Enabling older people with mental health needs to engage with community social care: A scoping review to inform a theory of change

**Abstract**

Despite apparent need, many older people with cognitive impairment and/or mental health needs do not fully engage with social care. This can manifest in different ways, including passive or aggressive attempts to avoid or repel care workers. However, little is known about how to support such individuals in their own homes and deliver effective care. Against this background, we undertook a scoping review with a view to developing a preliminary theory of change suggesting how care might be modified to engage this client group. The most recent search was conducted on 21/04/21. Papers were included if they i) focused on older people (65+) living at home with social care needs; and ii) described difficulties/problems with the provision/receipt of social care associated with individuals’ mental health needs. Twenty-six citations were identified through electronic database searches and reference screening, and the results were charted according to key theory of change concepts (long- term outcomes, preconditions, interventions, rationale & assumptions). All the included papers related to people with dementia. Four subgroups of papers were identified. The first highlight those external conditions that make it more likely an intervention will be successful; the second describe specific interventions to engage older people who by virtue of their mental health needs have not engaged with social care; the third explore what services can do to increase service uptake by older people with mental health needs and their caregivers more generally; and the fourth details theoretical approaches to explaining the behaviour of people with dementia. Each provides information that could be used to inform care delivery and the development of interventions to improve engagement with health and social care for these individuals.  The study concludes that different framing of engagement difficulties, such as that offered through positioning theory, may assist in future service design.

**Keywords**

Community care; social care; resistance to care; theory of change; service re-design; mental health; dementia

**What is known about the topic**

* Older people with mental health needs typically require more personal care, more hours of care and more supervision than older people with other long-term conditions
* Mental health needs can create barriers to accepting care by obscuring people’s understanding of their own care needs or the support being offered. Within the literature, such individuals are typically characterised as ‘resistive to care’; ‘uncooperative’ or ‘non-compliant’, with ‘resistance’ playing out in a variety of behaviours
* A raft of interventions have been developed to help individuals in institutional settings engage with social care. However, these are not necessarily transferable to people’s own homes.

**What this paper adds**

* This paper synthesises what is known about those home-dwelling older people with mental health and social care needs who social care staff and families find hard to engage;
* It identifies the characteristics of family caregivers, service users and service providers which increase the likelihood that care will be accepted; and
* Highlights the features of service delivery which appear to improve care uptake;
* It also reveals a lack of evidence to inform care provision for older people with mental health disorders other than dementia, including depression, anxiety and schizophrenia who social care staff and families find hard to engage.

**Background**

Welcome rises in life expectancy have resulted in a global increase in the absolute number and proportion of people aged 65 or over around the world. In 2019 there were 703 million people aged 65+. However, by 2050 it is anticipated that this figure will have grown to 1.5 billion, constituting approximately one in six of the global population (United Nations, 2019). Whilst many older people will lead healthy, independent lives, research suggests that at any one time up to 25% of older people have mental health needs (Andreas et al., 2017; World Health Organization, 2017). The UK is a typical example: late-onset dementia affects approximately seven per cent of older people (rising from 1.7% of 60-65 year olds to 29.9% of 90-94 year olds); depression and anxiety affect more than 20 per cent; drug and alcohol misuse are growing; and still others are affected by schizophrenia, bipolar disorder and paranoid states (Age UK, 2016; Livingston et al., 2017; Royal College of Psychiatrists, 2014). This population have costly and disparate care needs. Many disorders are chronic in nature or subject to relapse, and all elements of a person’s functioning can be affected. The onset of cognitive impairment, for example, can impair people’s memory, reasoning and communication skills, compromising their ability to undertake normal daily activities of living (Ames, O’Brien, & Burns, 2016); neuropsychiatric symptoms (agitation, irritability etc) affect almost everyone with dementia at some point (Livingston et al., 2017); and older people with depression may experience loss of appetite and poor sleep, neglect themselves and withdraw from others (Royal College of Psychiatrists, 2014). The common co-existence of physical and mental health conditions, frailty and polypharmacy further complicate people’s needs (Barnett et al., 2012).

In order to remain in their own homes, older people with mental health needs typically require more personal care, more hours of care and more supervision than older people (Legislation.gov.uk, 2014) with other long-term conditions (Chen, Reed, Happich, Nyhuis, & Lennox-Smith, 2014; ). This includes social care, the definition of which here is taken from the 2014 Care Act in England, and refers to the provision of personal and practical care and support which people require in order to achieve a specified list of outcomes (see Box X).

*Insert Box X*

This may be delivered within people’s own homes or other community settings such as day centres and includes care and support provided by a wide range of paid staff (‘formal’ caregivers e.g. care workers, personal assistants, occupational therapists and social workers) for the person themself (e.g. help with bathing, the provision of meals or engagement in social activities) and/or their (‘informal’, unpaid) carer (e.g counselling, training or respite).

Despite eligible need, however, not everyone wants social care (; Lim, Goh, Chionh, & Yap, 2012). Many people fear losing their independence or have concerns about receiving intimate care from other people (be they relatives or strangers). Others have had negative experiences of formal care services, perceive the available help as unsuitable or (where care must be paid for privately) worry about costs (Herron & Rosenberg, 2017; ). Research suggests that family members often request support for their relative with dementia (Fauth, Femia, & Zarit, 2016). However, similar factors may lead them to decline support on their loved ones’ behalf or indeed their own (Ishii, Streim, & Saliba, 2012). Over and above this, mental health needs can themselves create barriers to accepting assistance. In one commonly cited scenario, for example, a patho-psychological ‘lack of insight’, whereby a person’s understanding of their own care needs or the care being offered is obscured by their mental health needs, may result in the proffered support being interpreted as a threat or intrusion. Other contributing psychological processes in the context of depression include low motivation and a belief that ‘nothing can be done’ (Fauth et al., 2016; ).

Within the literature, these individuals are typically characterised as ‘resistive to care’, ‘uncooperative’ or ‘non-compliant’, with ‘resistance’ playing out in a variety of behaviours ( Volicer, Citrome, & Volavka, 2017). Some people seek to avoid those individuals who attempt to provide care, whilst others may be verbally or physically defensive. For example, people may simply refuse entry to care workers, refuse to accept specific care activities (e.g. bathing, dressing), may decline to cooperate with care (e.g. ignore requests from carers, or decline carers access to the property), or else shout or physically interject as care workers go about their work.

Such responses are related, but distinct, to other behaviours that caregivers find difficult to manage, including agitation and aggression. These broader “behavioural and psychological symptoms of dementia” have been widely studied, with psychosocial interventions, such as person-centred approaches, since designed to help. However, ‘care resistance’ is specifically expressed in the context of care delivery, whether that be the provision of personal care or access to day care or other community support ( Volicer et al., 2017). For example, whilst agitation may be exhibited in any number of circumstances, including in the absence of any interpersonal exchange, ‘care resistance’ is a specific behavioural response to care activity (Volicer et al 2017). Whilst there is overlap between care resistance and agitation, studies show they are empirically distinct, and require different management strategies (Volicer, Bass, & Luther, 2007).

Recent decades have seen a plethora of work examining the causes and consequences of care resistance (Algase et al., 1996; Choi, Budhathoki, & Gitlin, 2017; Durand et al., 2009; Kim & Park, 2017; Kovach, Noonan, Schlidt, & Wells, 2005; Volicer & Hurley, 2003)and various systematic reviews have summarised the growing range of interventions designed to prevent or mitigate such behaviours (Abraha et al., 2017; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Nordgren, 2018). To date, however, these have focused on people in institutional settings (predominantly hospitals and care homes) and far less attention has been given to those home-dwelling individuals with mental health needs whom staff and family carers struggle to engage, notwithstanding their high prevalence.

There is evidence that care resistance is quite common amongst older people living at home. Three large Scandinavian studies found between seven and 15 per cent of older home care recipients were ‘resistive to help’, whilst other cross-EU research identified similar difficulties in just under half of home-dwelling older adults with dementia who were considered at risk of care home entry (Risco et al., 2015). The consequences of failing to engage with social care are, moreover, profound, including an increased risk of pharmacological intervention, social exclusion, chronic self-neglect and institutionalisation (Herron & Rosenberg, 2017).

Providing social care for this client group poses significant challenges for formal and informal caregivers (Fauth et al., 2016), and many lack the necessary confidence and skills to undertake this role (Ledgerd et al., 2016). Indeed, research suggests that problems engaging people in social care represent a substantial source of stress for caregivers, which can in turn lead to caregiver burnout and/or detrimentally affect the caregiver’s approach to the care recipient (SCIE, 2011). . Further, those interventions developed for use in institutional settings are not necessarily transferable to people’s homes. Not only are the nature and extent of people’s needs in the community likely to be different from those of people in care homes and hospitals, so too is the environment. However, despite the fact that most older people with mental health needs live at home, no review of interventions/strategies that might assist this client group to engage with social care has been conducted, resulting in the lack of an overall picture of the existing research that could inform care delivery and underpin the development of future approaches.

*The need for a scoping review – Towards a theory of change*

Against this background, this paper presents a scoping review of the literature on the difficulties/problems posed by home-dwelling older people with mental health needs who caregivers struggle to engage with social care, and potential ways of promoting their engagement. Alongside supporting the future development of community services, the review sought evidence to populate a Theory of Change (ToC) (Anderson, 2009; De Silva et al., 2014) with the aim of enabling future services to be designed with clearer links to the evidence-base. A ToC is a theory of how and why interventions work and, as such, is a suitable framework for designing, evaluating and refining complex interventions where mechanisms of change may be context-dependent, especially where interpersonal relationships are central to the process (De Silva et al., 2014). This framework also enabled us to identify the relevance of and type of evidence available on the assumptions, resources and pre-conditions needed to increase care acceptance in those with mental health needs. The formulation of a ToC is often portrayed as a flowchart or causal pathway and necessitates the specification of a number of key concepts as described and illustrated in Table 1.

*Table 1 about here*

**2. Methods**

As the extant literature had not previously been reviewed, a scoping review was undertaken. The study was guided by the PRISMA extension for Scoping Reviews (Tricco et al., 2018), and this section is structured accordingly. The study followed a written protocol which is available from the authors.

