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Risk assessment for people living with dementia: a systematic review.

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Title: Risk Assessment for People living with Dementia: A Systematic Review

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Abstract

Objective:

This systematic review identified key components of risk assessment for people with dementia, examined attitudes towards risk identification and risk assessment, and appraised existing risk assessment tools.

Methods:

Systematic searches of five databases on two platforms (EBSCO, OVID) and grey literature databases (Open Grey, Base) were conducted. Studies were screened for inclusion based on predetermined eligibility criteria and quality assessed using the Mixed Methods Appraisal Tool. Findings were tabulated and synthesised using thematic synthesis.

Results:

Our review found people with dementia, their family carers, and healthcare professionals differed in how risk is conceptualised, with views being shaped by media perceptions, personal experiences, sociocultural influences, dementia knowledge and dementia severity. We found that mobilisation (causing falls inside and getting lost outside) is the most frequently identified risk factor. Our findings show people with dementia are generally risk-tolerant, while healthcare professionals may adopt risk-averse approaches because of organisational requirements. We found factors that disrupt daily routines, living and caring arrangements, medication management, and unclear care pathways contribute towards adverse risk events. We discovered that most studies about risk and risk assessment scales did not consider insight of the person with dementia into risks although this is important for the impact of a risk. No risk instrument identified had sufficient evidence that it was useful.

Conclusion:

Accurate risk assessment and effective communication strategies that include the perspectives of people with dementia are needed to enable risk-tolerant practice. No risk instrument to date was shown to be widely acceptable and useful in practice.

Title: Risk Assessment for People living with Dementia: A Systematic Review

Keywords

- Dementia
- Risk identification
- Risk assessment
- Home - safety
- Risk enablement
- Decision-making
- Care-planning

Introduction

Over 55 million people live with dementia globally and numbers are increasing as the population ages (WHO, 2021; Prince et al., 2015). Around two-thirds (61%) of people living with dementia (PLwD) are in the community, of which a third live alone (Prince et al., 2014). UK policy priority is to find the best ways to help PLwD live well at home for as long as possible (DH, 2016). PLwD have complex needs, including comorbid physical illness. They are supported mainly by their families but also use health and social care services (Wittenberg et al., 2019).

Practice and policy guidance require health and social care professionals to identify, manage and reduce risk in dementia to enable PLwD to remain at home for longer (DH, 2009, 2016). Part of the initial clinical assessment is to identify, evaluate and manage risk for this purpose. However, anxiety about the consequences of risk-related decisions is a major concern for practitioners (Ruston & Backhouse, 2022).

As cognition deteriorates, PLwD often become more vulnerable through self-neglect, accidents and a greater risk of abuse and exploitation (Manthorpe & Moriarty, 2010). Positive risk management, also known as risk enablement, balances the advantages from taking risks against the harms done by trying to avoid risk that can lead to excessive restrictions. It can result in beneficial outcomes such as increased confidence, self-satisfaction and preserved independence (Manthorpe & Moriarty, 2010; Morgan et al., 2004; Morgan & Williamson, 2014; DH, 2016). A recent systematic review found interventions used to mitigate risk in dementia homecare had both favourable and unfavourable outcome in that they reduced risk, improved safety and increased wellbeing but also created loss of autonomy and additional risks for clients and homecare workers (Backhouse et al., 2022).

It is essential to balance independence and risks when planning care (Taylor, 2006; Mitchell & Glendinning, 2008), and PLwD want to and should be involved in that decision-making process (Pel-Littel et al., 2021; Wied et al., 2019). Effective risk identification and assessment can inform the most appropriate way to manage risk and promote risk enablement that involves balancing the rights of

PLwD to retain as much control as possible, with those of society and families' wishes to reduce risks and promote safety at home. Furthermore, differences often exist in the perceptions and attitudes towards risk held by PLwD to those held by their carers, and those of health and social care professionals (Pel-Littel et al., 2021; Daly et al., 2018). So, to ensure effective person-centred risk assessment it is important to understand how risk is conceptualised and viewed by PLwD, their family carers, and the healthcare professionals (HCP) involved (Cott & Tierney, 2013). Comprehending how risk is assessed, recognised, negotiated, managed, and enabled is a key part of changing policy and practice to implement personalisation within care assessment, and enable health and social care professionals to develop appropriate interventions to promote safety, delay care home admissions, and decrease carer burden (Lea et al., 2014; Carr, 2011). As to our knowledge there is no systematic review on this subject, we aimed to systematically:

1. Explore key components of risk assessment for PLwD in the community and within care homes.
2. Report on the attitudes to risk identification and risk assessment of PLwD, their family carers and health and social care professionals.
3. Appraise existing risk assessment tools.

Methods

This systematic review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) standardised reporting guidelines (Moher et al., 2015) adheres to the PRISMA 2020 statement (Page et al., 2021), and is registered with PROSPERO (CRD42020187519).

URL: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=187519

Search Strategy

Search terms were informed by discussions with clinical and academic dementia experts and librarians with expertise in database searching and literature review. The search terms were adapted for use in bibliographic databases with database-specific filters when available (e.g Boolean

operators). Subsequently, we combined MeSH terms and free-text words (keywords). We used search terms including: 'risk assessment', 'risk assessment tool', 'risk identification' and terms were connected using AND with search terms for 'dementia'. Figure S1, supplementary information, details the search strategy used in EBSCOhost and OVID interfaces.

Information sources

We searched five electronic databases from inception on 10th June 2020 and again on 23rd April 2022: MEDLINE, CINAHL, PsycInfo, EMBASE, EMCARE via the EBSCOHost and OVID interfaces. We also searched Cochrane Library and PROSPERO for ongoing or completed systematic reviews. We conducted forwards and backwards citation searching of included studies and examined the 'cited by' function. Grey literature was searched for additional studies using BASE and OpenGrey, which included reviewing conference proceedings and dissertation thesis abstracts.

Data management and selection process

We used EndNote X7.0.2 (https://www.myendnoteweb.com/) and Rayyan (Ouzzani et al., 2016) to store, organize and manage references and abstracts. After removing duplicates, three reviewers (EP, LW, MM) worked as pairs to independently screen all titles and abstracts and select articles potentially meeting eligibility criteria for full-text review. They then independently screened the full text of the remaining articles to determine if articles met the inclusion criteria. Any disagreements were discussed with the third reviewer and study lead (JH), and a decision reached.

Inclusion criteria

No restrictions were applied in terms of language, country, or publication year. Studies were included if they were:

1. Peer-reviewed primary research
2. Involved PLwD regardless of sex, age, type or stage of dementia, living in the community or in nursing homes.

3. Provided evidence of assessing risk for people living at home with dementia or reported on perspectives of risk assessment and attitudes towards risk assessment for HCPs, PLwD and their carers.
4. Reported any outcome or component related to risk assessment in dementia (e.g. safety, risk of harm, neglect).
5. Any study design - quantitative or qualitative.

Exclusion criteria

We excluded studies if they reported:

1. Pharmaceutical interventions and risk
2. Risk factors for dementia development
3. Only risk enablement, management and strategies implemented in dementia.

Data extraction

We developed a data extraction template in Excel. EP and CK piloted it independently for two included studies, compared the data extracted and refined the template. Data were then extracted and entered for all included papers. This comprised information on study characteristics: authors, year of publication, setting, study design, sample size; and participants age, sex, dementia type and severity, the objectives of the review, risk assessments, key elements of risk and attitudes to assessing risk in dementia. Where a study had incomplete data, reviewers attempted to contact the authors to obtain more study data but did not receive any responses.

Quality assessment

Two reviewers (EP and CK) independently assessed the quality of included studies using the Mixed Method Appraisal Tool (MMAT: Hong et al., 2018), and any discrepancies were resolved by consulting a third reviewer (JH). Using one tool for the range of methods in included papers maximised appraisal consistency and across studies comparison.

Data synthesis and analysis

We calculated Cohen's kappa to measure the level of agreement for screening and selection of the papers (Higgins et al., 2022). We used thematic synthesis to analyse the qualitative data extracted (Thomas & Harden, 2008). Once familiar with the data, two reviewers (EP & CK) created a coding frame and regularly met to discuss their coding and amend the framework if needed. Once coded the team met to explore relationships and hierarchies between codes. Extracted data were organised into descriptive themes and then finally into analytical themes (Thomas & Harden, 2008). Five primary themes emerged from the data extraction, corresponding to the systematic review's objectives.

Quantitative data were extracted and tabulated using a separate form. Where appropriate, data were synthesised narratively as the data heterogeneity made it unsuitable for meta-analysis (Popay et al., 2006).

[Insert **Figure 1:** PRISMA flow diagram here]

Results

The Prisma Flow diagram (Page et al., 2021) displays the systematic search and screening results (Figure 1). The search yielded 9,328 citations after duplicate removal, out of which 20 papers met the eligibility criteria for the review. The inter-rater reliability score for study selection was $\kappa=0.973$ suggesting 'near perfect agreement' (Higgins et al., 2022).

Quality Assessment of included studies

Fourteen studies met all MMAT quality criteria and four studies met over half of the criteria. Two studies (Adams, 2001; Evans & Means, 2006) were rated as lower quality due to inadequate detail about the methods used and data synthesis. Table S1: supplementary information, shows the quality assessment of included studies.

