UNDERSTANDING THE EXPERIENCE OF DEMENTIA CARERS

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Thesis overview

In the Prime Minister's "Challenge on Dementia" (2020), the government stated that it wanted England to be the best country in the world for dementia care and support for people with dementia, their carers and families (Department of Health, 2015). In the last decade, there has been considerable growth into research on supporting dementia carers. In this thesis, I aim to extend existing knowledge and make a unique contribution to the research landscape through two research papers:

1) A **systematic review** of literature informed by realist methods that aims to explore the *mechanism of change* in evidence based psychological interventions for dementia carers. In this chapter, I will explore *what works, for whom, how,* and *in what contexts*? These results will be synthesised in context-mechanism-outcome configurations to guide service delivery.
2) An **empirical project** exploring the experiences of on an understudied subgroup of dementia carers: long distance dementia carers. In this chapter, I will present a narrative inquiry to best understand the unique needs of individuals that are caring for their parents, from a distance.

The realist synthesis within the systematic review will offer services evidence based suggestions for supporting dementia carers. However, every context of caring is different and warrants exploration. As little is known about long distance carers, I undertook a narrative analysis on stories shared by this underrepresented group. I will link the chapters by considering how the configurations could be applied to the experiences of distance carers, based on the insights gained through the empirical study. This work has almost taken on a new meaning in the context of COVID-19, where many more carers are facing the challenge of caring remotely. My hope post qualification would be to build on this work by using the models in practice through the provision of carer support, including long distance carers, through provisions of therapeutic support that can be delivered remotely.

Chapter 1: What makes the difference? A realist review of the mechanisms underpinning therapeutic change in psychological interventions for dementia carers.

I[1] prepared this review for submission to *The Journals of Gerontology, Series B: Psychological and Social Sciences***.** This journal accepts systematic reviews and focuses on gerontological research informing public policy; stating that: "Articles in the journal have clear implications for theoretical or methodological innovation in the psychology of aging or contribute significantly to the empirical understanding of psychological processes and aging… Applied research with theoretical significance is welcome, as are conceptually interesting examples of cutting-edge analytic approaches". The review includes innovative realist methods, is theoretically focused, and makes recommendations to practice; therefore, I hope the journal will be interested. The journal word count is 6000 words and has been extended slightly to provide sufficient detail for viva examination.

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[1] I am using first person singular pronouns to represent work undertaken independently as part of my doctoral study. When the paper is submitted, I will refer to our research collective as "we". At times, I refer to "we" in this paper where others have played a more direct part in supporting me with this work.

Abstract

Background

Family caregivers are essential to the healthcare system. However, they frequently experience negative psychological consequences and clinically significant levels of depression, anxiety and stress. Evidence suggests psychological interventions are effective in promoting the emotional health of dementia caregivers. However, we know little about the mechanisms underpinning therapeutic change. We conducted a systematic realist synthesis to build a theory to explain how interventions work using a context-mechanism-outcome framework. Improving our understanding of mechanisms will enable service providers to tailor appropriate interventions for carers in diverse contexts.

Methods

We conducted a systematic review informed by realist methodology. We searched EMBASE, PsychInfo, CINAHL and grey literature using the following terms: dementia, caregiver, psychological intervention and mechanism. We included papers with psychological interventions that had a significant effect on desired outcomes, that outlined the process of change. We will describe an iterative process that has involved stakeholder expertise and feedback, in line with realist quality standards.

Results

Searches returned 967 papers. Papers were screened, and 27 empirical papers were included. We identified conceptual models underpinning change, the key ingredients creating therapeutic change and the resources involved. These were synthesised into four context-mechanism-outcome frameworks to guide evidence based, service delivery.

Conclusions

The mechanisms of change presented offer service providers a model for tailoring specific interventions to the needs of each caregiver. Realist methodologies can help us better understand research findings and provide us with the best opportunity to influence policy and improve outcomes for people affected by dementia.

Introduction

Dementia Carers

Dementia affects 50 million people worldwide, and this number is projected to increase to 152 million by 2050 (World Health Organisation, 2017; Sapkota & Subedi, 2019). In the UK, there are an estimated 885,000 people living with dementia (Wittenberg *et al.,* 2019). There are approximately 700,000 carers for people living with dementia, and we will see a 40% rise in the number of carers in the next 15 years (Lewis *et al.*, 2014; Carers UK, 2015). Statistics suggest that one in three people will care for a person with dementia in their lifetime (Department of Health, 2015). Unpaid care in the UK is equivalent to £11.6 billion, equating to 44 per cent of the total cost of dementia care (Prince *et al.*, 2014; Giebel *et al.*, 2016). Informal care represents the largest contributor to dementia care costs, saving limited NHS and social care resources (Farre *et al.*, 2016; Michalowsky *et al.*, 2015; Giebel *et al.*, 2016). Dementia carers are often described as experiencing significant psychological burden, along with social and financial distress (World Health Organisation, 2018).