*Eligibility criteria*

In place of a PICO (Population, Intervention, Comparator and Outcomes) statement (suitable for systematic reviews), the eligibility criteria were informed by Peter and colleagues’ (2015) framework for scoping reviews (Peters et al., 2015). This necessitates definitions of an explicit concept, population and context.  With respect to the former, the concept of interest was ‘difficulties accepting or receiving social care’. The closest match in the academic literature is ‘resistance-to-care’, which is dominant in the psychiatry, nursing and psychology fields. However, this tends to be applied narrowly to assertive and overt ‘behavioural symptoms’, and is usually restricted to use with people with advanced dementia in institutional settings. Further, it is often limited to resistance to assistance with activities of daily living (ADLs) (Galik, Resnick, Vigne, Dee Holmes, & Nalls, 2017;).

This review expands this definition to explore difficulties attributable to other mental health conditions, more subtle forms of difficulty, other social settings and wider eligible social care needs. For this review, difficulties accepting and receiving social care were thus defined as “declining, avoiding, withdrawing or otherwise preventing or disrupting efforts by formal services and family caregivers to provide social care”.

The population of interest were older people (65+) with mental health needs and an identified need for social care. As such interventions for people whose mental health need were considered to contribute to their reluctance to engage, and studies of measures to promote the more general uptake of social services in older people with mental health needs were included.

The context was that potential care recipients were living in a community, rather than an institutional setting.

No restrictions were placed on publications with respect to geography, date or method.  However, the literature was limited to papers published in peer-reviewed journals. Review-based papers were included where the synthesis or analysis added more conceptually than could be learned from the individual citations reviewed therein.  Publications were excluded if they were not available in English or where the focus was on health or medical interventions rather than social care.

*Information sources*

Searches were undertaken in four electronic databases: Pro-quest (ASSIA & Social Services Abstracts), Scopus, Ovid (PsycINFO, Medline, Embase & Social Policy and Practice) and Web of Knowledge and further citations were identified through scans of included publications’ reference lists. The search was conducted on 11/10/2019 and updated on 21/04/2021, whereby additional includes were added to the existing themes.

*Searches*

Key search terms and surrogates were developed using keywords from core inclusions already known to the authors (e.g. Ishii et al., 2012) and developed following an iterative process. This included reviewing the titles and abstracts of references generated by dummy search runs, the raw number of citations identified, and whether or not the search strategy captured a short list of ‘key’ articles. The final search strategy had three main search blocks pertaining to 1) older people; 2) social care; and 3) difficulties engaging with care. An example search strategy for Ovid is given in Appendix 1.

*Selection of evidence*

A two-stage screen was conducted. First, the titles and abstracts of the identified references were reviewed for relevance by one of three reviewers. Second, the full texts of all retained references were independently assessed by two researchers against the inclusion/exclusion criteria. The reviewers met throughout the assessment to review progress and discuss uncertainties and any disagreements were resolved through discussion.

*Data charting and synthesis*

The review sought to inform the development of a ToC. As such, information was extracted on study’s short, medium and long-term outcomes; the external conditions that needed to be in place in order for these to be reached / factors increasing the likelihood the intervention would be successful; the intervention itself; and the rationale for the intervention (see Table 1 above). Additional information was extracted on study characteristics ( e.g. studies’ authors, year of publication, objectives ), as well as the specific aspects of the target concept (difficulties accepting and receiving care) the publication addressed. The data extraction process was piloted by two reviewers independently before discussing together. Three researchers independently analysed the data to identify the main themes pertaining to each key element of the ToC, and these were subsequently refined through group discussion.

**Results**

*Selection of evidence*

Database searches yielded 10,838 references, of which 3579 were duplicates and removed. Initial screening suggested 98 of the remaining 6804 publications (plus 20 identified by reference tracking) were potentially relevant, of which 26 met the full study inclusion criteria (See Figure 1).

*Figure 1 about here*

*Study Characteristics*

Studies were primarily conducted in Canada (Hawranik & Strain, 2001; Herron & Rosenberg, 2019a, 2019b; Morgan, Semchuk, Stewart, & D'Arcy, 2002), the Netherlands (Boots, Wolfs, Verhey, Kempen, & De Vugt, 2015; Wolfs et al., 2012; Wolfs, De Vugt, Verkaaik, Verkade, & Verhey, 2010), the UK (Durand et al., 2009; Herat-Gunaratne et al., 2019; Kaisey et al., 2012), Australia (Low et al., 2015; Macleod, Tatangelo, McCabe, & You, 2017; Xiao, Habel, & Bellis, 2015), and the USA (Gitlin et al., 2010; Jablonski, Winstead, & Geldmacher, 2019). All the included studies focused on people with dementia and/or cognitive impairment and their families, whilst one involved a wider population [people receiving home care, of whom 55% had a chart diagnosis of dementia and 39% scored >6 on the Geriatric Depression Scale (Low et al., 2015)]. Study designs employed both quantitative and qualitative methods, including randomised controlled trials, interviews and literature reviews (see Tables 2-5).

Papers were categorised into four groups:

* The first comprised papers that, whilst not describing particular interventions to enhance service engagement, highlighted those external conditions that make it more likely that support will be accepted. These papers were used to identify assumptions within the proposed ToC;
* The second examined interventions specifically designed to engage older people who by virtue of their mental health needs have proved difficult to engage with social care. These papers were used to identify interventions, preconditions, and long-term outcomes;
* The third explored what services can do to increase the uptake of social care services by older people with mental health needs and their families more generally. These papers were used to identify interventions, preconditions, and long-term outcomes; and
* The fourth detailed theoretical approaches to explaining the behaviour of people with dementia whom caregivers find hard to engage. These papers helped identify interventions, preconditions and existing theoretical / conceptual frameworks.

The remainder of this section synthesises the evidence these studies provide for a ToC.

1. *Assumptions (External conditions that facilitate the acceptance of care that sit outside the control of the intervention / service)*

Five papers identified conditions that facilitate the acceptance of care (Table 2). Three studies investigated the service provider, caregiver and service user characteristics associated with the acceptance or rejection of social care (Durand et al., 2009; Hawranik & Strain, 2001; Kaisey et al., 2012), one developed a typography of the characteristics of family caregivers who do not use services/the reasons for non-service use (Brodaty, Thomson, Thompson, & Fine, 2005) and another developed a conceptual framework of the rejection of care, analysing the role played by the severity of individuals’ dementia (Ishii et al., 2012). As such, each provided information on those external factors that, although outside the control of any intervention, make it more likely that this will be successful (see Table 2). These contextual or environmental factors are called ‘assumptions’ within the ToC framework (see Table 1 above).

*Table 2 about here*

Two studies highlighted the importance of adequately resourcing service providers to care for this client group, facilitating flexibility in the provision of care (Durand et al., 2009; Ishii et al., 2012), whilst four studies identified those characteristics of the individual’s informal and formal caregivers which made it more likely individuals would engage with care (Brodaty et al., 2005; Durand et al., 2009; Ishii et al., 2012; Kaisey et al., 2012). Focusing on informal caregivers, Kaisey and colleagues found that both the amount of time family members spent on care and their own health status were important in this capacity, with individuals whose caregivers spent more time caring or with higher comorbidity more likely to accept care management (Kaisey et al., 2012). Others pointed to the need for family caregivers to perceive a need for support, to be aware of the services available (potentially through contact with a social worker) (Henry & et al., 2005) and to be willing to relinquish their care-giving responsibilities (Durand et al., 2009). The close adherence of care professionals to indicators of dementia in the assessment process was also associated with the uptake of care, whilst Ishii and colleagues emphasised the importance of caregivers being able to reduce individuals’ exposure to ‘triggers’ by the provision of more patient-centred care and the reduction of pain, the latter enhancing their ability to communicate with the individual (Ishii et al., 2012).

All five studies presented data on those service user characteristics that appeared to increase the chances of their accepting care. However, these varied from service to service. Whilst increasing age was associated with the uptake of home care (Hawranik & Strain, 2001), younger service users were more likely to accept care management (Kaisey et al., 2012). Similarly, whilst greater incapacity in terms of need for help with activities of daily living was associated with the use of home care (Hawranik & Strain, 2001) and people with a longer history of cognitive impairment were more willing to accept day care (Durand et al., 2009), a lesser degree of dementia was associated with the acceptance of care management (Kaisey et al., 2012). In two studies a higher level of medical comorbidity/physical disability was associated with the acceptance of social care (Hawranik & Strain, 2001; Kaisey et al., 2012), it posited that this made the receipt of care more socially acceptable, but in Ishii and colleagues’ review, increased medical needs were associated with the rejection of care (Ishii et al., 2012). That said, only a minority of the studies included in the latter were in home care settings. Evidence on individuals’ household composition was also mixed: not living with a family caregiver was associated with the acceptance of home care (Hawranik & Strain, 2001), but cohabiting with a family caregiver was associated with the acceptance of care management (Kaisey et al., 2012). People’s personal beliefs also appeared important: service users who believed they needed the service, would not be put in a home, would not lose their independence and were not fearful of new people were all more likely to accept support (Durand et al., 2009).

1. *Interventions specifically designed to engage older people with mental health needs with social care*

Five papers described interventions specifically designed for older people who, by virtue of their mental health needs, had proved difficult to engage with social care, despite obvious need (Table 3). One of these outlined a number of approaches health and social care professionals might use when trying to engage older people with conventional care and assistive technologies and explored their ethical implications (Nordgren, 2018).

*Table 3 about here*

Three of the four empirical studies sought to improve the ability of family caregivers to care for their relatives via bespoke coaching/training programmes (Gitlin et al., 2010; Jablonski et al., 2019; Nogales-Gonzalez, Losada-Baltar, Marquez-Gonzalez, & Zarit, 2014). These had a number of factors in common. First, the professionals delivering the intervention (variously occupational therapists, advanced practice nurses, psychologists and research staff) worked with the family caregivers to tailor the intervention to the users’ specific needs. Second, key activities included both training in the use of problem-solving approaches and the provision of education about dementia, common medical conditions that exacerbate it and/or communication skills. Two were delivered face-to-face (Gitlin et al., 2010; Nogales-Gonzalez et al., 2014), whilst the third was delivered via an internet-based platform (Jablonski et al., 2019). The fourth involved similar activities, but was provided to formal rather than informal caregivers (case managers and care workers), with intervention champions accompanying care workers on home visits (Low et al., 2015).