Characteristics of included studies

The characteristics of the 20 studies are reported in Table 1 and referenced P1-P20 (Adams, 2001[P1]; Bantry-White & Montgomery, 2015[P2]; Behrman et al., 2017[P3]; Benbow & Kingston, 2017[P4]; Bourgeois & Couturier, 2009[P5]; Choi et al., 2014[P6]; Clarke et al., 2010[P7]; Dickins et al., 2018[P8]; Evans et al., 2016[P9]; Evans & Means, 2006[P10]; Lach et al., 1995[P11]; Lee et al., 2019[P12]; Pickering et al., 2019[P13]; Poulin de Courval et al., 2006[P14]; Sandberg et al., 2017[P15]; Stevenson & Taylor, 2018[P16]; Stevenson & Taylor, 2017[P17]; Stevenson et al., 2019[P18]; Struckmeyer et al., 2020[P19]; Taylor et al., 2017[P20]). Of the twenty studies included in the review, eleven were qualitative[P1,P3,P4,P7-P10,P15-P18], four used quantitative methods[P6,P13,P14,P19] and five used mixed methodology[P2,P5,P11,P12,P20].

Most studies were based in the UK (n=11). Others were from America[P11,P13,P19], Canada[P12,P14], Australia[P8], France[P5], South Korea[P6] and Sweden[P15]. One study[P5] was translated from French to English by a bilingual researcher. The number of participants in Evans & Means, (2006)[P10] study was unclear, while the total number of participants in the remaining 19 studies was 739. These comprised PLwD (n=291), their carers (n=268), social or HCPs supporting PLwD (n=221) and healthy older people (n=20). Sex of participants was not reported in six studies[P2,P7,P10-P12,P19]. In the remaining sample of 648 participants, there were more females (n=458) than males (n=190).

[Insert **Table 1:** Study characteristics of included papers]

All included papers focused on risk assessment in dementia. One explored how risk is conceptualised by PLwD[P8], five explored how HCPs construct and communicate risk assessment[P1,P7,P17,P18], and how risk is assessed and communicated[P20]. Seven studies explored risk-related experiences and perceptions of risk in dementia with either PLwD[P4,P5,P15,P18], carers [P3-P6,P11,P13,P16,P17], or HCPs[P3,P4,P9,P10]. Most studies (n=15) were conducted in community settings, and one study[P9] in a care home. Four studies reported the development of scales by HCPs to assess risk and safety[P2,P12,P14,P19]. Table 2

shows an overview of study outcome measures and findings of qualitative studies and Table 3 of quantitative studies.

[Insert **Table 2**: Qualitative results: findings from qualitative and mixed method studies]

[Insert **Table 3:** Quantitative results: findings from quantitative and mixed method studies]

Data synthesis

Five themes emerged from the thematic synthesis of the included studies:

1) ***Conceptualisation of risk*** –individual perceptions of risk, including how different individuals define, construct, and identify risk situations.
2) ***Components of risk*** –key elements included in risk and safety assessments.
3) ***Contributors to risk*** –factors that impact the risk level and how risk assessments are conducted.
4) ***Perspectives on risk assessment*** –how individuals assess risk and approaches to risk management.
5) ***Risk reduction*** –strategies to mitigate risk following an assessment.

In addition to the five themes identified, we appraised the four risk assessment scales.

Theme 1 – Conceptualisation of Risk

This theme explores differences in how PLwD, carers and HCPs conceptualise and define risk; there are three sub-themes: definition, construction, and identification of risk.

Definition of risk

PLwD perceive risk to be associated with lack of psychological or physical safety. Examples include unfamiliar settings or situations that create disorientation and feelings of anxiety[P15,P18]. Consequently, risk is associated with feeling loss of control, fear of the unknown, and uncertainty about what might

happen. Feeling safe, particularly whilst maintaining independence and autonomy is valued positively[P18].

Carers associate risk with exposure to harm and accidents. Whilst both carers and HCPs conceptualise risk as the consequence of a potential action and are concerned by severity rather than likelihood of it happening[P16,P17]. Risk susceptibility is determined by whether the risk is judged as being acceptable, primarily by the HCP but influenced by the risk management culture of their organisations[P2,P17]. Furthermore, risk is perceived to be ongoing and continuously changing as dementia progresses[P17,P18]. While level of risk is often determined by the PLwD's living situation and availability of family support[P15] and their willingness to engage with the support offered[P17]. Table S2: supplementary information, identifies factors influencing definitions of risk.

Construct of risk

Concepts of risk are constructed by socio-cultural factors interlinked with health, psychosocial and environmental influences, knowledge and understanding of dementia[P8,P10,P18]. Socio-cultural factors include life history (e.g. previous occupation), media representations of dementia, personal experiences, the individual's personality, and emotional responses to prior events, such as falls, going missing, or health emergencies[P8,P18]. Consequently, risk is viewed as being idiosyncratic and constructed in the context of multiple influences on the individual and associated with emotions such as anxiety[P18]. In addition, HCP's concepts of risk are influenced by concerns about harm to the individual and others, resource and environmental limitations, while attempting to balance the rights of individuals and others alongside organisational risk assessment cultures[P9,P17]. Table S2: supplementary information, identifies factors influencing the conceptualisation of risk.

Identification of risk

Risk identification explores how carers identify concerns about PLwD causing harm to self or others, or harm resulting from the actions of others[P1]. In practice, carer's accounts of daily life experiences

and disease progression enable HCPs to detect and acknowledge if a situation constitutes a risk, for example, someone with dementia going missing[P1,P16].

Theme 2 – Components of risk assessment

This theme concerns the identification of risk factors and actual risks that form the components of risk assessment. Twelve studies explore perspectives of PLwD, carers and HCPs[P2,P4,P5,P8,P10-P12, P14,P16,P18,P20].

Risk components relate to external (i.e., the physical environment, such as living arrangements or external support) and internal (i.e., the individual, such as progression of dementia) factors. These often have a harmful impact on PLwD, their carers and/or family members, and other members of the wider community.

Risk components are categorised into eight overarching domains: constant/pervasive risks; safety inside the home; safety in the community; food and nutrition; substances/dangerous objects; emotional and behavioural issues including self-care; interpersonal/social; financial. Table 4 reports the risk components identified in each study. Mobilisation both inside and outside of the home is the most frequently identified risk and discussed in all papers. Mobilisation is associated with falling or slipping. Other common risk factors are associated with driving and road safety, navigation outside of the home and orientation. The most frequently identified risks within the home are related to food preparation and safety in the kitchen and taking medication.

Eight studies identify fire-related risks either in general or from electrical and gas appliances[P5,P6,P8,P10,P11,P14,P16,P17]. Five studies identify risk related to financial exploitation[P4,P12,P16,P17,P20]. Some studies identify risk factors related to emotional wellbeing, inadvertent and intentional self-harm[P6], neglect of personal hygiene[P17,P20] or accidents while showering or bathing[P10,P16], food and alcohol consumption or malnourishment[P6,P11,P12,P14,P17,P18,P20].

Less commonly identified were accidents related to self-regulation of temperature (clothing, heating)[P11], leaving hot water running[P6], use of sharps or firearms[P11]; incidents involving the police[P4]; mood disorders[P20]; and loss of important documents[P17].

[Insert **Table 4:** Identified risk factors from included studies]

Theme 3 - Contributors to risk

Eight papers examine factors that impact on risk levels and risk assessment[P3,P7-P9,P13,P16,P17,P20]. Two subthemes are identified, factors that increase risk likelihood and severity, and factors that influence risk assessment.

Factors that affect the likelihood or severity of risk

Five studies identify factors contributing to risk by either influencing the likelihood that an adverse event will occur or the resultant harm[P3,P9,P13,P16,P17]. These factors broadly cover daily routines, dementia progression, living arrangements, caring arrangements, and medication management. For example, increased carer stress and disruption to daily routines reportedly increases the likelihood of abusive or neglectful behaviour, whereas carers and PLwD participating in social activities together acts as a protective factor against neglect[P13]. Also, unclear pathways through support services increases risk for PLwD and their carers[P3]. Table S3: supplementary information, identifies factors contributing to risk and their outcomes.

Factors that influence risk assessment

Three papers outline factors that contribute, either positively or negatively, to the assessment of risk in dementia[P7,P8,P20]. Negative ramifications of risk assessment are that personal responsibilities and freedoms are often reduced for PLwD and restrictions put in place. PLwD and carers perceive risk as an accepted part of daily life but frequently following a diagnosis, capacity may be questioned by HCPs without assessment and assumed to be lacking regarding decisions that may result in risks[P8]. Risk enablement can support people to live at home longer, while poor service utilisation or provision

increases carer stress and hastens care home placement[P8]. Staff acknowledge risk-averse practices may cause harm to PLwD through reducing independence, but also may reduce adverse consequences and professional responsibilities limit their ability to change practice[P8]. Organisational cultures impact risk assessment through nurturing either risk-averse or risk-tolerant approaches[P7]. For example, work cultures supportive of person-centred care are viewed as enabling risk-tolerance, while those which emphasise the deficits of PLwD limit creative solutions to manage risk, and staff ability to advocate for risk-tolerant strategies[P7]. Professionals' own risk-averse attitudes also contribute to problem-oriented thinking, increasing the likelihood of risk-averse organisational and team cultures[P7]. Decisions regarding risk are also influenced by staff workload and the availability of services[P7].

Effective risk management requires communication between the assessing professional, PLwD and carers. Taylor et al., (2017)[P20] outline challenges to communicating risk following assessment, which from most challenging to least challenging are: conflicting ideas on client's best interests; PLwD lacking insight into the risk; unrealistic expectations of services; risk of damage to professional or client relationship; lack of data on likelihoods and fear of complaint.