The need for support

Numerous studies report that caring for a person with dementia is more stressful than caring for a person with a physical disability (Brodaty, 2009; Cassie & Sanders, 2008; Mohide *et al.*, 1998). Dementia carers respond to a care recipient's health and social care needs, neuropsychiatric symptoms, disrupted behaviour and mood disturbances; whilst also coping with multiple roles and family conflicts (Cheng *et al.*, 2019). Dementia carers report higher levels of clinically significant depression, anxiety and stress than the general population (Cooper *et al.*, 2008; Simpson & Carter, 2013; Taylor *et al.*, 2008). As many as 30-55% of dementia carers report symptoms of anxiety or depression (Qiu *et al.*, 2019). NICE (2018) guidelines acknowledge that dementia carers are at an increased risk of depression, and recommend that carers receive: person-centred psychoeducation and skills training tailored to their individual needs and circumstances; and, advice about their rights. Carers have a right to an assessment of their needs to minimise the impact of caring (Department of Health, 2014).

The evidence base

Previous reviews have identified that psychological interventions are effective in improving the well-being of dementia carers (Selwood *et al.*, 2007; Kishita *et al.*, 2018; Elvish *et al.,* 2013). The strongest evidence exists for Cognitive Behavioural Therapy (CBT) (Kwon *et al.*, 2017), and individual behavioural management therapy (Selwood *et al.,* 2007). CBT was developed by Beck (1964), incorporating a cognitive model hypothesising that people's emotions and behaviours are influenced by their cognitions and perception of events and changing these can be therapeutic. Behavioural management therapy, informed by behavioural theory, focuses specifically on responses to the care recipient's behaviour, improving understanding and finding resolutions which alleviate caregiver distress. There is also evidence for the effectiveness of psychoeducation, counselling and psychotherapy, mindfulness-based interventions and technological aids (Cheng *et al.,* 2019).

Issues translating evidence to practice

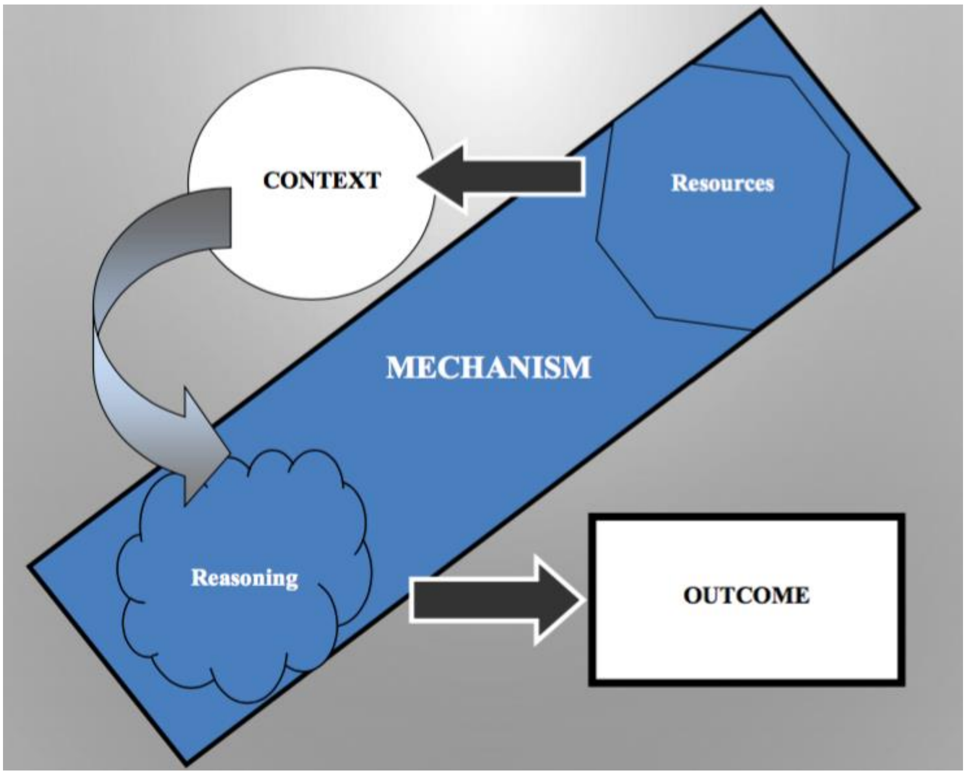
Despite an impressive array of evidence-based intervention studies, we know little about why they work and in what contexts, as not many have explored this and examined the mechanism of change involved (Cheng *et al.*, 2019). Therapies are often packaged into different interventions, and more research on therapeutic mechanisms is needed to guide service delivery (Cheng *et al.,* 2019). There is a tension in translating quasi-experimental studies on effectiveness into practice. Whilst research studies are useful in assessing the effectiveness of interventions as a total package, often in tightly controlled conditions, they fail to provide valid information when applied to complex and dynamic systems; such as health care organisations (Stumberg & Martin, 2009). There is a need for innovative research methods to address the complexity in health systems research. There is also a concurrent challenge for health and social care systems in England to offer high-value care in the context of growing demand and increasing financial pressures (Piercy *et al.*, 2018).

