutional care |
| Kim <i>et al.</i> , 2019 | | HR 4.33, 95% CI 2.84 - 6.59 | HIGHER risk of hip fracture in institutional care |

OR: Odds Ratio; HR: Hazard Ratio; subdistribution Hazard Ratio: sHR; CI: Confidence Interval; ADL: Activities of Daily Living

Table 3: Risks, consequences and associated risks in dementia homecare

| Reference/s | First order risks | Interventional actions | Second order risk | Risk to who |
|---------------------------------|---|---|---|---|
| Cross-sectional Studies | | | | |
| Moermans <i>et al.</i> , 2018 | Poor cognitive ability Greater daily living dependency Family carer burden | Physical restraints, psychotropic medication, non-consensual care | Involuntary care | Person with dementia |
| Hamers <i>et al.</i> , 2016 | Poor cognitive ability Greater daily living dependency Family carer burden Living alone | Physical restraints, psychotropic medication, non-consensual care | Involuntary care | Person with dementia |
| Mengellers <i>et al.</i> , 2020 | Poor cognitive ability Greater daily living dependency Family carer burden Living alone | Physical restraints, psychotropic medication, non-consensual care | Involuntary care | Person with dementia |
| Mengellers <i>et al.</i> , 2018 | Caregiver (nurse, GP, healthcare professional, family carer) burden Living alone | Physical restraints, psychotropic medication, non-consensual care | Involuntary care Caregivers feel uncomfortable | Person with dementia Homecare worker |
| Galinsky <i>et al.</i> , 2010 | Workers perceived risk from violence in client's home and/or neighbourhood | Shortened visits | Reduction in care provision for clients Fear of being hit, kicked, pinched, shoved or bitten | Person with dementia Homecare worker |
| Tudor Car <i>et al.</i> , 2017 | Reduced care resources Poor training of carers Patient self-neglect Social isolation, falls Unsafe home environment | Poor quality care provision A need for home safety proofing, better recruitment, oversight and working conditions for homecare workers | None specified | Person with dementia |

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| | | | | |
|---------------------------------|--|---|---|---|
| Gjellestad <i>et al.</i> , 2020 | Greater ADL needs Disruptive behaviour Resistance to care Unmet needs | Forced admission to health institution not supported by adequate documentation Lack of transparency Coercion | Risk of safety and wellbeing to client Ethical dilemmas for family carers and health professionals | Person with dementia Homecare worker Family carer |
| Qualitative Studies | | | | |
| Mole <i>et al.</i> , 2019 | Time / knowledge constraints Budget constraints Poor nutritional skills Role performed within boundaries of policies and procedures | Ineffective/poor quality/constrained care provision / nutritional support | Malnutrition Loss of clients | Person with dementia |
| Yeh <i>et al.</i> , 2018 | Lone working Unpredictable client behaviour Communication difficulties Conflict with clients' family members | Provision of dementia homecare at end of life / remove self from client/ peer support for homecare workers | Undetected exhaustion/fatigue/isolation Emotional toll | Homecare worker |
| Abrams <i>et al.</i> , 2019 | Lone working Challenges to safeguarding Distressing behaviours Low nutrition Neglect | Provision of dementia homecare at end of life Policies put in place Adapting approach | Professional boundaries are challenged/risk to professional integrity | Homecare worker |
| Fæø <i>et al.</i> , 2020 | Need to improve safety/care for people with dementia to remain at home | Use of assistive technology Supervision of medication use and nutrition | Reduction in client autonomy/loss of independence Reduced homecare visits | Person with dementia |
| Sandberg <i>et al.</i> , 2020 | People with dementia at risk of injury, fire (smoking), getting lost, poor personal hygiene, loneliness | Development of risk management strategies to manage risks: adapt approach to person, rearrange environment (lock doors, move items, remove stove) | Risk management strategies created ethical dilemmas for homecare workers Institutionalisation | Person with dementia Homecare worker |
| Lundberg, 2017 | Care activities are timed in standardised slots and conflict with family carers over the complexities | Restricted care /non patient-centred care to achieve tasks | Reduction in client autonomy Ethics and regulatory codes | Person with dementia |