Theme 4 – Perspectives on Risk Assessment

Nine papers discuss perspectives on risk assessment, which include the perceptions of PLwD[P8,P10,P18], carers[P1,P3,P8-P10,P16], and HCPs involved in dementia care[P3,P7,P8,P10,P17]. Table S4: supplementary information, outlines individual attitudes towards risk assessment and the approaches they use to make judgments and decisions regarding risk.

People Living with Dementia

PLwD regard themselves as being largely risk-tolerant, considering some risk as acceptable. Maintaining independence in continuing activities is perceived to support their mental and physical wellbeing. PLwD judge that maintaining their quality of life, through engaging in meaningful activities

enables a sense of purpose[P18]. Regarding risky situations, PLwD emphasise that they often have strategies in place to manage or resolve any perceived risk, for example, seeking familiar objects or asking for help if they became lost[P8].

Carers

Similarly, carers often think that positive risk-taking is beneficial and it is better to manage risks rather than trying to eliminate them, therefore balancing the need for autonomy with safety. They also believe restricting freedoms may impact negatively on the PLwD, being potentially counterproductive by creating more risks through their relative becoming inactive or uncooperative and unwilling to accept care[P16].

Carers raise risk concerns they want help with, while many concerns are not reported to HCPs[P3] due to differences between HCP and carers' perceptions of safety or anxiety about care packages being withheld. Risks that are discussed with HCPs include medication, support, and safety inside the home. Conversations about risk with PLwD are dependent on the ability of the care recipient to comprehend and have insight into the issues discussed and carers feel reluctant to discuss risk that may cause anxiety, when their relative does not understand the danger well[P16]. Carers were often unsure whether PLwD would report risk concerns to them.

Healthcare Professionals

HCPs identify a need for collaborative decision-making in risk assessment. Community psychiatric nurses regularly discuss risk and risk management strategies with carers[P1]. Challenges arise where HCPs and carers have differing views about responsibility for decision-making in risk management. However, HCPs highlight the potential for collaborative working with carers to promote autonomy and minimise risk, by developing systems for carers to identify and report safety risks[P3].

HCPs identify challenges in implementing risk assessments, including adopting risk-averse approaches to ensure PLwD will be safe. Judgement on risks balance two needs: firstly, the need to

reduce harm, and secondly, the fear of being judged and being held accountable for potential harm to PLwD. This was sometimes problematic, as it created conflict with PLwD who wanted to remain independent and active[P16]. However, HCPs recognise the need to accept some level of risk to enable PLwD to maintain autonomy[P7,P9]. Context and circumstances dictate this process, and it is important to consider life history, preferences, and current circumstances.

Theme 5 - Risk reduction

The final theme refers to the strategies individuals use to reduce or avoid risk following identification of risk, reported in five studies[P1,P3,P11,P15,P16]. PLwD report utilising strategies to minimise risk, for example, when they are in an unfamiliar setting or a confusing and risky situation. PLwD use the following four strategies to mitigate risk: a) seek something recognisable, b) convince themselves that the situation is as it should be, c) avoid the risky situations, d) accept assistance from one's environment[P15].

Carers report discussions with PLwD primarily involve increasing awareness of the risk, such as reminding their relative that they may fall. Other strategies include accompanying the PLwD to activities, increased vigilance (monitoring environment), home adaptations, hiding objects, general supervision and taking over activities or tasks[P11,P16]. Carers may be reluctant to report concerns to HCPs for fear that the PLwD would receive substandard care, to avoid bothering the professional, or to avoid receiving an overly bureaucratic response[P3].

Community psychiatric nurses report that following the risk assessment, action is usually taken to mitigate the risk following discussion with other HCPs or family members[P1]. HCPs follow formal procedures, aligned with local safeguarding guidelines to report, and manage identified risks. Risk-averse and over-bureaucratic processes can result in difficulties with implementing person-centred approaches for minimising risk and optimising quality of life for PLwD[P3]. Overall, HCPs believe that people who raise concerns regarding risk receive a better level of care and support[P16].

Risk Assessment Scales

Four studies report instruments to evaluate safety and measure risk; see Table S5: supplementary information, for included domains and key components.

Bantry-White & Montgomery's (2015)[P2] scale measures safety when walking outdoors for PLwD and the overarching construct is prevention and protection from harm while wandering or being lost. The scale consists of 38 items divided into five domains. Perceptions of the structured assessment schedule were mixed, as clinical reviewers considered some components useful and others too vague. Some clinicians wanted a more flexible approach to assessing wandering and safety and had difficulty in distinguishing the objective versus the subjective risks associated with danger or harm to the person's safety while wandering or going missing.

The person-centred risk assessment framework (PCRAF) consists of two components: the PCRAF framework and My Plan, to engage PLwD in risk assessment and create a positive person-centred care plan[P12]. It is a comprehensive framework designed to encourage awareness of existing risks among clinical teams, promote independence and involve PLwD in care-planning[P12]. The seven domains include risky situations (e.g. falls, driving) that may result in destabilisation of co-existing chronic illnesses that lead to emergency department visits, hospitalisations and premature care home placement. Despite HCPs reporting high satisfaction it has several limitations and challenges to implementation being time-consuming and not yet fully integrated into the assessment process. Furthermore, it requires an established relationship between PLwD and HCPs. Therefore, an initial assessment or diagnostic visits may not be the best time to administer the PCRAF as PLwD and their carers are still grappling with the diagnosis.

The Safety Assessment Scale (SAS)[P14] was developed for use by HCPs working in community settings to assess home safety in PLwD, to minimise the risk of accidents, provide recommendations to carers and enhance case management. It consists of 32 items with nine domains related to risks of accidents and includes open-ended questions related to the person's behavioural and

environmental risks. SAS shows good validity and reliability and can be used by a range of different HCPs. A shorter version has been developed with 19 items maintaining seven out of the initial nine sections.

The Home Environment Assessment Protocol-Revised (HEAP-R)[P19] is a modified version of the HEAP scale (Gitlin et al, 2002) that assesses home-safety for PLwD through observation and questions. HEAP-R consists of five domains: hazards, adaptions, physical cues, clutter and comfort, reducing the original number of items from 192 to 60. The HEAP-R was pilot-tested in a study with three interrelated phases: assessment of content validity by experts, criterion validity by carer-PLwD dyads, and test-retest reliability by occupational therapists. The HEAP-R is used by occupational therapists and demonstrated good validity and reliability in measuring safety for clutter, hazards, and adaptions. However, its usability remains untested with other allied HCPs. Further research is indicated to determine clinical cut-points that accurately and meaningfully enable decision-makers to assess safety and risks within someone's home.

Discussion

We identified only 20 relevant papers on risk assessment but were able in this first systematic review to identify how risk is conceptualised, the key components of risk assessment, perspectives about how risk is assessed, obstacles to conducting risk assessments, distinguish factors that contribute towards risk events and differing attitudes to risk identification and assessment in dementia.

This review found that PLwD, carers and HCPs conceptualise risk differently. Risk is defined as being part of everyday life and construction of risk is influenced by media perceptions, personal experiences, sociocultural influences, and dementia severity. Conceptualisation, therefore, transcends individual constructs and represents a complex and individualised view (McDermott, 2010; Lupton, 2013). PLwD associate risk with unusual situations that create feelings of fear and uncertainty and want to feel safe while retaining their independence. PLwD particularly value feeling safe at home (Bamford et al.,

2021), and may perceive being out of their home as more unsafe. Carers perceive risk as exposure to danger and harm and prefer to manage rather than eliminate risk. Post-diagnostic support and education is needed to help families with decision-making around risk (Bamford et al., 2021). HCPs judge risk in dementia according to the severity of the consequences of an activity or situation rather than the likelihood of it occurring. They adopt risk-averse approaches because of the certainty of reduced harm for PLwD, and the fear of being held accountable. This contrasts with PLwD, who express concerns about diminished personal freedom and autonomy in decision-making following a diagnosis of dementia, when susceptibility to risk may be presumed and if present the PLWD may not have insight.

Our review showed HCPs were sensitive to PLwD's need for autonomy and independence and supported risk enablement in care-planning where possible. Similarly, Wied et al., (2019) found that HCPs do not deny PLwD their right to make their own decisions and they are supported with decision-making in terms of care. A key challenge for HCPs is communication with PLwD and carers when perceptions of risk differ or there is lack of insight (Stevenson & Taylor, 2017). Within this review scant attention is given to insight and exploring the PLwD's level of awareness about their impairments and how these impact on their safety. Only one risk assessment scale included a question about insight, which was linked to wandering and whether the PLwD was 'aware that they get lost?' (Bantry-White & Montgomery, 2015). Some PLwD do not acknowledge their condition or lack awareness of deficits in sensory, perceptual, motor, affective, or cognitive functioning and may underestimate their dementia-related impairments (Alexander et al., 2021; Tagai et al., 2020). Self-reported awareness of impairments in mild-moderate dementia can change over-time, so lack of insight is not always explained by cognitive or functional deficits and awareness should be measured at different timepoints in the illness trajectory (Alexander et al., 2021).