Applying realist theory to bridge the gap

In response to issues of implementing evidence into practice, there has been an expansion in the application of realist techniques in the medical field (Craig *et al.*, 2008; Moore, 2015). Realism considers *what works*, *for whom*, *why* and in *what context* (Wong *et al.*, 2013). Realism provides the techniques to deconstruct interventions into components, which can then be reconstructed with the causal webs that led to the observed outcomes (Marchal *et al.*, 2012). A realist synthesis uses existing literature to build a theory to explain what we observe in the data, to better our understanding of what brings about the change (Pawson, 2004). This understanding is presented in a context[2]-mechanism-outcome[3] framework (Figure 1).

Figure 1

Context - Mechanism - Outcome Framework for Realist Reviews



These frameworks facilitate the implementation of evidence into practice by making findings transferable to a wide range of settings, in a way that is more relevant to policy makers and those delivering services (Kernick & Mannion, 2005; Van Belle *et al.*, 2010). Theory-driven inquiry also strengthens the general knowledge base as it frames findings in existing theories (Weiss, 1995). These configurations describe the resources needed to make a difference and help others develop theoretically plausible and acceptable psychological interventions.

Focusing on mechanisms as a way forward

Research should focus on mechanisms to understand the key ingredients of change in psychological interventions (Cheng *et al.*, 2019). Mechanisms are causal forces or processes,

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[2] Contexts are multiple: Time, Place, Individuals, Teams, Institutions, Economies, Cultures, Society, Norms, History, Public Policy.

[3] Outcomes/outcome-patterns comprise the intended and unintended consequences of interventions, resulting from the activation of different mechanisms in different contexts. They can be proximal, intermediate or distal.

which operate at a different level of the system than the outcome they generate (Emmel *et al.*, 2018). Whilst causal processes exist in the real world, they are not usually observable; consequently, the discovery of mechanisms involves imagination (Emmel *et al.*, 2018). Mechanisms involve the description of at least three things: 1) the components of the system, 2) the relationships between those components, and 3) the processes through which those components and relationships generate the outcome that they do. By this account, mechanisms intend to be *explanatory* rather than descriptive. This review will focus on the classical construct of mechanisms "reasoning and resources": i.e. *what* is needed; and, *how* it is hypothesised to work (Dalkin, 2015; Emmel *et al.*, 2018).

Rationale for Realist Review

With the prevalence of dementia increasing, it is vital that we understand how to meet the psychological and emotional needs of the expanding number of people in caring roles. This is an active area of research, with a substantial existing evidence base. However, the development and implementation of care models remains challenging. A review focusing on the underlying mechanisms would guide the implementation of evidence into practice and ensure longer term sustainability. Using realist methods would provide services with the insight into the resources needed to deliver successful interventions, and the outcomes they should expect to achieve. Context-mechanism-outcome configurations would enable others to selectively use limited resource and enhance the possibility of therapeutic gain.

For the first time, we conducted a systematic review informed by realist methods focusing on the underlying mechanism in evidence based psychological interventions for dementia carers.

Aims

1. To use realist review methodology to explore the "resources and reasoning" in evidence based psychological interventions for dementia carers.

   This will involve:

   - exploring the aims of interventions.
   - identifying conceptual models and theories guiding intervention design.
   - understanding the key components (resources, techniques and processes) involved in creating change.
   - describing key outcomes demonstrating therapeutic change.

2. To synthesise results into multiple context-mechanism-outcomes configurations to provide frameworks for service delivery.

   This will involve developing models presented as multiple diagrams, showing how psychological interventions achieve therapeutic outcomes for dementia carers in different contexts.

Methods

We followed the six steps of realist reviews[4]: 1) Identifying the review question; 2) Searching for studies; 3) Quality appraisal; 4) Extracting the data; 5) Synthesising the data; and, 6) Dissemination of the findings (Pawson, 2004). The process of realist reviews differs from systematic reviews of effect in two key ways: 1) Primary and secondary material are searched for alongside grey literature to provide more context; 2) The review is informed by stakeholder and expert knowledge through an iterative and consultative process to bridge the gap between research and practice (Lilford, 2001).