Little information was given regarding these studies’ assumptions (the contextual and environmental factors that affect the intervention’s likely success). However, Gitlin and colleagues reported that those caregivers who completed the course had higher baseline levels of upset and lower baseline levels of confidence in managing the target behaviours (Gitlin et al., 2010), whilst other studies assumed that caregivers would be able to access and use the video-conferencing service (Jablonski et al., 2019) and would recognise the need for training (Nogales-Gonzalez et al., 2014). The strategies proposed by Nordgren and colleagues also assumed that the reason for service refusal stemmed from service users’ poor cognitive functioning rather than being a rational decision (Nordgren, 2018).

In each case, the rationale for the advocated approach was the belief that the individual’s behaviour arose from a combination of user, caregiver and environmental factors that, with training and knowledge, could be identified and mitigated by the caregiver (Gitlin et al., 2010; Jablonski et al., 2019; Low et al., 2015; Nogales-Gonzalez et al., 2014). One study also suggested that adding social and recreational support to case-managed home care would promote engagement and wellbeing per se (in keeping with the activity theory of aging) (Low et al., 2015). In line with this, the pre-conditions for a successful intervention (the short and medium-term outcomes that must be achieved in order for the long-term outcome to be achieved) included the service user having a higher level of wellbeing and being more favourably disposed towards the provision of support (Low et al., 2015; Nordgren, 2018) and the caregiver being less distressed and more confident in their behaviour management skills (Gitlin et al., 2010; Jablonski et al., 2019; Low et al., 2015; Nogales-Gonzalez et al., 2014)

1. Wider attempts to increase *the uptake of services by older people with mental health needs and their families*

Fourteen studies provided information on the (positive and negative) service factors that affect the uptake of social care services by older people with mental health needs and their families more generally with a view to understanding the influences on people’s decision-making (Table 4). Eight studies focused on the experience of the (mostly family) caregiver (Boots et al., 2015; Gilmore, 2019; Herat-Gunaratne et al., 2019; Herron & Rosenberg, 2019a, 2019b; Macleod et al., 2017; Rapaport et al., 2020; Xiao et al., 2015). Two explored the extent to which people with dementia *and* their families used available care and treatment (Wolfs et al., 2012; Wolfs et al., 2010), another two explored the barriers and facilitators to accessing formal care (Morgan et al., 2002; Stephan et al., 2018). The last presented a single case study whereby it was perceived that services could learn from the challenges presented (Matsuoka et al., 2020) (See Table 4).

*Table 4 about here*

Key themes included the need for care professionals to provide a clear overview of the services available and regularly revisit and review these as individuals’ and families’ needs changed (Macleod et al., 2017; Morgan et al., 2002; Stephan et al., 2018; Wolfs et al., 2012; Wolfs et al., 2010). Sharing learning from other caregivers (Herron & Rosenberg, 2019a; Morgan et al., 2002; Wolfs et al., 2012), offering advice and anticipating transitions in care (enabling people to plan in advance) were also seen as important (Wolfs et al., 2012; Wolfs et al., 2010), as was empowering service users and caregivers to make their own decisions (Macleod et al., 2017; Morgan et al., 2002; Stephan et al., 2018; Wolfs et al., 2012; Wolfs et al., 2010). Providing family caregivers with disease-specific knowledge (Boots et al., 2015; Morgan et al., 2002; Stephan et al., 2018; Xiao et al., 2015), and specialist support (including counselling and/or help to overcome their own reluctance to accept assistance) (Herron & Rosenberg, 2019a; Morgan et al., 2002; O'Shea, Timmons, O'Shea, & Irving, 2019; Rapaport et al., 2020; Stephan et al., 2018; Wolfs et al., 2010) were also perceived to be helpful. One paper also emphasised the importance of protecting the confidentiality of individual service users outside the home (Morgan et al., 2002).

Continuity of professional involvement or support via the allocation of a care manager or care navigator were found to facilitate the uptake of care (Herron & Rosenberg, 2019a; Macleod et al., 2017; Matsuoka et al., 2020; O'Shea et al., 2019; Stephan et al., 2018) as was working collaboratively with other services and informal carers to provide more person-centred care (Gilmore, 2019; Herron & Rosenberg, 2019b; Matsuoka et al., 2020; Morgan et al., 2002; Stephan et al., 2018). In keeping with this, various studies highlighted the need for services to take account of the person’s history and their previous interests (and current capabilities) (Gilmore, 2019; Herron & Rosenberg, 2019a; O'Shea et al., 2019; Rapaport et al., 2020), routines (Herron & Rosenberg, 2019a) and existing relationships (Gilmore, 2019; Herron & Rosenberg, 2019a, 2019b; Matsuoka et al., 2020; Rapaport et al., 2020; Stephan et al., 2018) in order to provide meaningful activities and engagement (Gilmore, 2019; Herron & Rosenberg, 2019a, 2019b; O'Shea et al., 2019; Rapaport et al., 2020), along with carers attending for the assigned visit duration (Herron & Rosenberg, 2019a).

Two papers focussed on culture with the need for culturally and linguistically appropriate information, education programmes and bilingual care workers being highlighted(Herat-Gunaratne et al., 2019; Xiao et al., 2015). Indeed, it is likely that all these papers assume that the services themselves were appropriate for the target population. Five of these argue that in the absence of services that conform to people’s interests, histories, cultural norms and beliefs, family caregivers would continue to manage alone or seek out services better able to address the service user’s needs within their own community (Gilmore, 2019; Herat-Gunaratne et al., 2019; Herron & Rosenberg, 2019b; O'Shea et al., 2019; Xiao et al., 2015).

The key rationale behind these suggestions was that exploring care options burden (Boots et al., 2015; Morgan et al., 2002; Stephan et al., 2018; Wolfs et al., 2010) with a single point of contact burden (Morgan et al., 2002; Stephan et al., 2018) could both increase people’s acceptance of their needs/diagnosis and facilitate the identification of needs, whilst the provision of information and knowledge was seen to empower the user/caregiver dyad and reduce caregiver burden (Boots et al., 2015; Morgan et al., 2002; Stephan et al., 2018; Wolfs et al., 2010). As such the main pre-conditions for the provision of support comprised knowledge of the available services (Morgan et al., 2002; Stephan et al., 2018; Wolfs et al., 2012; Wolfs et al., 2010; Xiao et al., 2015) and the disease (Boots et al., 2015; Macleod et al., 2017; Morgan et al., 2002; Stephan et al., 2018; Xiao et al., 2015), the acceptance of dementia/the need for help (Boots et al., 2015; Morgan et al., 2002; Stephan et al., 2018; Wolfs et al., 2012) access to appropriate services (Herat-Gunaratne et al., 2019; Herron & Rosenberg, 2019a, 2019b; Macleod et al., 2017; O'Shea et al., 2019; Rapaport et al., 2020; Stephan et al., 2018; Xiao et al., 2015) and working more closely with informal carers to better tailor service provision (Gilmore, 2019; Herron & Rosenberg, 2019b).

1. *Theoretical approaches to explaining the behaviour of people with dementia that caregivers find hard to engage with social care*

Finally, two papers put forward conceptual frameworks to aid understanding of the person with dementia and their reluctance to engage with care (Kovach et al., 2005; Volicer & Hurley, 2003). These encompassed a number of behavioural models (e.g. the Needs-Driven Dementia-Compromised Model, The Antecedent-Behaviour-Consequences Model), a psychiatric model, and a combination of both (See Table 5). The rationale was that being able to interpret the behaviour of people with mental health needs improves caregivers’ ability to reduce resistance to care and informs the choice of management techniques (Kovach et al., 2005; Volicer & Hurley, 2003). As such, the papers reiterated many of the pre-conditions mentioned above, but also highlight the need for caregivers to understand the presumed causes of behavioural symptoms (including signalling unmet needs) and to eliminate any physical or environmental causes of people’s behaviour. Strategies to engage people with social care thus included providing anticipatory support to prevent or moderate the occurrence of the behaviour and modifying activities to fit people’s preferences

*Table 5 about here*

*Availability of the literature to inform the Theory of Change (ToC)*

A summary of the findings to support the development of the Theory of Change are presented in table 6.

[insert table 6]

Here information on assumptions was found to be limited, with most pertaining to the pre-conditions, demonstrating that there is a better understanding of the steppingstones needed to achieve change.

**Discussion**

Many older people are reluctant to engage with social care provision. Even in the absence of any cognitive or emotional disturbance, accepting social care is a significant life event, often with varied adverse psychological and social responses. The presence of mental health needs or cognitive disorders accentuate what is already a challenging process (Durand et al., 2009; Fauth et al., 2016; Howse et al., 2004). Engagement difficulties are reportedly amongst the most stressful features of the work of homecare staff (Alzheimer's Society, 2016), yet relatively little attention has been paid to this phenomenon as it relates to older people living at home.

One central motivation of this review was to turn the focus of attention away from older people being the locus of all difficulties. Much attention has focused on people living with dementia, and the “behavioural symptoms” of their condition. This one-dimensional view tends to draw service responses to one off treatment, rather than how care can be redesigned to minimise such difficulties in the first place. It also tends to focus on just one disease process (dementia) at the expense of similar engagement problems experienced by those with other health mental health disorders. This is the first review to search and synthesise the existing literature, and it was constructed to be of practical value in supporting service design.

The review found that just 26 studies fulfilled the eligibility criteria of which only five described specific interventions to improve service engagement. This reflects a preponderance within the field to focus on nursing and hospital care, without sufficient recognition that engagement difficulties are also common in home-based support. This is a significant gap. The design and commissioning of home care is often ill-suited to cater for those with engagement difficulties, such as being reliant on short visits, and using care rosters that prevent continuity. Homecare workers often work single-handedly and so cannot easily draw upon extra support from colleagues (as can care home staff), and supervision from senior staff is more remote. Like the care home literature, the review identified no studies relating to those with mental health needs other than dementia. These challenges warrant more research, to understand how care design can be better informed by evidence.

*Informing a Theory of Change*

One element of a ToC concerns “assumptions” for care delivery: those external conditions, largely outside the control of services, that facilitate (or hinder) effectiveness. Our review points to the important finding that growing need for care is linked to both greater use of home support, but also more difficulties in engaging with that support (see also Volicer 2003). However, it is the *perception* of need for care that stands out in this review. For example, Durand and colleagues interviewed 50 people with dementia who had declined day services, identifying that perceptions of their own needs were key (Durand et al., 2009). The idea that people with mental illness, and dementia in particular, often lack insight into their need is widely researched. In neuro-psychological theories, this lack of insight explains why resistance is commonplace: in the person’s worldview, they may not need what is offered. As noted above, one problem of this narrative is that it locates the “problem” within the service user, without reflection as to the service context such behaviours manifest. Other theoretical approaches to ageing research might offer more nuanced perspectives, and may also offer routes towards framing care differently, and thus modifying narratives. This is discussed in more detail below.