Taking risks is traditionally perceived as a negative action that should be minimised or eliminated to avoid harm (Clarke & Mantle, 2016). However, participant groups were largely unified in their views surrounding action versus inaction and both PLwD and carers believe that positive risk-taking is

necessary to maintain quality of life and enable engagement in meaningful and enjoyable activities (Morgan and Williamson 2014; Mapes, 2017). Risk enablement helps maintain independence by focusing on the skills and assets of PLwD, as 'building on preserved activities' can yield positive and beneficial outcomes (Rapaport et al., 2020). However, difficulty acknowledging risks within familiar settings or activities where the person feels they have control may create obstacles for implementing strategies to reduce risk. Risk exposure is ongoing and changes as dementia progresses. Consequently, enabling positive risk-taking becomes challenging as dementia severity and vulnerability increase and the likelihood of risk-averse practices increases (Berry et al., 2015).

Our review found that PLwD are generally risk-tolerant and report strategies to manage risk within their daily lives. Assessment and management often occur simultaneously, with risk reduction strategies being implemented at the time risks appear. However, susceptibility to risk is not always evident until a person's behaviour causes an accident and it becomes apparent that they can no longer safely carry out an activity (Bourgeois & Couturier, 2009). Similarly, carers adopt largely informal approaches to risk identification and management. As potential risks arise, pragmatic and measured approaches are taken to reduce risk. Of note, carers can be reluctant to discuss some risk issues with their relative or with HCPs to avoid intrusive interventions. The carers' role is pivotal to facilitating engagement between PLwD and HCPs and these differing perspectives about what constitutes an acceptable risk and reticence can lead to inadequate knowledge, assessment and delays in accessing support (Tuijt et al., 2021; Bodemer & Gaissmaier 2012; Manthorpe & Moriarty, 2010). In contrast, HCPs are bound by organisational rules and regulations surrounding risk processes. However, these policies may underestimate the complexity of risk assessment judgements and means decision-making centres around what is defensible as well as PLwD and carer preferences (Taylor, 2006). This may be exacerbated by a lack of service availability or service utilisation for carers (Clarke et al., 2010). Effective communication ensures that information, preferences, and concerns are shared and enables informed decision-making (Fetherstonhaugh et al., 2013, 2016). However, lack of consensus and standardisation in defining and measuring risk behaviours, such as wandering, distorts how risk factors are reported and risk reduction measures

are dependent on accurate assessment (Ali et al., 2016). While structured risk assessments are useful for systematically identifying safety hazards, high scores may be insufficient for predicting likelihood of an accident, but additional indicators can be assessed through dialogue with carers (Bourgeois & Couturier, 2009).

Risks were related to physical and emotional harm to PLwD and others, such as fires, falls, safety crossing roads, driving safety, exposure to cold, not taking medication correctly, vulnerability through exploitation and social isolation, and exposure was mostly gradual and persistent rather than sudden or unexpected. The pervasive nature of exposure to risks suggests that strategies can be introduced to target key areas and mitigate risk in dementia. Mobilisation inside and outside the home was the most frequently identified risk factor. The risk of falls is significantly associated with impaired cognition, increased frailty, gait changes, reduced ADL ability and depression in PLwD (Park et al., 2020). These have a significant impact on quality of life, health and healthcare costs, and expedite care home placement and mortality (NICE, 2013). Strategies such as falls prevention programmes, exercise, vitamin D supplementation and reducing hazards in the home environment (flooring, lighting, furniture and fittings) can reduce the risk and be incorporated into care plans (Moncada & Mire, 2017; NICE, 2013). Other concerns about safety within the home include food preparation and medication administration. Assistive technology advancements which support independent living may help mitigate risk and allow PLwD to remain at home (Kruse et al., 2020). Yet, despite the range of technologies available for PLwD and carers there is very little evidence of widespread practical application (Lorenz et al., 2019). This may be due to conflicting evidence about their clinical and cost effectiveness and barriers such as PLwD being reluctant to use assistive technology aids due to lack of familiarity with equipment or feeling stigmatised (Howard et al., 2021; Kruse et al., 2020).

Implications for practice

This review highlights the need to develop clear and transparent risk communication pathways to enable better informed assessments and individualise care-planning for risk management. Focusing

on safety by avoiding risky situations, as opposed to enablement can result in approaches that may hasten an individual's cognitive decline through inactivity (Clarke & Mantle, 2016). Thus, risk assessment and management processes should focus as much as possible on the adaption and support that can sustain activities, as opposed to avoidance (Clarke & Mantle, 2016). Modifying organisational risk cultures away from risk aversion and towards positive risk management would support professionals when making decisions with patients and families to strike the right balance between safety and autonomy. "Effective risk communication is key and needs to be informed by a framework of policy and best practice that make PLwD central to the decision-making process (Stevenson et al., 2019; Morgan & Andrews, 2016). Shared approaches to risk should balance rights and protection by developing outcomes-focused, person-centred safeguarding practices (Stevenson et al., 2018; Morgan & Andrews, 2016; Manthorpe & Moriarty, 2010). Where concerns about insight and capacity make this more complicated, positive risk taking can be achieved through personalising approaches that use the least restrictive practices and are in line with principles of the Mental Capacity Act (DH, 2005). This assumes the PLwD has capacity unless it is established otherwise; and enables good, calculated decisions about risk (Morgan & Andrews, 2016; Manthorpe & Moriarty, 2010). Additionally, carer knowledge and skills at recognising and managing their relative's exposure to risk is also as a primary factor in risk modification (Horvath et al., 2005). The value of maintaining autonomy through risk enablement with risk-taking is part of maintaining quality of life rather than something to be avoided. Risk assessment processes should therefore promote and maintain improvements in quality of life.

Implications for research

This review included studies that evaluated risk assessment tools and all reported good reliability and validity (Struckmeyer et al., 2020; Lee et al., 2019; Bantry-White & Montgomery, 2015; Poulin de Courval et al., 2006). Scales represent valuable tools to develop person-centred risk assessments. However, some scales were too specific to be used pragmatically across all clinical environments and multi-disciplinary professionals (Struckmeyer et al., 2020; Bantry-White & Montgomery, 2015). Our

findings identify the key components of risk assessment, which supports the content validity for developing future risk assessment tools. Scales should be able to work across health and social care and acceptability and implementation of risk assessment should be the focus of future research. To date, three of the four scales we identified have very narrow risk assessments and none have been evaluated completely for usability and whether they can help produce strategies which are acceptable to PLwD and their carers and reduce risk.

Strengths and Limitations

The strengths of this review include the rich range of evidence, including papers in all languages from databases inception and including the grey literature. Multiple reviewers were involved in all stages of the review process. It collated multiple perspectives from individuals with dementia and those involved in their care. By triangulating these perspectives, we were able to build a holistic view of risk assessment in dementia.

Studies within this review were conducted in western, high-income countries. This limits generalisability of our findings to low and middle-income countries. Most studies were observational and there was little testing of observations, but most studies were of good quality. Overall, the evidence collated and summarised enables clear and coherent messages to be drawn out, contributing to the meaningfulness of this review.

Conclusion

In conclusion, our systematic review summarises the major components of risk to be included in a risk assessment tool for PLwD and offers insight into the complexity of risk and the diversity of perspectives on risk assessment and management. Safety concerns remain paramount and accurate risk assessment and excellent communication is needed to enable risk-tolerant practices and ensure these approaches can be evaluated effectively. PLwD and carers should play an active and prominent role in the risk assessment process. We did not find any instrument which to date had been shown to

be widely acceptable and useful in practice. The review clearly demonstrates the need for further research and evidence-building about risk assessment in dementia care.

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References

Adams, T., 2001. The social construction of risk by community psychiatric nurses and family carers for people with dementia. *Health, risk & society*, *3*(3), pp.307-319. https://doi.org/10.1080/13698570120079903

Alexander, C.M., Martyr, A., Savage, S.A., Morris, R.G. and Clare, L., 2021. Measuring awareness in people with dementia: results of a systematic scoping review. *Journal of Geriatric Psychiatry and Neurology*, *34*(5), pp.335-348. https://doi.org/10.1177/08919887209247

Ali, N., et al., 2016. Risk assessment of wandering behavior in mild dementia. *International journal of geriatric psychiatry*, *31*(4), pp.367-374. https://doi.org/10.1002/gps.4336

Backhouse, T., Ruston, A., Killett, A., Ward, R., Rose-Hunt, J. and Mioshi, E., 2022. Risks and risk mitigation in homecare for people with dementia—A two-sided matter: A systematic review. *Health & Social Care in the Community*, *30*(6), pp.2037-2056.