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| | of care needed for people with dementia | | interfere rather than support patient centred care | |
|--|--|--|---|---|
| Smebye <i>et al.</i> , 2016 | Conflict between people with dementia, family carers and professional carers on how to manage risk People with dementia's inability to accept their level of dependency | Paternalism justified considering beneficence and non-maleficence | Reduction in client autonomy Ethical challenges for homecare workers | Person with dementia Homecare worker |
| Leverton <i>et al.</i> , 2021 ^a | Home environment compromising the delivery of care and client autonomy by inhibiting access to parts of clients' homes. Homecare workers position within power structures limit their ability to advocate for client's voices. | Using adaptations in the home to balance risk and autonomy for client with clients' and homecare workers' safety and wellbeing | Adaptations resulting in the depersonalising of client's home, affecting the client's sense of identity and familiarity of home | Person with dementia Homecare worker |
| Leverton <i>et al.</i> , 2021 ^b | Healthcare professionals delegating Refusals of care Client behaviours Isolation Short staffed | Non-consensual care Peer support Workers working longer | Emotional toll Ethical challenges Client feels distressed or undervalued Tired homecare workers Unreliable care | |
| Riachi, 2017 | Communications difficulties with people with dementia Distress, psychological harm | Use of the SPECAL method to deliver person-centred care which resulted in greater wellbeing and less anxious behaviour amongst clients | None specified | Person with dementia Homecare worker |
| Evans <i>et al.</i> , 2016 | Poor hygiene, inadequate nutrition, keeping safe, other health problems, coping with technology, lack of support from family members for person with dementia, locked doors, fire risks | None specified | Challenges for homecare workers | Person with dementia |

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| | Cognitive impairment reduces client's ability to cope | | | |
|-------------------------|--|--|----------------|---|
| Backhouse & Ruston 2021 | Limited training Lone working Time allocation Communication difficulties Client behaviours Refusals of care | Distraction / communication skills Time management/taking longer Utilise training and experience Adapting care Using workplace support | None specified | Person with dementia Homecare worker |

Table 4: Study synthesis showing first order risks, interventional actions, and consequences

| First order risks: initial management targets | | | |
|---|---|--|--|
| Intrapersonal <u>Person with Dementia:</u> -Level of care need -Client behaviours/actions <u>Homecare worker:</u> -Perceived personal risk -Unmet training needs | Interpersonal <u>Homecare worker:</u> -Interpersonal difficulties -Individual responsibility when lone working -Competing demands | Environmental -Person with dementia's home environment -Person with dementia's living situation | Institutional -Lack of support for homecare workers -Working conditions -Constraints on care |
|  | | | |
| Interventional actions | | | |
| Beneficial interventions -Person-centred care -Assistive technology -Using peers, training, experience -Time management -Distraction and communication techniques -Provision of end-of-life care -Development of risk management strategies -Adaptations to balance risk/autonomy safety/wellbeing | Harmful interventions -Physical restraints -Psychotropic medication -Non-consensual care / institutionalisation -Poor quality care provision -Reduction in care provision for clients | | |
|  | | | |
| Consequences | | | |
| Intended consequences: benefits | | Unintended consequences: second order risks | |
| Person with Dementia: -Greater wellbeing -Less anxious behaviour -Better tailored/improved care -Feeling of safety -More support for clients and family carers -Maintenance of personhood | Homecare Worker: -Feeling of safety -More support | Person with Dementia: -Transitions or mortality -Poor quality care provision -Malnutrition -Distress or feeling undervalued -Involuntary care -Reduction of care provision -Increase in family carer burden -Reduction in autonomy/loss of independence | Homecare Worker: -Loss of professional integrity -Exhaustion/fatigue/ isolation -Fear of violence -Challenging situations -Loss of clients -Emotional toll -Regulatory codes constrain person-centred care |