Turning to more specific features of ‘interventions’ within the ToC framework, we identified important evidence. Many of these might be considered ‘best practice’ across all community care rather than defining specialist support for people with mental health needs. For example, the idea that potential transitions in care (such as between services or settings) should be anticipated and planned would scarcely be out of place in any care service with any age group (SCIE, 2021). Nevertheless, with many community care systems facing substantial financial constraints (Kuluski, Ho, Hans, & Nelson, 2017; Robertson, Gregory, & Jabbal, 2014; Watkins et al., 2017), it is evident that ‘best practice’ is far from ‘common practice’, and service planners may need to attend to ongoing shortcomings if care ‘resistance’ is not to create growing challenges as societies age.

A key difference between community- and institution-based support is the role of informal care. Family carers offer a substantial form of support in the delivery of social care, with it being estimated that 1.4 million family carers provide over 50 hours of unpaid care a week (Carers UK, 2015), a figure that is predicted to increase to 9 million by 2037 (Greenwood, Pound, Brearley, & Smith, 2019). Yet even this support can be ‘resisted’, as highlighted by three papers in this review offering bespoke training to family carers to support their efforts. These involved helping carers to tailor their interventions to users’ specific needs, and providing education about dementia and communication. The focus was on carers maintaining awareness, in challenging circumstances, of the underlying processes causing difficulties, and on problem-solving approaches likely to succeed. Such interventions are part of a wider class of general psychosocial interventions for informal carers, which appear beneficial for carer outcomes, although it is unclear as yet what benefits translate to service users themselves (Dickinson et al., 2017) .

*Towards alternative theoretical framing*

A final notable finding is the dominance of a narrow range of theoretical frameworks used within the study of care ‘resistance’, usually as a ‘behavioural’ symptom of psychiatric morbidity. This perhaps reflects both the dominance of psychiatric, nursing and psychological research in dementia care, but also the severe illness (most commonly dementia) within care homes and hospitals that it is commonly studied. However, as noted above, there is a danger that such framing pathologises what is a relatable concern when considered alongside gerontological research, and may be unsuited to community care. Even without cognitive or emotional disturbance, being able to self-care has been found to be an integral, and much-protected, part of the social identity of ageing people (Dale, Söderhamn, & Söderhamn, 2012; de São José, Barros, Samitca, & Teixeira, 2016). By contrast, the receipt of care, in signalling advancing age and growing frailty, can prompt a sense of threat at both a psychological and social level (Calnan et al., 2012). That is, where care is interpreted as being related to “oldness” and dependence, older people are more likely to avoid its use.

None of the papers in the review incorporated wider socio-psychological theories that might be more suited to care resistance, given that care is an inherently interpersonal exchange rooted in a social context. We propose that, ‘positioning theory’ may offer greater insights into how care is understood, and how reluctance to engage in care might be addressed (Allen & Wiles, 2014; Bourbonnais & Ducharme, 2015; Davies & Harre, 1990). Under such an approach, individuals are positioned according to external stimulus (in this case, the receipt of care), and may seek to reposition themselves (by rejecting or avoiding care) according to the underlying storyline, or implications, they associate with those positions. Importantly, these positions and storylines can be influenced by how care is offered, through the care relationships involved. For example, one study identified that for many people care was more acceptable where there was an element of reciprocity, such as where the service user positioned the carer as “outgoing” and therefore likely to enjoy the interaction. Other participants would accept care where it had been “authorised”, after doctor recommendations; or where the carer was positioned as a “special” person. Furthermore, humour, for example, could be used to modify otherwise negative framing, and so moderating any negative reaction to care (Allen & Wiles, 2014). This theory has already been used to study childless older adults within gerontology, with a call for its increased use within the field more broadly (Allen & Wiles, 2014; RE. & JL., 2013). Further research to examine how positioning in care exchanges could encourage engagement would be welcome.

***Limitations***

The study applied a scoping review methodology, which is appropriate to a field that has yet to be reviewed, but constrains how findings should be interpreted. There was no quality appraisal used, meaning that we can offer no view on the calibre of the included studies. Further, in applying a ToC framework, the review team imposed an *a priori* structure to the findings. This was in the interests of seeding a later stage of the research programme of which this review was part. However, the ToC framework is not free from ambiguity, with overlap between its constituent parts. An additional limitation relates to the inclusion of review-based papers, where findings from the synthesis contributed more than the individual papers. This is pragmatic, but there is a danger of some ‘contamination’ from primary papers that would not have met our inclusion criteria.

***Conclusion***

This review found a dearth of evidence supporting practice with older people who face difficulties engaging with social care. What exists offers several dimensions of good practice that may support service redesign. However, the literature is entirely focused on people living with dementia, meaning that the many other causes of engagement difficulties have gone unexamined. Moreover, the focus on dementia comes with a framing that concentrates on "behavioural symptoms" located within the individual, rather than encouraging a focus on service design. Alternative framings, such as positioning theory, may assist understanding and offer new directions for care.

***References***

Abraha, I., Rimland, J. M., Trotta, F. M., Dell'Aquila, G., Cruz-Jentoft, A., Petrovic, M., . . . Cherubini, A. (2017). Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. the SENATOR-OnTop series. *BMJ Open, 7*(3). doi:10.1136/bmjopen-2016-012759

Age UK. (2016). Hidden in plain sight.  The unmet mental health needs of older people.

Algase, D., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and Other Dementias, 11*(6), 10-19.

Allen, R., & Wiles, J. (2014). Receiving Support When Older: What Makes It Ok? *The Gerontologist, 54*(4). doi:10.1093/geront/gnt047

Alzheimer's Society. (2016). Fix Dementia Care: Homecare.

Ames, D., O’Brien, J., & Burns, A. (2016). Dementia. In (Fifth Edition ed.). Boca Raton: CRC Press.

Anderson, A. (2009). The Community Builder’s approach to Theory of change. A Practical Guide to Theory Development.

Andreas, S., Schulz, H., Volkert, J., Dehoust, M., Sehner, S., Suling, A., . . . Härter, M. (2017). Prevalence of mental disorders in elderly people: the European MentDis\_ICF65+ study. *British Journal of Psychiatry, 210*(2), 1472-1465 (Electronic).

Barnett, K., Mercer Sw Fau - Norbury, M., Norbury M Fau - Watt, G., Watt G Fau - Wyke, S., Wyke S Fau - Guthrie, B., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet, 380*(9836), 37-43.

Belling, R., Whittock, M., McLaren, S., Burns, T., Catty, J., Jones, I., . . . Wykes, T. (2011). Achieving Continuity of Care: Facilitators and Barriers in Community Mental Health Teams. *Implementation Science, 6*, 1-7. doi:doi:10.1186/1748-5908-6-23

Boots, L. M. M., Wolfs, C. A. G., Verhey, F. R. J., Kempen, G. I. J. M., & De Vugt, M. E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: The paradox between needing and accepting help. *International Psychogeriatrics, 27*(6), 927-936. doi:10.1017/S1041610214002804

Bourbonnais, A., & Ducharme, F. (2015). The social positioning of older people living with Alzheimer’s disease who scream in long-term care homes. *Dementia, 14*(6), 751-768. doi:10.1177/1471301213510166

Brodaty, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry, 20*(6), 537-546. doi:10.1002/gps.1322

Calnan, M., Tabb, W., Calnan, S., Hillman, A., Read, S., & Bayer, A. (2012). ‘I often worry about the older person being in that system’: exploring the key influences on the provision of dignified care for older people in acute hospitals | Ageing & Society | Cambridge Core. *Ageing & Society, 33*(3). doi:doi:10.1017/S0144686X12000025

Carers UK. (2015). Alone and caring: Isolation, loneliness and the impact of caring on relationships.

Challis, D., Tucker, S., Wilberforce, M., Brand, C., Abendstern, M., Stewart, K., . . . Bowns, I. (2014). National Trends and Local Delivery in Old Age Mental Health Services: Towards an Evidence Base. A Mixed-Methodology Study of the Balance of Care Approach, Community Mental Health Teams and Specialist Mental Health Outreach to Care Homes. *Programme Grants for Applied Research, 2*(4). doi:10.3310/pgfar02040

Chen, L., Reed, C., Happich, M., Nyhuis, A., & Lennox-Smith, A. (2014). Health care resource utilisation in primary care prior to an after a diagnosis of Alzheimer’s disease: a retrospective, matched case-control study in the United Kingdom. . *BMC Geriatrics, 14*(76).

Choi, S. S. W., Budhathoki, C., & Gitlin, L. N. (2017). Co-Occurrence and Predictors of Three Commonly Occurring Behavioral Symptoms in Dementia: Agitation, Aggression, and Rejection of Care. *American Journal of Geriatric Psychiatry, 25*(5), 459-468. doi:10.1016/j.jagp.2016.10.013

Dale, B., Söderhamn, U., & Söderhamn, O. (2012). Self-care ability among home-dwelling older people in rural areas in southern Norway. *Scandinavian journal of caring sciences, 26*(1). doi:10.1111/j.1471-6712.2011.00917.x

Davies, B., & Harre, R. (1990). Positioning: The Discursive Production of Selves. *Journal for the Theory of Social Behaviour, 20*, 43-63. doi:10.1111/j.1468-5914.1990.tb00174.x

De Silva, M. J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C., & Patel, V. (2014). Theory of Change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. *Trials, 15*, 267. doi:10.1186/1745-6215-15-267

de São José, J., Barros, R., Samitca, S., & Teixeira, A. (2016). Older persons' experiences and perspectives of receiving social care: a systematic review of the qualitative literature. *Health & social care in the community, 24*(1). doi:10.1111/hsc.12186

Department for Work and Pensions. (2020). Family Resources Survey: financial year 2018/19. *National Statistics*.

Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., & Robinson, L. (2017). Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews. *International psychogeriatrics, 29*(1). doi:10.1017/S1041610216001447

Durand, M., James, A., Ravishankar, A., Bamrah, J. S., & Purandare, N. B. (2009). Domiciliary and day care services: Why do people with dementia refuse? *Aging and Mental Health, 13*(3), 414-419. doi:10.1080/13607860902879318

Fauth, E., Femia, E., & Zarit, S. (2016). Resistiveness to care during assistance with activities of daily living in non-institutionalized persons with dementia: associations with informal caregivers' stress and well-being. *Aging & mental health, 20*(9), 888-898. doi:<http://dx.doi.org/10.1080/13607863.2015.1049114>

Galik, E., Resnick, B., Vigne, E., Dee Holmes, S., & Nalls, V. (2017). Reliability and Validity of the Resistiveness to Care Scale among Cognitively Impaired Older Adults. *J Am Med Dir Assoc, 18*(1), 59-64. doi:10.1016/j.jamda.2016.08.008

Giebel, C., Zubair, M., Jolley, D., Bhui, K., Purandare, N., Worden, A., & Challis, D. (2015). South Asian older adults with memory impairment: improving assessment and access to dementia care. *International journal of geriatric psychiatry, 30*(4). doi:10.1002/gps.4242

Gilmore, I. (2019). Engaging the person with young-onset dementia: working in partnership to support meaningful activity. *International Journal of Care and Caring, 3*(2), 295-300. doi:10.1332/239788219x15538570345636

Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010). Targeting and Managing Behavioral Symptoms in Individuals with Dementia: A Randomized Trial of a Nonpharmacological Intervention. *Journal of the American Geriatrics Society, 58*(8), 1465-1474. doi:10.1111/j.1532-5415.2010.02971.x

Greenwood, N., Pound, C., Brearley, S., & Smith, R. (2019). A qualitative study of older informal carers’ experiences and perceptions of their caring role. *Maturitas, 124*, 1-7. doi:doi:10.1016/j.maturitas.2019.03.006

Hawranik, P. G., & Strain, L. A. (2001). Cognitive impairment, disruptive behaviors, and home care utilization. *Western Journal of Nursing Research, 23*(2), 148-162. doi:10.1177/019394590102300204

Henry, B., & et al. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry, 20*(6), 537-546.

Herat-Gunaratne, R., Cooper, C., Mukadam, N., Rapaport, P., Leverton, M., Higgs, P., . . . Burton, A. (2019). "In the Bengali Vocabulary, There Is No Such Word as Care Home":Caring Experiences of UK Bangladeshi and Indian Family Carers of People Living With Dementia at Home. *The Gerontologist*. doi:<http://dx.doi.org/10.1093/geront/gnz120>

Herron, R. V., & Rosenberg, M. W. (2017). "Not there yet": Examining community support from the perspective of people with dementia and their partners in care. *Social Science & Medicine, 2017*(173), 81-87.

Herron, R. V., & Rosenberg, M. W. (2019a). Dementia in rural settings: Examining the experiences of former partners in care. *Ageing and Society, 39*(2), 340-357. doi:10.1017/S0144686X17000952

Herron, R. V., & Rosenberg, M. W. (2019b). Responding to Aggression and Reactive Behaviours in the Home. *Dementia (London, England), 18*(4), 1328-1340. doi:10.1177/1471301217699676

Howse, K., Ebrahim, S., & Gooberman-Hill, R. (2004). Help-avoidance: why older people do not always seek help. *Reviews in Clinical Gerontology, 14*(1), 63-70. doi:10.1017/S0959259804001212

Ishii, S., Streim, J. E., & Saliba, D. (2012). A conceptual framework for rejection of care behaviors: review of literature and analysis of role of dementia severity. *J Am Med Dir Assoc, 13*(1), 11-23.e11-12. doi:10.1016/j.jamda.2010.11.004

Jablonski, R., Winstead, V., & Geldmacher, D. (2019). Description of Process and Content of Online Dementia Coaching for Family Caregivers of Persons with Dementia. *Healthcare, 7*(1), 13-13. doi:10.3390/healthcare7010013

Kaisey, M., Mittman, B., Pearson, M., Connor, K. I., Chodosh, J., Vassar, S. D., . . . Vickrey, B. G. (2012). Predictors of acceptance of offered care management intervention services in a quality improvement trial for dementia. *International Journal of Geriatric Psychiatry, 27*(10), 1078-1085. doi:10.1002/gps.2830

Kim, S. K., & Park, M. (2017). Effectiveness of person-centered care on people with dementia: A systematic review and meta-analysis. *Clinical Interventions in Aging, 12*, 381-397. doi:10.2147/CIA.S117637

Konno, R., Kang, H. S., & Makimoto, K. (2012). The best evidence for minimizing resistance-to-care during assisted personal care for older adults with dementia in nursing homes: A systematic review. *JBI Database of Systematic Reviews and Implementation Reports, 10*(58), 4622-4632. doi:<http://dx.doi.org/10.11124/jbisrir-2012-431>

Kovach, C. R., Noonan, P. E., Schlidt, A. M., & Wells, T. (2005). A model of consequences of need-driven, dementia-compromised behavior. *Journal of Nursing Scholarship, 37*(2), 134-140. doi:10.1111/j.1547-5069.2005.00025\_1.x

Kuluski, K., Ho, J., Hans, P., & Nelson, M. (2017). Community Care for People with Complex Care Needs: Bridging the Gap between Health and Social Care. *International journal of integrated care, 17*(4). doi:10.5334/ijic.2944

Kuronen, M., Koponen, H., Nykänen, I., Karppi, P., & Hartikainen, S. (2015). Use of anti-dementia drugs in home care and residential care and associations with neuropsychiatric symptoms: A cross-sectional study. *BMC Geriatrics, 15*(1). doi:10.1186/s12877-015-0102-4

Ledgerd, R., Hoe, J., Hoare, Z., Devine, M., Toot, S., Challis, D., & Orrell, M. (2016). Identifying the causes, prevention and management of crises in dementia. An online survey of stakeholders. *International Journal of Geriatric Psychiatry, 31*(6), 638-647. doi:10.1002/gps.4371

Legislation.gov.uk. (2014). Care Act 2014. Retrieved from <https://www.legislation.gov.uk/ukpga/2014/23/section/9/enacted>

Lim, J., Goh, J., Chionh, H. L., & Yap, P. (2012). Why do patients and their families not use services for dementia? Perspectives from a developed Asian country. *International Psychogeriatrics, 24*(10), 1571-1580. doi:10.1017/S1041610212000919

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., . . . Mukadam, N. (2017). Dementia prevention, intervention, and care. *Lancet, 16*(390), 2673-2734.

Low, L. F., Baker, J. R., Harrison, F., Jeon, Y. H., Haertsch, M., Camp, C., & Skropeta, M. (2015). The Lifestyle Engagement Activity Program (LEAP): Implementing Social and Recreational Activity into Case-Managed Home Care. *Journal of the American Medical Directors Association, 16*(12), 1069-1076. doi:<http://dx.doi.org/10.1016/j.jamda.2015.07.002>

Macleod, A., Tatangelo, G., McCabe, M., & You, E. (2017). "There isn't an easy way of finding the help that's available." Barriers and facilitators of service use among dementia family caregivers: a qualitative study. *International Psychogeriatrics, 29*(5), 765-776. doi:10.1017/s1041610216002532

Matsuoka, T., Kato, Y., Shibata, K., Nakamura, K., Nishimura, Y., & Narumoto, J. (2020). Importance of long-term involvement for older people living in severe squalor: A case report. *Asian Journal of Psychiatry, 52*, 102146-102146. doi:10.1016/j.ajp.2020.102146

McCrone, P., Dhanasiri, S., Patel, A., Knapp, M., & Lawton-Smith, S. (2008). Paying the Price: The Cost of Mental Health Care in England to 2026.

Menne, H. L., Ejaz, F. K., Noelker, L. S., & Jones, J. A. (2007). Direct Care Workers' Recommendations for Training and Continuing Education. *Gerontology & Geriatrics Education, 28*(2), 91-108. doi:10.1300/J021v28n02\_07

Michaelsen, J. (2012). Emotional Distance to So-Called Difficult Patients. *Scandinavian journal of caring sciences, 26*(1). doi:10.1111/j.1471-6712.2011.00908.x

Moermans, V., Mengelers, A., Bleijlevens, M., Verbeek, H., Tan, F., Capezuti, E., . . . Hamers, J. (2020). Involuntary Treatment in Dementia Care at Home: Results From the Netherlands and Belgium. *Innovation in Aging, 4*(Suppl 1), 664-665. doi:10.1093/geroni/igaa057.2299

Morgan, D. G., Semchuk, K. M., Stewart, N. J., & D'Arcy, C. (2002). Rural families caring for a relative with dementia: barriers to use of formal services. *Social science & medicine (1982), 55*(7), 1129-1142. doi:10.1016/s0277-9536(01)00255-6

NICE. (2019). Quality statement 3: Continuity of care and support | People’s experience using adult social care services | Quality standards | NICE. Retrieved from <https://www.nice.org.uk/guidance/qs182/chapter/quality-statement-3-continuity-of-care-and-support>

Nogales-Gonzalez, C., Losada-Baltar, A., Marquez-Gonzalez, M., & Zarit, S. H. (2014). Behavioral intervention for reducing resistance in care recipients to attending adult day care centers: A pilot study. *Clinical Gerontologist: The Journal of Aging and Mental Health, 37*(5), 493-505. doi:<http://dx.doi.org/10.1080/07317115.2014.907592>

Nordgren, A. (2018). How to respond to resistiveness towards assistive technologies among persons with dementia. *Medicine, Health Care and Philosophy, 21*(3), 411-421. doi:10.1007/s11019-017-9816-8

O'Shea, E., Timmons, S., O'Shea, E., & Irving, K. (2019). Multiple Stakeholders' Perspectives on Respite Service Access for People With Dementia and Their Carers. *The Gerontologist, 59*(5). doi:10.1093/geront/gnz095

Peters, M. D., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D., & Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc, 13*(3), 141-146. doi:10.1097/xeb.0000000000000050

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. (2013). The Global Prevalence of Dementia: A Systematic Review and Metaanalysis. *Alzheimer's & Dementia, 9*(1). doi:10.1016/j.jalz.2012.11.007

Rapaport, P., Burton, A., Leverton, M., Herat-Gunaratne, R., Beresford-Dent, J., Lord, K., . . . Cooper, C. (2020). "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). doi:10.1186/s12877-019-1406-6

RE., A., & JL., W. (2013). The utility of positioning theory to the study of ageing: Examples from research with childless older people. *Journal of aging studies, 27*(2), 175-187. doi:10.1016/j.jaging.2013.02.001

Risco, E., Cabrera, E., Jolley, D., Stephan, A., Karlsson, S., Verbeek, H., . . . Zabalegui, A. (2015). The association between physical dependency and the presence of neuropsychiatric symptoms, with the admission of people with dementia to a long-term care institution: a prospective observational cohort study. *International journal of nursing studies, 52*(5), 980-987. doi:<http://dx.doi.org/10.1016/j.ijnurstu.2015.02.013>

Ritchard, L., & et al. (2016). Identifying the causes, prevention and management of crises in dementia. an online survey of stakeholders. *International Journal of Geriatric Psychiatry, 31*(6), 638-647.