Bamford, C., et al., and PriDem study team, 2021. Key components of post-diagnostic support for people with dementia and their carers: a qualitative study. *PloS one*, *16*(12), p.e0260506. https://doi.org/10.1371/journal.pone.0260506

Bantry White, E. and Montgomery, P., 2016. Supporting people with dementia to walkabout safely outdoors: development of a structured model of assessment. *Health & Social Care in the Community*, *24*(4), pp.473-484. https://doi.org/10.1111/hsc.12226

Behrman, S., Wilkinson, P., Lloyd, H. and Vincent, C., 2017. Patient safety in community dementia services: what can we learn from the experiences of caregivers and healthcare professionals?. *Age and Ageing*, *46*(3), pp.518-521. https://doi.org/10.1093/ageing/afw220

Benbow, S.M. and Kingston, P. 2017. Spontaneous concerns about risk and abuse reported by people with dementia and their carers. *The Journal of Adult Protection*, 19(2), pp.92–99. https://doi.org/10.1108/JAP-12-2016-0030

Berry, B., Apesoa-Varano, E.C. and Gomez, Y. 2015. How family members manage risk around functional decline: The autonomy management process in households facing dementia. *Social Science & Medicine*, 130, pp.107–114. https://doi.org/10.1016/j.socscimed.2015.02.014Get rights and content

Bodemer, N., and W. Gaissmaier. 2012. “Risk Communication in Health.” In: Roeser, S., Hillerbrand, R., Sandin, P.and Peterson, (Eds.), *Handbook of risk theory: Epistemology, decision theory, ethics, and social implications of risk* (Vol. 1).Springer Netherlands. ISBN : 978-94-007-1432-8

Bourgeois, J. and Couturier, P. 2009. Safety at home for people with dementia: Preliminary evaluation of situations-at-risk in a French geriatric memory clinic AGRICA View project SAFES Cohort Study View project. *Psychologie & Neuropsychiatrie du Vieillissement*, 7(3), pp.213-224. DOI: 10.1684/pnv.2009.0174

Carr, S. (2011). Enabling risk and ensuring safety: self-directed support and personal budgets. *The Journal of Adult Protection*, 13(3), pp.122–136. https://doi.org/10.1108/14668201111160723

Choi, M.-H., et al., 2014. Extraction and Analysis of Risk Elements for Korean Homecare Patients with Senile Dementia. *The Journal of Behavioral Health Services & Research*, 43(1), pp.116–126. https://doi.org/10.1007/s11414-014-9429-4

Clarke, C.L., et al., 2010. Reframing risk management in dementia care through collaborative learning. *Health & Social Care in the Community*, 19(1), pp.23–32. https://doi.org/10.1111/j.1365-2524.2010.00944.x

Clarke, C., & Mantle, R. 2016. Using risk management to promote person-centred dementia care. *Nursing Standard (2014+)*, *30*(28), 41. DOI: 10.7748/ns.30.28.41.s47

Cott, C.A. and Tierney, M.C. 2013. Acceptable and unacceptable risk: balancing everyday risk by family members of older cognitively impaired adults who live alone. *Health, Risk & Society*, 15(5), pp.402–415. https://doi.org/10.1080/13698575.2013.801936

Daly, R.L., Bunn, F. and Goodman, C., 2018. Shared decision-making for people living with dementia in extended care settings: a systematic review. *BMJ open*, *8*(6), p.e018977. http://dx.doi.org/10.1136/bmjopen-2017-018977

Department of Health, 2005. *Mental Capacity Act*. London: Stationery Office. https://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

(Accessed 25 Sep 2023).

Department of Health, 2009. *Living well with dementia: A national dementia strategy*. Department of Health Publications: London. https://www.gov.uk/government/news/living-well-with-dementia-a-national-dementia-strategy (Accessed 25 Sep 2022).

Department of Health, 2016. *Prime Minister's Challenge on Dementia 2020: Implementation Plan.* Department of Health Publications: London. Retrieved from www.gov.uk/government/uploads/system/uploads/attachment_data/file/505568/dementia-implementation-plan.pdf (Accessed 25 Sep 2022).

Dickins, M., Goeman, D., O'Keefe, F., Iliffe, S. and Pond, D. 2018. Understanding the conceptualisation of risk in the context of community dementia care. *Social Science & Medicine*, 208, pp.72–79. https://doi.org/10.1016/j.socscimed.2018.05.018

Evans, E.A., Perkins, E., Clarke, P., Haines, A., Baldwin, A. and Whittington, R. 2016. Care home manager attitudes to balancing risk and autonomy for residents with dementia. *Aging & Mental Health*, 22(2), pp.261–269. https://doi.org/10.1080/13607863.2016.1244803

Evans, S. and Means, R. 2006. Perspectives on risk for older people with dementia in extra care housing in the UK: Findings from a longitudinal study. *International Journal on Disability and Human Development*, 5(1) pp.77-82. https://doi.org/10.1515/IJDHD.2006.5.1.77

Fetherstonhaugh, D., Tarzia, L., Bauer, M., Nay, R., & Beattie, E. 2016. "The red dress or the blue?" How do staff perceive that they support decision-making for people with dementia living in residential aged care facilities?. *Journal of Applied Gerontology*, *35*(2), pp.209-226. DOI: 10.1177/0733464814531089

Fetherstonhaugh, D., Tarzia, L., & Nay, R. 2013. Being central to decision making means I am still here! The essence of decision making for people with dementia. *Journal of Aging Studies, 27*,143–150. https://doi.org/10.1016/j.jaging.2012.12.007

Gitlin, L., Schinfeld, S., Winter, L., Corcoran, M., Boyce, A., & Hauch, W. 2002. Evaluating home environments of persons with dementia: Inter-rater reliability and validity of the Home Environmental Assessment Protocol (HEAP). *Disability and Rehabilitation*, *24*, 59–71. https://doi.org/10.1080/09638280110066325

Higgins, J.P., et al., (editors). 2022 Cochrane Handbook for Systematic Reviews of Interventions version 6.3 (updated February 2022). Cochrane. Available from www.training.cochrane.org/handbook. **ISBN** 9781119536659 (epub)

Hong, Q.N., et al., 2018. The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, 34(4), pp.285–291. DOI: 10.3233/EFI-180221.

Horvath, K. J., et al., 2005. "Caregiver Competence to Prevent Home Injury to the Care Recipient with Dementia." *Rehabilitation Nursing* 30(5), pp.189–196. https://doi.org/10.1002/j.2048-7940.2005.tb00109.x

Howard, R., et al., 2021. The effectiveness and cost-effectiveness of assistive technology and telecare for independent living in dementia: a randomised controlled trial. *Age and ageing*, *50*(3), 882-890. https://doi.org/10.1093/ageing/afaa284

Kruse, C.S., Fohn, J., Umunnakwe, G., Patel, K. and Patel, S., 2020 Evaluating the facilitators, barriers, and medical outcomes commensurate with the use of assistive technology to support people with dementia: a systematic review literature. *Healthcare,* 8(3) p. 278). *8*, 278. MDPI. https://doi.org/10.3390/healthcare8030278

Lach, H.W., Thomas Reed, A., Smith, L.J. and Carr, D.B. 1995. Alzheimer's disease: Assessing safety problems in the home. *Geriatric Nursing*, 16(4), pp.160–164. https://doi.org/10.1016/S0197-4572(05)80022-9

Lea, E., et al., 2014. Improving student nurses' aged care understandings through a supported placement. *International Nursing Review*, 62(1), pp.28–35. https://doi.org/10.1111/inr.12156

Lee, L., et al., 2019. Person-centred risk assessment framework: assessing and managing risk in older adults living with dementia. *Neurodegenerative Disease Management*, 9(1), pp.47–57. https://doi.org/10.2217/nmt-2018-0031

Lorenz, K., Freddolino, P. P., Comas-Herrera, A., Knapp, M., & Damant, J. 2019. Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia*, *18*(2), pp.725-741. DOI: 10.1177/1471301217691617

Lupton, D. 2013. Risk and emotion: towards an alternative theoretical perspective. *Health, Risk & Society*, 15(8), pp.634–647. https://doi.org/10.1080/13698575.2013.848847

Manthorpe, J. and Moriarty, J. 2010 Nothing Ventured, Nothing Gained: Risk Guidance for People with Dementia, London, Department of Health, available on- line at

https://www.gov.uk/government/publications/nothing-ventured-nothing-gained-risk-guidance-for-people-with-dementia. (Accessed 25 Sep 2022).

Mapes, N. 2017. Think outside: positive risk-taking with people living with dementia. *Working with Older People*, 21(3), pp.157–166. https://doi.org/10.1108/WWOP-03-2017-0007

McDermott, S. 2010. Professional judgements of risk and capacity in situations of self-neglect among older people. *Ageing and Society*, 30(6) pp.1055–1072 https://doi.org/10.1017/S0144686X10000139

Mitchell, W. and Glendinning, C. (2008). Risk and adult social care: Identification, management and new policies. What does UK research evidence tell us? *Health, Risk & Society*, 10(3), pp.297–315. https://doi.org/10.1080/13698570802163677

Moher, D., et al., 2015. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, 4(1) pp.1-9. https://doi.org/10.1186/2046-4053-4-1

Moncada, L.V.V. and Mire, L.G., 2017. Preventing falls in older persons. *American family physician*, *96*(4), pp.240-247. https://www.aafp.org/pubs/afp/issues/2017/0815/p240.html (Accessed 25 Sep 2022).

Morgan, S. and Andrews, N., 2016. Positive risk-taking: from rhetoric to reality. *The Journal of Mental Health Training, Education and Practice*, *11*(2), pp.122-132.

Morgan, S & Williamson, S., 2014. *How can 'positive risk-taking' help build dementia-friendly communities?*https://policycommons.net/artifacts/1863098/how-can-positive-risk-taking-help-build-dementia-friendly-communities/2611427/ (Accessed 25 Sep 2022).

Morgan, D. G., Stewart, N. J., D'arcy, K. C., & Werezak, L. J. 2004. Evaluating rural nursing home environments: dementia special care units versus integrated facilities. *Aging & Mental Health*, *8*(3), 256-265. https://doi.org/10.1080/1360786041000166796

National Institute for Health and Care Excellence, 2013. *Falls in older people: assessing risk and prevention*. Clinical guideline [CG161] NICE. https://www.nice.org.uk/guidance/cg161 (Accessed 25 Sep 2022).

Ouzzani, M., Hammady, H., Fedorowicz, Z. and Elmagarmid, A., 2016. Rayyan—a web and mobile app for systematic reviews. *Systematic reviews*, *5*(1), pp.1-10. https://doi.org/10.1186/s13643-016-0384-4

Page, M. J., et al., 2021. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Systematic reviews*, *10*(1), pp.1-11. https://doi.org/10.1016/j.ijsu.2021.105906

Park, H.J., Lee, N.G. and Kang, T.W., 2020 Fall-related cognition, motor function, functional ability, and depression measures in older adults with dementia. *NeuroRehabilitation*, *47*(4), pp.487-494. DOI: 10.3233/NRE-203249

Pel-Littel, R.E., et al., 2021 Barriers and facilitators for shared decision making in older patients with multiple chronic conditions: a systematic review. *BMC geriatrics*, *21*(1), pp.1-14. https://doi.org/10.1186/s12877-021-02050-y

Pickering, C.E.Z., Yefimova, M., Maxwell, C., Puga, F. and Sullivan, T. 2019. Daily Context for Abusive and Neglectful Behavior in Family Caregiving for Dementia. *The Gerontologist*, 60(3), pp.483–493. https://doi.org/10.1093/geront/gnz110

Popay, J., et al., 2006. Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version*, *1*(1). https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=ed8b23836338f6fdea0cc55e161b0fc5805f9e27. (Accessed 25 Sep 2022).

Poulin de Courval, L. P., et al., 2006. Reliability and validity of the Safety Assessment Scale for people with dementia living at home. *Canadian Journal of Occupational Therapy*, *73*(2), 67-75. DOI: 10.1177/000841740607300201

Prince, M.J., Wimo, A., Guerchet, M.M., Ali, G.C., Wu, Y.T. and Prina, M., 2015 *World Alzheimer Report 2015 – The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. London: Alzheimer's Disease International. http://www.alz.co.uk/research/world-report-2015 (Accessed 25 Sep 2022).

Prince, M., et al., 2014 Dementia UK: update (Second edition) [Research Report} King's College London. Hal-03516999. https://hal.science/hal-03516999 *Retrieved 29 October 2022*.

Rapaport, P., et al., "I just keep thinking that I don't want to rely on people." a qualitative study of how people living with dementia achieve and maintain independence at home: stakeholder perspectives. *BMC geriatrics*, *20*(1), pp.1-11. https://doi.org/10.1186/s12877-019-1406-6

Ruston, A., & Backhouse, T. 2022. Caring for people with dementia in their own homes: Homecare workers' experiences of tolerating and mitigating risk. *Ageing and Society,* 1-17. https://doi.org/10.1017/S0144686X22000575

Sandberg, L., Rosenberg, L., Sandman, P.O. and Borell, L. (2015). Risks in situations that are experienced as unfamiliar and confusing – the perspective of persons with dementia. *Dementia*, 16(4), pp.471–485. DOI: 10.1177/1471301215603836

Stevenson, M., McDowell, M.E. and Taylor, B.J., 2018. Concepts for communication about risk in dementia care: A review of the literature. *Dementia*, *17*(3), pp.359-390.

Stevenson, M., Savage, B., and Taylor, B.J. 2019. Perception and Communication of Risk in Decision Making by Persons with Dementia. *Dementia*, 18(3), pp.1108–1127. DOI: 10.1177/1471301217704119

Stevenson, M., and Taylor, B.J. 2018. Risk communication in dementia care: family perspectives. *Journal of Risk Research*, 21(6), pp.692–709. https://doi.org/10.1080/13669877.2016.1235604

Stevenson, M., and Taylor, B.J. 2017. Risk Communication in Dementia Care: Professional Perspectives on Consequences, Likelihood, Words and Numbers. *The British Journal of Social Work*, 47(7), pp.1940–1958. https://doi.org/10.1093/bjsw/bcw161

Struckmeyer, L. R., Pickens, N., Brown, D., & Mitchell, K. 2020. Home Environmental Assessment Protocol–Revised Initial Psychometrics: A Pilot Study. *OTJR: Occupation, Participation and Health*, *40*(3), 175-182. DOI: 10.1177/1539449220912186

Tagai, K., Nagata, T., Shinagawa, S., & Shigeta, M. 2020. Anosognosia in patients with Alzheimer's disease: current perspectives. *Psychogeriatrics*, *20*(3), 345-352. https://doi.org/10.1111/psyg.12507

Taylor, B.J. 2006. Risk Management Paradigms in Health and Social Services for Professional Decision Making on the Long-Term Care of Older People. *British Journal of Social Work*, 36(8), pp.1411–1429. https://doi.org/10.1093/bjsw/bch406

Taylor, B.J., Stevenson, M. and McDowell, M. 2017. Communicating risk in dementia care: Survey of health and social care professionals. *Health & Social Care in the Community*, 26(2), pp.291–303. https://doi.org/10.1111/hsc.12519

Thomas, J. & Harden, A. 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology, 8, 45. pp.1-10. DOI: 10.1186/1471-2288-8-45

Tuijt, R., et al., 2021. Exploring how triads of people living with dementia, carers and health care professionals function in dementia health care: a systematic qualitative review and thematic synthesis. *Dementia*, *20*(3), pp.1080-1104. DOI: 10.1177/1471301220915068

Wied, T. S., Knebel, M., Tesky, V. A., & Haberstroh, J. 2019. The human right to make one's own choices–Implications for supported decision-making in persons with dementia. *European Psychologist*. *24*(2), pp.146–158. https://doi.org/10.1027/1016-9040/a000372

Wittenberg, R., et al., 2019. The costs of dementia in England. *International Journal of Geriatric Psychiatry*, *34*(7), pp.1095-1103. DOI: 10.1002/gps.5113

World Health Organization. 2021. Global status report on the public health response to dementia. Geneva: World Health Organization; (https://www.who.int/publications/i/item/9789240033245 (Accessed 18th October 2022).

Figure 1: PRISMA flow diagram

Table 1: Study characteristics of included papers

Author(s)	Location	Setting	Study design	Aim(s)	Sample	Data collection method(s)	Data analysis method(s)
Adams (2001)[P1]	UK	Community	Qualitative	To explore the social processes that lead to risk identification and management from the perspectives of informal carers and community psychiatric nurses (CPN).	Primary Informal Carers (n=24) Female (n=15) >60 years old (n=23)	Interviews during domiciliary visits Field notes based on domiciliary visits	Conversation and discourse analysis
Bantry White & Montgomery (2015)[P2]	UK	Community	Mixed methods	To develop and assess the content validity of an assessment schedule to evaluate safety in community-dwelling people with dementia who walkabout outdoors	Reviewers with clinical/research experience in dementia or working with dementia patients (n=14)	Reviewers rated clarity and relevance of assessment scale items on 5-point scale. Qualitative feedback on content validity	Descriptive statistics Descriptive analysis of qualitative responses
Behrman et al (2017)[P3]	UK	Community	Qualitative	To explore how patient safety in community dementia services is understood by carers and healthcare professionals	Carers (n=10), Female (n=5). Healthcare professionals (n=10), Female (n=8)	Guided interviews with pre-designed topic guide	Transcripts coded using structural framework and inductive themes generated.
Benbow & Kingston (2017)[P4]	UK	Community	Qualitative	To explore concerns about risk and abuse expressed by people with dementia and their carers.	People with dementia (n=20), male (n=16), mean age 74 Family carers (n=21), females (n=19), mean age 67	Narratives (spoken or written)	Secondary thematic analysis of theme of risk, abuse and vulnerability
Bourgeois & Couturier (2009)[P5]	France	University Memory clinic-community	Mixed methods	To describe the safety problems experienced at home in a sample of people with dementia and to identify the factors associated with these situations-at-risk.	People with dementia (n=38) Female (n=25) Mean age: 82.5 ± 5.9	GES tool & semi-structured interviews - 15 minutes duration	Spearman's rho correlation between GHG score, cognitive (MMSE) score, and activities of daily living (ADLD and AIVQ); Mann-Witney U association between GHG score and living situation (lives alone or not)

Author(s)	Location	Setting	Study design	Aim(s)	Sample	Data collection method(s)	Data analysis method(s)
Choi et al (2014)[P6]	South Korea	Community	Quantitative	To report accident cases and associated risk elements experienced by Korean people with dementia using a survey	Carers (n=55) Female (n=44) Age: 40-50 (74%)	Samsung Dementia Questionnaire (S-SDQ) and Activities of Daily Living Scale (ADL) for principal carers of people with dementia	Keywords relating to risk extracted from survey results. Median ADL & S-SDQ scores grouped into high vs low frequency Cross-tabulation of survey questionnaire scores and frequency of risk elements.
Clarke et al (2010)[P7]	UK	Professional setting (recruited from Dementia Care Forum)	Qualitative	To assist in the development of a risk assessment and management framework for use by practitioners working with people with dementia and their families.	Professionals working with people with dementia (n=20)	CLG-Action Learning Groups– 5x2 hour focus groups over a 7-month period involving discussions and problem solving in risk and risk assessment in dementia	Thematic analysis
Dickins et al (2018)[P8]	Australia	Community	Qualitative	Exploration of risk conceptualisation from perspectives of people with dementia, carers, family and health professionals	Carers (n=22), Healthy older people (n=20), People with dementia (7), Nurse (8) Staff (23) Female (n=60) Mean age: 59.8±15.5	Interviews and focus groups	Inductive Thematic analysis
Evans et al (2016)[P9]	UK	Care home	Qualitative	To determine how care home managers negotiate the conflict between maintaining a safe environment while enabling the autonomy of residents with dementia.	Care home staff (n=18) Female (n=16)	Semi-structured interviews	Thematic analysis
Evans & Means (2006)[P10]	UK	Extra care housing/ sheltered accommodation	Qualitative	To explore perspectives of care professionals on risk management and supporting independence for people with dementia in supported living facilities	Unspecified numbers of: People with dementia, tenants in extra care, relatives of people with dementia, extra care housing managers, carers	Interviews with care professionals working within supported living for people with dementia	Not specified.