Robertson, R., Gregory, S., & Jabbal, J. (2014). The social care and health systems of nine countries. *Commission on the Future of Health and Social Care in England*.

Royal College of Psychiatrists. (2014). Depression in older adults.

SCIE. (2011). Report 46: Self-neglect and adult safeguarding: findings from research.

SCIE. (2021). Person-centred care: Prevention practice examples and research - SCIE. *Prevention and Wellbeing.* Retrieved from <https://www.scie.org.uk/prevention/choice/person-centred-care>

Sims-Gould, J., Byrne, K., Beck, C., & Martin-Matthews, A. (2013). Workers' Experiences of Crises in the Delivery of Home Support Services to Older Clients: A Qualitative Study. *Journal of applied gerontology : the official journal of the Southern Gerontological Society, 32*(1). doi:10.1177/0733464811402198

Skovdahl, K., Fahlström, G., Horttana, B., Winblad, B., & Kihlgren, M. (2008). Demanding Behaviours and Workload in Elderly Care in Sweden: Occurrence at Two Time Points Within a Decade. *Scandinavian journal of caring sciences, 22*(3). doi:10.1111/j.1471-6712.2007.00500.x

Stephan, A., Bieber, A., Hopper, L., Joyce, R., Irving, K., Zanetti, O., . . . Meyer, G. (2018). Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. *BMC geriatrics, 18*(1). doi:10.1186/s12877-018-0816-1

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., . . . Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine, 169*(7), 467-473. doi:10.7326/m18-0850

United Nations. (2019). World Population Ageing 2019: Highlights.

Volicer, L., Bass, E., & Luther, S. (2007). Agitation and resistiveness to care are two separate behavioral syndromes of dementia. *Journal of the American Medical Directors Association, 8*(8). doi:10.1016/j.jamda.2007.05.005

Volicer, L., Citrome, L., & Volavka, J. (2017). Measurement of agitation and aggression in adult and aged neuropsychiatric patients: review of definitions and frequently used measurement scales | CNS Spectrums | Cambridge Core. *CNS Spectr, 22*(5), 407-414. doi:doi:10.1017/S1092852917000050

Volicer, L., & Hurley, A. C. (2003). Management of behavioral symptoms in progressive degenerative dementias. *Journals of Gerontology - Series A Biological Sciences and Medical Sciences, 58*(9), 837-845.

Watkins, J., Wulaningsih, W., Zhou, C., Marshall, D., Sylianteng, G., Rosa, P., . . . Maruthappu, M. (2017). Effects of health and social care spending constraints on mortality in England: a time trend analysis. *BMJ Open, 7*(e017722). doi:10.1136/bmjopen-2017-017722

Wergeland, J. N., Selbaek, G., Hogset, L. D., Soderhamn, U., & Kirkevold, O. (2014). Dementia, neuropsychiatric symptoms, and the use of psychotropic drugs among older people who receive domiciliary care: A cross-sectional study. *International Psychogeriatrics, 26*(3), 383-391. doi:<http://dx.doi.org/10.1017/S1041610213002032>

Wilberforce, M., Abendstern, M., Tucker, S., Ahmed, S., Jasper, R., & Challis, D. (2017). Support workers in community mental health teams for older people: roles, boundaries, supervision and training. *Journal of advanced nursing, 37*(7), 1657-1666.

Wolfs, C. A. G., de Vugt, M. E., Verkaaik, M., Haufe, M., Verkade, P. J., Verhey, F. R. J., & Stevens, F. (2012). Rational decision-making about treatment and care in dementia: A contradiction in terms? *Patient Education and Counseling, 87*(1), 43-48. doi:10.1016/j.pec.2011.07.023

Wolfs, C. A. G., De Vugt, M. E., Verkaaik, M., Verkade, P. J., & Verhey, F. R. J. (2010). Empowered or overpowered? Service use, needs, wants and demands in elderly patients with cognitive impairments. *International Journal of Geriatric Psychiatry, 25*(10), 1006-1012. doi:10.1002/gps.2451

World Health Organization. (2017). Mental Health of Older Adults. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/mental-health-of-older-adults>

Xiao, L., Habel, l., & Bellis, A. (2015). Perceived Challenges in Dementia Care by Vietnamese  Family Caregivers and Care Workers in South Australia. *Journal of Cross-Cultural Gerontology, 30*, 333–352.

**Box X. The provision of social care in England**

|  |
| --- |
| Under the terms of the Care Act (2014) and accompanying statutory guidance, local authorities must assess the need for and provide social care to people whose needs make them eligible to receive it.  Determining the eligibility of a person’s identified needs is a three-stage process. First, it must be shown that the person’s needs relate to a physical or mental impairment or illness. Second, as a result of these needs, the adult must be unable to achieve two or more of ten outcomes set out in national eligibility criteria:   * Managing and maintaining nutrition * Managing personal hygiene * Managing toilet needs * Being appropriately clothed * Being able to make use of the adult’s home safely * Maintaining a habitable home environment * Developing and maintaining family or other personal relationships * Accessing and engaging in work, training, education or volunteering * Making use of necessary facilities or services in the local community * Carrying out any caring responsibilities the adult has for a child   Third, it must be shown that the inability to achieve these outcomes has a significant impact on the adult’s wellbeing.  Sources: The CA 2014; Care and Support Guidance; Care and Support (Eligibility Criteria) Regulations; SCIE 2015 |