Author(s)	Location	Setting	Study design	Aim(s)	Sample	Data collection method(s)	Data analysis method(s)
Lach et al (1995)[P11]	USA	Community	Mixed methods	To identify common safety problems, explore relationship between dementia severity and safety concerns and to evaluate the results of a home safety instrument	Carers of patients with Alzheimer's disease (n=35) Mean age: 59	Telephone interviews & 2x follow-ups. Clinical Dementia Rating Scale rated dementia severity.	Fisher's exact test and the chi-square test.
Lee et al (2019)[P12]	Canada	Memory clinic	Mixed methods	To pilot a person centered risk-assessment framework for managing risk among people with dementia in primary care.	Healthcare providers N = 7) People with dementia and care partners (N = 12)	Survey and Telephone Interviews	Descriptive statistics for quantitative data Thematic analysis for qualitative data.
Pickering et al (2019)[P13]	USA	Community	Quantitative	To identify risk and protective factors for abusive and neglectful behaviour in the context of daily caregiving.	Carers of Alzheimer's patients (n=50) Female (n=46) Mean age: 53	Online baseline survey Twice daily "diary" surveys for 21 days	Frequency analysis of abusive/neglectful behaviours.
Poulin de Courval et al (2006)[P14]	Canada	Community	Quantitative	To develop and assess the reliability and validity of the Safety Assessment Scale (SAS) in community dwelling people with dementia	Phase 1: non-specified number of healthcare professionals Phase 2: People with dementia (n=176) Female (n =103)	Phase 1: questionnaire completed by expert groups to assess item selection and content validation. Phase 2: assessment of validity and reliability of SAS through face-to-face interviews with the primary carers and people with dementia	Assessment of content, criterion, and construct validity. Assessment of reliability.
Sandberg et al (2017)[P15]	Sweden	Community	Qualitative	To explore how people with dementia living at home experience and handle risk in their daily lives.	People with dementia (n=12) Female (n=6)	Interviews with open-ended questions	Qualitative content analysis
Stevenson & Taylor (2018)[P16]	Northern Ireland	Community	Qualitative	To explore experiences and concepts of risk from the perspectives of family carers.	Family carers of people with dementia (n=22) Female (n=16) Modal age group: 71-80	Focus groups	Constant Comparative Method (underpinned by grounded theory)

Author(s)	Location	Setting	Study design	Aim(s)	Sample	Data collection method(s)	Data analysis method(s)
Stevenson & Taylor, (2017)[P17]	Northern Ireland	Professional setting-five Health and Social Care (HSC) Trusts	Qualitative	To explore how risk is conceptualised and communicated in dementia care by health and social care professionals	Practitioners in dementia care (n=35) Female (n=30)	Focus groups	Constant Comparison Method (underpinned by grounded theory)
Stevenson et al. (2019)[P18]	Northern Ireland	Community	Qualitative	To explore people with dementia perspectives, experiences, conceptualisation, and communication of risk	People with dementia (n=17) Male (n=9)	Individual interviews	Constant Comparison Method (underpinned by grounded theory)
Struckmeyer et al (2020)[P19]	USA	Online	Quantitative	To determine the content validity, criterion validity and test-retest reliability of the Home Environment Assessment Protocol Revised (HEAP-R)	People with dementia/carer dyads (n=21) Occupational Therapists (n=17), experts (identified through publications on dementia care/home modification) (n=9)	Online survey	Variety of quantitative statistical analytical methods were utilised
Taylor et al (2017)[P20]	Northern Ireland	Online-community dementia care teams	Mixed methods	To explore and understand risk communication in dementia care through a quantitative survey	Health and social care professionals (n=70) Female (n=54)	Online survey	Correlational analysis (quantitative) and thematic analysis (qualitative components)

Table 2: Qualitative results: findings from qualitative and mixed method studies

Author	Study design	Key and secondary themes	Executive summary of findings	Limitations	Recommendations
Adams (2001)[P1]	Qualitative	No themes were constructed. Findings highlight the staged process through which risk was discussed and addressed.	CPN and the carer frequently spoke about risks. They began with the identification of risk and concluded with addressing it.	Not reported	Not reported
Bantry White & Montgomery, (2015)[P2]	Mixed methods	Several themes were generated to support understanding of the value, usefulness, feasibility and acceptability of the structured risk assessment schedule. These themes were not identified.	The assessment schedule was identified as being useful for assessment and decision making in clinical settings.	People with dementia were not consulted in the development of the schedule. Their concerns and views would have represented a useful addition to the schedule.	Research with people with dementia is needed to determine acceptability of assessment schedules in this population. Further research needed to enhance knowledge of aetiology of getting lost to support safe walking outdoors.
Behrman et al (2017)[P3]	Qualitative	• What safety means in the context of community dementia services. • Where safety failures lie. • How safety failures are reported.	Carers and professionals have different attitudes to balancing safety and autonomy. Carers and healthcare professionals identify a range of safety issues.	Small study based in a single healthcare trust. Larger samples are needed to determine whether findings are applicable beyond this setting.	Raising awareness and practically supporting carers is needed to foster collaborative working with healthcare professionals. From this work, potential interventions could be piloted which could include a system for carers to identify and report safety risks.
Benbow & Kingston (2017)[P4]	Qualitative	Themes associated with risks included: • Driving • Safety in the home • Safety outdoors • Financial risks • Falls • Risks to and from others • Actual or potential police incidents • Neglect.	Risks and abuse were highlighted as a significant concern. Healthcare professionals should be proactive in discussing and addressing these issues with people with dementia and carers.	The project was not designed to explore risk and abuse specifically. Therefore, some potential concerns may not have been raised. Participant numbers were small. Some participants were interviewed as couples, potentially limiting disclosure.	Driving and financial risks were frequently highlighted. Important that these are raised in future practice by healthcare professionals.

Author	Study design	Key and secondary themes	Executive summary of findings	Limitations	Recommendations
Bourgeois & Couturier (2009)[P5]	Mixed methods	Risks identified included: • Risks associated with food • Risks with drugs • Wandering • Driving • Risk of fire	People with dementia are exposed to risky situations due to cognitive decline. Frequently occurring risky situations include fire, nutrition, and polypharmacy,	Participants were recruited from memory clinic, meaning there may have been some recruitment bias. Cannot generalise and compare these people with a different population (e.g. in the emergency room). Home security was indirectly assessed by the carer. Therefore, responses may have depended on level of involvement in care.	Clinicians can propose concrete solutions to reduce the risks and allow maintenance at home. During consultations, can make carers aware of the risks incurred and facilitate adherence to recommendations for common home security guidelines. Reducing risks in the home of people with dementia reduces stress and improves quality of life for carer and people with dementia.
Clarke (2010)[P7]	Qualitative	• Seeking certainty • Making judgements • Managing complexity • Gathering and using information	Tensions were identified between practitioners in relation to the factors that influenced their decision making in risk management.	Limited sample of 20 staff.	Future risk assessments should be comprehensive and allow care to be determined by individual needs.
Dickins et al (2018)[P8]	Qualitative	• Identification, management, and ramifications of risk • Competing conceptions of the meaning and implications of dementia • Acceptable risk and enablement	The nature of risk was identified to be complex within and across all participant groups. This complexity was highlighted in relation to risk identification, risk management, understanding of dementia and risk ramifications.	Participants were a relatively small group recently diagnosed individuals in Australia, limiting the generalisability of the findings.	Future risk management requires a contextual response, involving not only an understanding of the disease but also a person's individual history and preferences.
Evans et al (2016)[P9]	Qualitative	• How individual risk is structured in the physical environment • Preservation of dignity and threats to autonomy • How the needs of one resident are balanced against others.	Care home staff face several challenges in the delivery of person-centred care. A need for managing risks created a tension between risk management and autonomy. The environment was structured in a way to protect residents as a group, rather than as individuals.	Biased responses may have arisen due to care home staff wishing to present their institution in a positive light.	More research is needed to determine optimal staff to resident ratios and identify which person-centred approaches are most effective in providing safe care for residents.

Author	Study design	Key and secondary themes	Executive summary of findings	Limitations	Recommendations
Evans & Means (2006)[P10]	Qualitative	Staff awareness of two specific types of risk in relation to tenants with dementia: risk to self and risk to others.	Extra care housing is suitable to support People with dementia. However, this depends on whether an appropriate level of flexible, person-centered care is provided by well-trained and supportive staff.	None reported	As many risks for people with dementia are poorly understood, future practice should develop comprehensive risk assessment tools that help maintain safety whilst promoting independence.
Lach et al (1995)[P11]	Qualitative	Key themes: • Unsafe behaviour • Accidents within the home • Safety precautions.	Unsafe behaviour and accidents are commonplace for patients with Alzheimer's disease. Wandering was identified as the most common issue.	None reported	Research should test the 'Home Safety Inventory' in clinical settings. Research is needed to assess whether safety precautions taken by carers are effective in preventing accidents or unsafe behaviour
Lee et al (2019)[P12]	Mixed method	Themes relating to the strengths of the Person-centred risk assessment framework (PCRAF): • Comprehensive • Promoting Independence • Proactive approach to dementia • Empowers patients • Facilitates communication to increase risk awareness Themes relating to weaknesses of the PCRAF: • Not appropriate to administer during assessment visits • Not well integrated into assessment process • May duplicate other risk assessments • May fail to recognise risks.	There is value in adopting a person-centred approach to risk management using the PCRAF. However, there are feasibility issues identified with its implementation.	A small sample size was reported. Study was conducted over a short time period meaning that potentially insufficient numbers of participants were recruited.	Further refinement and testing needed to improve PCRAF usefulness for risk assessment and management in people with dementia.

Author	Study design	Key and secondary themes	Executive summary of findings	Limitations	Recommendations
Sandberg et al (2015)[P15]	Qualitative	Themes: • Risks in situations that are experienced as unfamiliar and confusing • Being in unfamiliar and confusing situations, which are difficult to comprehend • Handling unfamiliar and confusing situations to reduce risk.	From the perspectives of people with dementia, risky situations are perceived as unfamiliar and confusing, making them challenging to comprehend.	Results may have been culturally embedded, and not representative of all people with dementia as all participants were recruited from the same memory clinic. Single interviews may not have captured all necessary data.	Additional research is needed with people with dementia to determine support needed to reduce risks in their daily lives.
Stevenson & Taylor (2017)[P17]	Qualitative	Risk domains identified included: • Health • Emotional wellbeing • Abuse • Safety in the come or community • Other people	Risk in health and social care were conceptualised by their consequences, which presented both benefits and harm.	Initial coding was undertaken by one researcher, potentially introducing bias.	Future research should identify the frequency of problematic risks to allow for accurate estimation of risk likelihood.
Stevenson & Taylor (2018)[P16]	Qualitative	Key themes: • Concepts of risk • Perceived risk factors • Approaches towards risk • Discussion about risk with care recipients • Discussion about risk with care professionals	Risks were conceptualised in terms of their consequences rather than likelihood. Family members often conduct informal risk assessment and management which is shared with professionals. This process of risk communication plays a key role in shared, informed decision making.	Not reported	Future research should pay attention to language and nuances surrounding risk communication. This will enable professionals to develop confidence in risk management whilst caring for people with dementia.
Stevenson Savage & Taylor (2019)[P18]	Qualitative	Key themes: • Defining risk • Constructing risk • Risk communication in decision making processes	Risk concepts are interconnected with emotional experiences with decision making also closely connected to emotions. Risks were conceptualised as a situation or outcome rather than a probability.	Only experiences of people with dementia in early to moderate stages were included. Experiences may be different for those in latter stages of dementia. Inadequate socio-demographic information was captured as researchers did not record ethnicity, socio-economic background, and dementia stage	Tools to support people with dementia to consider and communicate risks are needed. Future research requires the development of aids to assist in risk management for professionals and carers.

Table 3: Quantitative results: findings from quantitative and mixed method studies

Author	Design	Primary and Secondary Outcomes	Executive Summary of Findings	Limitations	Recommendations
Bantry White & Montgomery (2015)[P2]	Mixed Methods	Relevance and clarity of scale items rated on a 4-point scale	Mean ratings between 3-4 for each item. Five items received relevance ratings >3.25, indicating these items were of lesser importance.	See table 3	See table 3
Bourgeois & Couturier (2009)[P5]	Mixed Methods	GES score examined in relation to: mini mental state examination score, activities of daily living, instrumental activities of daily life and patients living situation	People with dementia living alone experienced greater risk than those not living alone (U=90.5; p=0.04) No significant correlation between MMSE and GES score (r=0.07; p=0.68)	See table 3	See table 3
Choi et al., (2014)[P6]	Quantitative	Frequency of risk elements	Twelve risk elements extracted, 41% involved physical harm. Risk elements resulting in the most physical harm included: falls, collisions, slips and drops.	Limited sample size (n=55).	Future research should consider how ethnicity, culture and economic status affect risk elements.
Lach et al., (1995)[P11]	Mixed Methods	Reports of unsafe behaviour, accidents and precautions.	Unsafe behaviour: 71% reported people with dementia engaging in unsafe behaviour. Accidents: significant association between unsafe behaviour and accident reporting (p=.001). Safety Precautions: 68% of carers took precautions to avoid accidents.	See table 3	See table 3
Lee et al., (2019)[P12]	Mixed Methods	Perceptions of PCRAF (on 5-point likert scale, 1=not at all satisfied, 5=extremely satisfied)	Healthcare providers were satisfied with tool overall (mean=3.5±0.58) and moderately satisfied with ease of use. 75% agreed tool was relevant to their practice.	See table 3	See table 3
Pickering et al., (2019)[P13]	Quantitative	Odds of an abusive or neglectful behaviour on a given day.	Participating in a meaningful activity with care recipient protects against neglectful behaviour OR=0.19; CI 0.06-0.64; p=.01, but not abusive behaviour.	Analyses limited by sample size (n=50). Lack of racial diversity in the sample. Unclear whether neglectful behaviours were deliberate decisions by carers.	To include more detail of contextual factors known to increase risk. Additionally, explore factors known for successful caregiving outcomes e.g self-efficacy.
Poulin de Courval (2006)[P14]	Quantitative	Assessment of construct validity, sensitivity and specificity and reliability of the SAS scale.	Construct Validity: emergency sample scored higher on SAS that general sample (p<.001) Sensitivity and Specificity: Specificity increased when SAS score exceeded 15 (85.5%) and reduced at score 12 (64%). Reliability: Inter-rater reliability 0.88 for SAS long version, 0.87 for behavioural risk and 0.84 for environmental risk classes.	Other tools may be more suitable in specific areas of risk assessment (environmental hazards and functional limitations).	Future research should explore predictive validity of SAS. SAS would benefit from being utilised within interventions to assess the sensitivity of the scale.

Struckmeyer et al., (2020)[P19]	Quantitative	• Content validity of the HEAP-R • Concurrent criterion validity of HEAP-R related to gold-standard HEAP • Test-retest reliability of HEAP-R	Content Validity: (.980) Concurrent Criterion Validity: for hazards (r=972), adaptions (r=.742), clutter (r=.843), comfort (r=.958) Test-retest reliability: (hazards (r=.820), adaptions (r=.887), visual cues (r=.487), clutter (r=.696)	Content validity had potential to be subjective Dyads convenience samples. May not be representative.	The HEAP-R has reasonable psychometrics for possible application in clinical practice, but requires more rigorous scientific and psychometric investigation.

Table 4: Identified risk factors from included studies

Setting/Context	**Risk/Harm example**	Benbow & Kingston (2017)[P4]	Bourgeois & Couturier (2009)[P5]	Choi et al., (2014)[P6]	Dickins et al., (2018) [P8]	Evans & Means, (2006)[P10]	Lach et al., (1995)[P11]	Stevenson & Taylor (2018)[P16]	Stevenson & Taylor (2017)[P17]	Stevenson et al., (2019)[P18]	Taylor et al., (2017)[P20]
Moving around (including at home and outside)	*Falling, slipping dropping*	√	√	√	√	√	√	√	√	√	√
Temperature Regulation	*Temperature dysregulation*						√				
Use of electrical/ gas appliances	*Misuse, injury, fire, explosion*			√			√	√	√	√	√
Faucet	*Faucet control, problems in hot/cold water control - burns, not washing effectively*			√							
Bathing	*Flooding, accidents (e.g. risk of drowning)*					√		√			√
General	*Fire*	√	√	√		√			√		
Personal Admin	*Losing Mail*							√			
Road safety	*Inappropriate behaviour whilst driving and whilst others are driving, collisions, accidents, and incidents, completing administration required to drive*	√	√	√	√		√	√	√	√	√
Navigation outside the home	*Wandering outside home unsupervised, wandering from carer, getting lost and confused, going missing, having an incontinence accident*	√	√	√		√	√	√	√	√	√
Food Preparation	*Kitchen safety, leaving appliances on, burns*	√	√	√	√		√	√	√	√	
Food consumption	*Difficulty swallowing, choking, overeating, rotten food consumption, food poisoning*		√	√			√				√
Malnutrition	*Malnourishment*							√	√		√
Medication	*Medication mismanagement, overdose, distrust of medication*	√	√		√		√	√	√	√	√

Smoking Cigarettes	*Health consequences, fire*						√	√	√	√	
Alcohol	*Misuse of alcohol, forgetting medication*							√	√	√	√
Firearms	*Accidental or intentional firearm use*						√				
Use of sharps	*Accidental or intentional use of sharps*						√				
Intentional self-injury	*Harm to oneself, self-injury, suicide attempt*			√		√				√	
Emotional Wellbeing	*Loneliness, social isolation, deprivation, lack of meaningful activity, loss of control*	√			√			√		√	
Mental Illness	*Depression*										√
Personal Hygiene	*Poor / neglect of personal hygiene, defecation in an improper place, risk whilst showering or toileting*	√		√					√		√
Risks to others	*Injury during manual handling, physical or verbal violence and/or aggression, road safety, hitting out because of nightmares during sleep*	√		√		√	√	√	√	√	√
Risks to people with dementia	*Verbal/physical abuse from carers, contact with strangers*	√								√	√
Neglect (by others)	*Accusations of, and actual neglect*	√							√		
Responsive behaviours	*Aggression, restlessness, and disinhibition*				√		√				
Recreational activities	*Physical injury, getting lost/confused/scared, loss of confidence*									√	
Police Incidents	*Causing stress, detainment*	√									
Finances	*Financial abuse, mismanagement, money going missing*	√						√	√	√	√