**Table 1. Theory of Change: Terminology and Examples** (Adapted from De Silva, 2014)

|  |  |  |
| --- | --- | --- |
| **Terminology** | **Formal definition** | **Examples** |
| **Long- term outcome** | The final outcome the complex intervention can change on its own | e.g. An increased proportion of people engage with social care |
| **Preconditions**  **(intermediate outcomes)** | The intended results of the interventions (the short and medium-term outcomes that must be achieved in order for the long-term outcome to be achieved) | e.g. The service user allows care staff into their home |
| **Interventions** | The different activities that, in combination, form the complex intervention | e.g. Communication skills training for care staff |
| **Rationale** | The justification for the taken approach (based on evidence or experience) | e.g. Improving care staff’s communication skills will improve their ability to establish trusting relationships with service users |
| **Assumptions** | The external conditions (beyond the control of the complex intervention) that need to be in place for the long-term outcome to be reached / which make it more likely that the intervention will be successful | e.g. Local government funding permits the number and duration of care staff visits required / the service user has more physical co-morbidities (shown to make care more socially acceptable) |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Table 2:**  External conditions that facilitate the acceptance of care | | | | | | |
| **Reference** | **Study aim** | **Study design** | **People are more likely to accept care services if….** | | | |
| **Care providers** | **Caregivers** | **Service Users** | |
| ***Primary studies*** | | | | | | |
| Hawranik and Strain (2001) | To explore the association between type of cognitive impairment, disruptive behaviours and use of home care services | Secondary data analysis from the Manitoba Study on Health and Aging (n=124 community-dwelling elders and their family caregivers) | None | None | | The service user is not living with the family caregiver \*\*\*  The service user has ADL/IADL limitations \*\*\*  The service user is older\* |
| Durand et al (2009) | To examine the reasons why people refuse day care and explore the relationship between people’s willingness to accept day services and a range of clinical variables | Interviews using patient reported outcome measures (n=50 people who lived alone) | Resources permit flexibility in care provision;  The intervention / service can address misconceptions surrounding day care services | The family caregiver is able to relinquish their caring responsibilities for a few hours | | The service user has had memory needs for longer  The service user has particular personal beliefs (e.g. they need the service, that attending day care is not putting them in a home, and that attending won’t take away their independence)  The service user is not fearful of new people |
| Kaisey et al (2012) | To investigate the service user, family caregiver and healthcare system characteristics associated with the acceptance of care management | Secondary analysis of data from a randomised controlled trial of a care management intervention (n= 238 patient-caregiver dyads in the intervention group, 170 in the control group) | None | The family caregiver has higher comorbidity  The family caregiver spends more hours caregiving  The care professional adheres more closely to dementia indicators in the assessment process | | The service user and family caregiver are cohabitating  The service user is younger  The service user has less severe dementia  The service user has a greater level of medical comorbidity |
| ***Reviews*** | | | | | | |
| Brodaty et al (2005) | To develop a typography of the characteristics of family caregivers who do not use services and the reasons for service non-use | Literature review (N=109 includes) | Services are accessible and flexible to the needs of caregivers | There is a contact with a social worker (a link to available support)  The family caregiver perceives a need for support and is willing to use services  The family caregiver is aware of the available services | | The service user has a physical disability (making care more socially acceptable a)  The family caregiver / service user has knowledge of services and is willing to use them |
| Ishii et al (2012) a | To define rejection of care behaviours, provide a conceptual framework for rejection of care, review what is known about these factors and synthesize studies that focus on dementia severity | Conceptual review (N=55 includes) | The service is adequately resourced to deal with needs and is well established | The caregiver is able to effectively interact with the service user and reduce exposure to behavioural ‘triggers’ by providing more person-centred care  Those in the care setting can reduce the pain of the resident | | The service user has less medical need  The service user has a lower level of pain  The dementia is not severe |
| Add foo  a 8 papers were based in the community setting, 47 were based in institutional, outpatient or hospital settings | | | | | | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Table 3:** Interventions to increase service user engagement with care | | | | | |
| **Reference** | **Study aim** | **Study design** | **Interventions**  **(Activities)** | **Preconditions**  **(Short and Medium-term Outcomes)** | **Long-term outcome** |
| ***Primary studies*** | | | | | |
| Gitlin et al. (2010) | To help family caregivers eliminate, reduce or prevent distressing behaviours in family members with dementia | Two-group randomised trial (n=272) | Occupational therapists used a problem  solving approach to help family caregivers identify the antecedents and consequences or potential modifiable triggers of the target problem behaviour. They then brainstormed with caregivers to identify acceptable management strategies and coached them in applying these. Family caregivers were also instructed in stress reduction and self-care techniques  An advanced practice nurse met with family caregivers to provide education on common medical conditions that may exacerbate problem behaviours  (NB In addition to the above, serum and urine samples were collected from patients to uncover possible undiagnosed illness and patient medications were reviewed for appropriateness, polypharmacy, and dosing using published guidelines) | Family caregiver outcomes at 16 weeks:  Reduced upset with and enhanced confidence managing the behaviour  Less upset with all problem behaviours  Less negative communication  Less burden  Better well-being  Less depressive symptoms  Perceived intervention benefits | Improvement in targeted problem behaviour as selected by family caregivers  (Resistance to care was the most frequently targeted behaviour) |
| Nogales-González et al. (2014) | To assess the efficacy of training family caregivers in behaviour  modification techniques for reducing their relative’s resistance to attending  adult day care | Pilot quantitative efficacy study (n=3) | A psychologist provided six individual sessions for family caregivers of people with dementia, each of which lasted approximately 90 minutes. Although each intervention was tailored to the specific behavioural problems reported by the caregivers, the intervention  objectives, a general outline of its contents, and the proposal of techniques for each session were documented in a manual.  As a first step, participants were trained in the  classic Antecedents, Behaviour, Consequences model of functional analysis  Following the analysis of the antecedents, behaviours, and consequences reported by the family caregiver, the psychologist proposed a specific intervention programme for each problematic behaviour and trained the caregiver in the techniques to be implemented.  This training was complemented by general education about Alzheimer’s Disease care (e.g., communication skills or behavioural  vocabulary as reinforce or extinction). | Family caregivers have improved behaviour management skills | Each of the three participants reported a reduction  in the occurrence of behavioural problems related to attending adult day care |
| Low et al. (2015) | To evaluate the effect of the Lifestyle Engagement Activity Program (LEAP) on the engagement, mood and behaviour of home care clients, case managers and care workers | Quasi-experimental (n=189) | Researchers trained:  i/ Case managers to set meaningful goals  ii/ Care workers in taking a person-centred individualized approach; dementia and the unmet needs model of challenging behaviours; communication skills; autonomy  and control; reminiscence; music; physical activity; Montessori activities; humour; and reciprocity.  iii/ LEAP champions (existing home care staff) about organisational change and interpersonal skills.  LEAP champions accompanied care workers on buddy visits to support them in practicing client engagement techniques. | Home care client outcomes:  Reduced apathy, dysphoria and agitation  Improved satisfaction with care  Care staff outcomes:  Increased case manager and care worker self-efficacy  Improved case manager work satisfaction | Increase in self- or  family-reported client engagement  Increase in case managers’ and care workers’ confidence to  socially and recreationally  engage clients  No significant change in care worker-rated client engagement |
| Nordgren (2018) | Propose practical recommendations for health and social care professionals about how to respond to resistiveness towards conventional care and assistive technologies and discuss how ethical these are | Practice recommendations informed by a theoretical (ethical) framework | Methods for influencing people who say no to care:  Tailor communication to the person’s level of understanding and avoid elderspeak  Rephrase questions so as to encourage a positive response  Use rational persuasion  Nudge the person towards the response believed to be in their best interest (by changing the choice architecture)  Provide incentives  Appeal to authority  Deception (e.g. hiding medication in food)  Coercion (last resort) | The service user has a better understanding of the potential benefits of the proposed care  The service user is more favourably inclined towards the proposed care | The service user is more likely to accept the proposed care |
| Jablonski et al (2019) | To develop online dementia coaching for family caregivers of people with dementia who resist care | Methods paper that describes the process and content of the intervention (n=26) | The researchers delivered six real time coaching sessions to family caregivers via an internet-based platform. The first of these included most of the teaching and goal setting, whilst the remainder involved evaluating suggested strategies, refining and role-modelling / role playing these.  Four themes were deemed to characterise the coaching process: education; caregiver communication; affirmation of the caregiver; and individualized strategies | Family caregivers have learned new strategies to prevent and manage resistance to care | The approach was intended to reduce resistance to care behaviour but no formal outcome data was reported |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Table 4:** Wider attempts to increase service users’ /family caregivers’ use of services | | | | | |
| **Reference** | **Study aim** | **Study design** | **Interventions**  **(Activities)** | **Preconditions**  **(Short and Medium-term Outcomes)** | **Long-term outcome** |
| Morgan (2002) | Describes the study development process and reports selected findings focussing on the theme of low use of formal  supportive services such as home care and support groups by family caregivers | Focus groups (n=7 stakeholder groups) | Stigma is reduced through greater public awareness of dementia and the impact of the service user.  Service should be geographically and financially (needs assessment)accessible and increased flexibility in the amount and type of services available  Care providers should:   * Help maintain the confidentiality of the service user outside of their home * Provide a legitimate reason to caregivers for needing to use respite services (not time for yourself) and re-assure them they aren't alone in using services * Frame the service as something temporary e.g. the location of respite beds (nursing home vs. acute care facilities) * Provide timely access to experts who can assess, diagnose and manage dementia as this is a pre-requisite for accessing resources * Provide early information on services and respite (maybe provide buddy system with former carers) * Services should be decentralised, being managed by managers within each community * Monitor and provide regular support for family caregivers who are struggling to relinquish care or who are stressed and facing crisis | Caregivers:   * Feel more able to discuss difficulties they face. Therefore may be offered more support and may seek out community resources * They are more likely to accept the condition and its impact and will feel less of a burden to the "system" * May have fewer feelings of guilt when accepting care * Will be aware of appropriate services early on | Increased likelihood of accessing services |
| Wolfs et al (2010) | To investigate the extent and ways patients use available care and treatment options and identify factors / reasons that play a role in the non-utilization of these | Semi-structured telephone interviews with patients’ family caregivers (n=252) | Practitioners should*:*   * Provide a clear overview of the services available * Repeatedly revisit the care and treatment options during the care trajectory in line with the patient’s / family’s needs * Empower patients and family caregivers to identify the need for care and make decisions about the care they need * Provide regular counselling for family caregivers   Use a care management system | Patients and family caregivers are aware of the possible care options, and are empowered to make informed choices | Increased use of care services |
| Wolfs et al (2012)  (Part of same wider study as Wolfs et al 2010) | To gain caregivers' insights into the decision-making process in dementia patients with regard to treatment and care | Focus groups with family caregivers (n= 29) | Practitioners should:   * Play an active role in exploring the potential care and treatment options for identified needs. This could involve providing an overview of the services available; sharing/facilitating learning from other caregivers; and offering advice. * Regularly revise and discuss these options * Anticipate transitions in care and outline options for care and treatment in advance * Explicitly identify patient and family caregiver preferences at an early stage of dementia | Family caregivers and patients:   * Accept and become more familiar with the diagnosis of dementia (enabling adjustment to the disease) * Have early awareness of the care and treatment options | Increased acceptance of care |
| Xiao et al (2015) | To explore the perceived challenges of dementia care from Vietnamese family caregivers and Vietnamese professional caregivers | Interviews with Vietnamese family caregivers (n=6) and a focus group with Vietnamese care workers (n=7) | Culturally and linguistically appropriate education programmes on dementia  Education for GPs on how to care for people with dementia from culturally and linguistically diverse groups  Increased availability of information that is culturally and linguistically appropriate (e.g. via radio and newspapers)  Services that conform to the norms and beliefs of the Vietnamese culture (e.g. respite at home as opposed to in an institution)  Linguistically appropriate application  processes for services  Bilingual care workers | GPs know how to care for people from culturally and linguistically diverse groups  Family caregivers have greater knowledge of dementia and dementia care services  Language barriers to accessing dementia services have been removed  Services conform to the norms and beliefs of the Vietnamese culture | Increased caregiver willingness to seek help |
| Boots et al (2015) | To explore the needs and wishes of early-stage dementia family caregivers and the paradox between needing and accepting help with a view to tailoring interventions | Focus groups with family caregivers (n=28 caregivers of 25 people with dementia 13 of whom had early stage dementia) | In early therapeutic interventions, care professionals should:   * Provide family caregivers with disease-specific knowledge, enabling them to understand the manifestations of the disease and its changeable nature in the early stages * Help family caregivers identify their needs based on their individual situation * Encourage family caregivers to introduce structure and routine into their daily lives and designate personal time for themselves; acknowledge changes in roles and relationships; and focus on the enhancement of positive encounters with the person with dementia, including through the use of humour. | Family caregivers:   * Have increased understanding of the disease process * Accept the diagnosis of dementia (enabling adjustment to the disease) * Adjust their expectations and shift their focus from what they have lost to what might be possible * Use more positive communication | Increased family caregiver confidence  An increase in positive encounters with the care recipient |
| Macleod et al (2017) | To explore the barriers and facilitators of service use among family caregivers of people with dementia | Semi-structured interviews with family caregivers of people with dementia (n=24) | Organisations should:   * Provide easily accessible ongoing information about services and support * Ensure continuity of care staff * Offer personalised, high quality and flexible care services adapted to the needs of the individual * Provide access to a single ‘expert’ point of contact and assistance with navigating the care system   Formal caregivers should:   * Acknowledge the family caregiver as the person who knows the service user best * Teach informal caregivers how to overcome service user’s reluctance to accept support * Teach effective communication skills /strategies   Seek to modify caregiver beliefs that impact negatively on their own health / the ability to ask for help | Informal caregivers:  Perceive support as being of benefit to them (misconceptions addressed);  Do not feel they have failed in asking for support  Can readily access services  Have confidence in services’ quality  Are skilled in communicating with the service user | Increase in family caregiver service use |
| Stephan et al. (2018) | To explore the barriers and facilitators of access to and utilisation of formal care from  the perspectives of people with dementia, their informal carers and health and social care professionals | Mixed focus groups across eight European countries (55 focus groups; 261 participants). | A health care professional should act as a single constant key contact  The contact should be pro-active in initiating contact early and should work to build a consistent and trusting relationship.  Provides accessible needs tailored support and counselling(resources / geography)  Knowledge of care services & works collaboratively with services  Attitudes, beliefs and emotions are supportive towards dyad  Provide information and public awareness of dementia and services  The carer has support from other informal caregivers | Caregivers and service users :   * Are pro-active, has access to a key contact and available finances * have access to need-tailored support * have clear expectations and have previously had positive experiences * are involved in decision making and are able to trial visits * have accepted the diagnosis and adapted * have personal motives for accepting formal care | Service users and carers:   * are supported in addressing attitudes and beliefs towards formal care and dementia that are disinhibiting * have sufficient information and knowledge to make decisions re support and are involved in decision making |
| Herat-Gunaratne et al. (2019) | To explore how the cultural identities and values of South Asian caregivers of people with dementia influence their experiences, negotiation of the caring role and their relationship with services | Semi-structured interviews with family caregivers for people with dementia living at home who were in touch with health/social care services (n= 10) | Care providers should:   * Deliver culturally appropriate and competent care (e.g. culturally appropriate food) * Match the cultural background and language of the care professional to that of the service user * Ensure care professionals respect and understand the cultural background of the service user * Employ targeted awareness-raising campaigns | Service users’ needs/ preferences are addressed  Care professionals understand how to ensure care is culturally competent | Service users and family caregivers are more willing to accept formal care |
| Herron & Rosenberg (2019a) | They examine experiences of providing and accessing care over the course  of the condition and across various settings. | Qualitative case studies, including interviews with former partners (n=27) | There is support in central source of support for navigating care  Access to people who understand dementia in the community e.g. support groups  Service users will be engaged in meaningful activity (not a sitting service)  There is access to respite for carers  Carers stay for the duration of the visit (not arriving late/leaving early) and are in keeping with clients routines | Family carers have a better understanding of how to navigate the system  They are more likely to recognise the need for support early  Carers feel more able to engage their partner in meaningful activity and realise their own desires for respite | Service user and carer are more likely to utilise the care offered |
| Herron & Rosenberg (2019b) | Explores how informal carers care talk about, interpret and respond to aggressive behaviours | Qualitative interviews with former partners (n=7) | Service providers should:   * Train care staff to ensure they feel able to manage the behaviour of those with severe dementia * Work closely with the informal carer to manage care (they don't know the individual) * Should try and give more time to the service user | Informal caregivers:   * Perceive the capacity (time and knowledge of the service user) of formal caregivers to be greater than their * Feel their knowledge and management strategies are taken seriously by care providers * Feel that the views of the formal care staff are in line with theirs * Have more positive experiences of accepting care * Less likely to go into crisis | More likely to relinquish control (access services) if they feel their loved ones needs will be met |
| Imalda, G. (2019) | A case study, describing the challenges faced in ensuring that the PWD continued to experience purpose and meaning as the disease progressed. It focusses on the need for the caregiver and the care professional to respond to the unique way in which the person and to co-develop activities that are meaningful to them. | Case study (n=1) | Care providers should:   * Understand the interests and background of the person with dementia * Collaborate with informal caregivers to enable formal caregiver to better understand the behaviour of those with dementia. * Help PWD maintain original interests and hobbies / tailor them to their ability * Provide opportunities for meaningful engagement and reciprocity * Observe the behaviour of PWD and interpret / their actions in light of their interests and history | Improved engagement, improved identification of unmet need and reduced agitation of PWD  Collaboratively learn how to diffuse agitation | Respite for carer, reduced problem behaviours of PWD |
| O'shea et al. (2019) | To synthesize multiple stakeholders’ perspectives, including people with dementia, on accessing respite services in the context of dementia. | Semi-structured interviews were conducted with key stakeholders (n=35) | Staff know how to engage residents and provide meaningful activities.    Timing, responsiveness and ease of access should be satisfactory, with a central point of contact providing information about services (i.e., GP).  Primary care professionals are able to effectively signpost dyads  There is adequate staffing, provision and training to meet carer’s needs.  Service with users at a similar stage of dementia (not more advanced)  There was a preference for in-home services | Informal carer is able to work through transition periods with the service user without it damaging the relationship.  They are aware of support navigation of services  The carer and service user perceive the care being delivered to the service user as being person-centred and meaningful | The service is acceptable to the service user  Therefore they are more likely to use it. |
| Matsuoka, T., et al. (2020) | The article presents a case of someone living in severe domestic squalor and focusses on the importance of taking a multi-disciplinary approach to delivering care. | Case study (n=1) | Organisations should:   * Build a trusting relationship with the service user by providing continuity of care * Working collaboratively with other health and social care services   Working closely with informal carers | Allows for the gradual introduction of care services | Increased access to service, which can reduce domestic squalor |
| Rapaport et al. (2020) | To inform the development of psychosocial interventions to enable people with dementia to live well for longer at home, they qualitatively explored the views of people living with dementia, family carers and health and social care professionals, on how to achieve and maintain independence at home and what impedes this. | Qualitative interviews (n=52) | Care providers should:   * Provide a safe and familiar environment (adapting the environment, balancing autonomy and minimising harm) * Not disable care (building on preserved abilities, supportive not undermining) * Maintain relationships (making a contribution vs. not being a burden, helps the service user to get out and about and manage changing relationships) * Give the right support to carers and the service user (balancing needs, accepting help) | Caregiver should:   * Know the service user is in a safe and familiar environment * Know how to enable not disable the service user when providing care * Know the service users relationships and connectedness to the community will be supported * Be receiving the right support | The service user is better able engage with in-home care services |

|  |  |  |
| --- | --- | --- |
| **Table 5:** Theoretical approaches to explaining the behaviour of people with dementia that caregivers find hard to engage with social care | | |
| **Reference** | **Aim** | **Core material** |
| Volicer and Hurley (2003) | To clarify the terminology used to describe behavioural symptoms of dementia (particularly agitation and resistiveness to care and to identify the different management techniques required | Preconditions:   * caregivers understand the presumed causes of behavioural symptoms * any unmet needs are identified * any physical or environmental causes of the behaviour are eliminated * caregivers employ validated caregiving techniques based on a conceptual framework   Interventions (activities):  Suggested strategies to address resistiveness to care include:   * effective communication * modifying activities to fit the person’s preferences * postponing the intervention * distraction   Conceptual frameworks to facilitate the education of frontline caregivers:   * Needs-Driven Dementia-Compromised Model (a behavioural model) which postulates that the behaviours stem from umet needs and that environmental factors can be modified to reduce these behaviours and promote function; * Progressively Lowered Stress Threshold Model (a behavioural model) which postulates that the behaviours result from excess stress which can be managed by reducing the person’s stress level (e.g. through relaxation) and modifying routines and approaches; * Antecedent-Behaviour-Consequences Model (a behavioural model) which postulates that behaviours are determined by specific antecedents and that those behaviours that have potentially dangerous consequences for the individual or others can be prevented by eliminating these; * Habilitation Approach (another behavioural model) which seeks to maximise the functioning and morale of the person by modifying the environment, using effective communication strategies, using functional assistance to decrease disability, maintaining social skills as long as possible by practice, providing cues to decrease confusion, entering the person’s reality, and delaying or distracting if behaviour problems seem imminent; * Psychiatric Model in which medication is prescribed according to the nature of the individual’s presentation; * A comprehensive model that combines both behavioural and psychiatric strategies. |
| Kovach et al (2005) | To extend the original Needs-Driven Dementia-Compromised Model by explaining the consequences of behavioural symptoms for the person with dementia | Pre-conditions:   * Caregivers understand needs-driven behaviours as symptoms of unmet need   Suggested strategies to address resistiveness to care include:   * Provide anticipatory care (actions taken before the usual time of onset of a particular need or problem in order to prevent or moderate the occurrence of the problem)   Conceptual framework to improve understanding of the person with dementia and the consequences of behavioural symptoms and unmet needs:   * The Consequences of Needs-Driven Dementia-Compromised Behaviour Model |

**Table 6**: Theory of change summary of evidence

|  |  |
| --- | --- |
| **ToC concept** | **Summary of findings** |
| **Assumptions (Table 2)** | Assumptions primarily related to the:   * **Care provider** (resources, accessibility, flexibility of delivery and ability to address misconceptions), * **Caregivers** (ability to relinquish control, their own health needs, hours of caregiving, access and awareness of services available for support, their ability to interact with the service user) * **Service users** (physical health, co-habiting, ability to undertake tasks, personal beliefs, length of memory problems and severity, fears of accepting care/future, age, pain level and willingness to access support services). |
| **Interventions** | **Theoretical approaches (understand & reduce resistive behaviour)**: Antecedents, Consequences and Behaviour (ABC) Model, person-centred approaches, unmet needs model, Progressively Lowered Stress Threshold Model, Habilitation Approach, Psychiatric Model, Consequences of Needs-Driven Dementia-Compromised Behaviour Model and combinations of both behavioural and psychiatric strategies.  **Activities (increase SU engagement):** These were primarily orientated towards effective communication skills, individualising interventions and identifying triggers.  These interventions were primarily learning packages in the form of coaching or guidance to apply individualised strategies, with most including active approaches such as role-play or modelling activities. As well as underpinning this understanding with more in depth knowledge about dementia and problems that may exacerbate behaviour.  **Activities (increase service uptake):** interventions were primarily focussed on making services more accessible (e.g. flexibility of delivery and availability of information) and reducing stigma and acceptance through individualising how the use of a service is framed, enabling the service user and carer to make an informed decision and maintaining confidentiality of the service user.  Services should also work closely with the carer, iteratively reviewing services with the dyad and re-offering services that were previously rejected, whilst supporting changes that may be useful within their own caring routine.  Modifying activities to fit the person’s preferences and providing anticipatory care were also highlighted as important. |
| **Pre-conditions (intermediate outcomes)** | **Caregiver**   * Caregiver wellbeing outcomes * Improvements in knowledge regarding the causes of symptoms and their management (Inc. identifying unmet need and triggers) * ability to speak more freely about difficulties they faced * being more accepting of SU condition and the disease trajectory * feeling less of a burden to services * increased awareness of appropriate services. * Empowered to make decisions * Increased satisfaction with services. * Amended expectations of their loved one resulting in more positive interactions with SU.   **Service user**   * Reduced apathy, * Improved satisfaction with care * A better understanding of the proposed benefits of care. * Improved identification of unmet need was a key outcome * The opportunity to engage in meaningful activities.   **Care staff**   * improved self-efficacy * improved staff satisfaction   **Service providers:**   * Increased awareness of how to support different client groups * barriers reduced and preferences being met. |
| **Long- term outcomes** | **Overarching:** A reduction in resistance to care behaviours/ improved engagement.  **Formal and informal carer**: Improved confidence in engaging service users in care  **Informal carer:** improved confidence and access to information and support in accessing services and feeling able to relinquish control, improving their opportunity for respite and their own health |