Identifying the review question

We drew on external stakeholder expertise to focus the process and ensure the paper was useful and relevant in practice, in line with the quality standards for a realist review (Pawson, 2004). We[5] conducted a workshop at the Faculty of Psychology of Older People (FPOP) conference in June 2019, where we established a reference group of experts[6]. The reference group was consulted alongside an expert panel[7] of researchers and practitioners working in dementia care; and, dementia carers[8]. This ensured that the review was informed by people in the process of negotiating the interplay between research, practice and policy in the field (Saul *et al.*, 2013). The workshop attendees and reference group assisted with: developing the scope of the project, specifying the question, identifying how the findings and recommendations will be used, identifying articles and documents for

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[4] Although presented as linear process, it is an iterative process and so more of a more cyclical one.

[5] Myself and Sarah Butchard.

[6] Approximately 25 individuals attended the workshop and 15 attendees opted to remain involved in the process and join a reference group. These individuals were from NHS services, third sector organizations and research institutes or had lived experience caring for a person living with dementia.

[7] The expert panel included my supervisors, other leaders in dementia care research and older adult clinical psychologists in Mersey Care NHS trust.

[8] Dementia carers were identified from a mailing list held in Mersey Care NHS.

inclusion in the review, guiding the extraction of data, validating findings and providing feedback on the synthesis.

Searches

I registered the review on the International Prospective Register of Systematic Reviews (PROSPERO) in August 2019[9]. I completed searches on HDAS in September 2019, using the following databases: MEDLINE, PsychInfo, CINAHL, HMIC database. I used the following terms: dementia (dementia, Alzheimer$, memory loss, memory disorder, cognitive impairment), AND carer (carer, caregiver, famil*, relative*) AND mechanism (theory, theoret*, model, concept$, proces$, mechanism, components) AND psychological interventions (Psychological intervention*, therapy, psychotherapy).

Screening

In a realist synthesis, inclusion and exclusion decisions are based on two criteria: 1) *Relevance* – whether data can contribute to theory building; and 2) *Rigour* – whether the methods used to generate the relevant data are credible (Emmel *et al.*, 2018). Relevance and rigour determined inclusion criteria. Papers were relevant and included if they featured a psychological intervention that was targeted at dementia carers, and described the theoretical underpinning of the intervention.[10] To be rigorous, and included, interventions needed to have a significant effect on desired outcomes. Rigour was further considered through standardised quality appraisals described below.

Papers were excluded if:

1. They were not about dementia.
2. The intervention was targeted at the person living with dementia, not the carer.
3. There was no psychological intervention involved.
4. The psychological intervention was not evaluated or made no significant difference to the primary outcome meaning that it was not evidence based.
5. There was no mechanism of changed described.

Quality Appraisal

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[9] Reference number CRD42019143052.

[10] My primary supervisor, Sarah Butchard, screened ten percent of papers to check agreement.

We considered the quality of papers to better understand the context of included evidence[11]. We assessed rigour in qualitative studies and therapeutic case studies using the Qualitative Checklist from the Critical Appraisal Skills Programme (2018) (See Appendix 1, Table 2 for questions). We assessed rigour in quantitative studies using questions that we developed based on tools in previous published studies (Cooper *et al.*, 2017), and the Graphical appraisal tool for epidemiological studies (GATE) for public health interventions (Jackson *et al.,* 2006) (See Appendix 1, Table 3 for questions). I reviewed secondary material returned through the systematic search process and included literature relevant to building a theory about mechanisms in evidenced based psychological interventions for dementia carers. Rigour was considered in relation to the source of secondary data, and whether the material had been peer reviewed. Secondary material was integrated into the discussion to consider the application of models in practice. Grey literature was also reviewed through the HMIC database, but nothing was included through the screening process.

Data extraction

I extracted data from included interventions to produce tables and a narrative synthesis (Popay *et al.*, 2006) in the following process:

1) Describing the characteristics of the study: *study design*, *country*, *population*, *service* and *intervention design*. This informed the **context**.
2) Identifying the reasoning and resources described in the intervention: extracting the stated *aims*, *conceptual models*, underpinning *theories*, therapeutic *techniques* and described *processes*. This informed the hypothesised **mechanism** of change.
3) Considering the targeted *outcomes* and *observed change* in results. This highlighted relevant **outcome** for interventions.

We discussed extracted data from included papers in a regional older adult psychology meeting in Mersey Care NHS Foundation Trust in February 2020[12]. We drew on stakeholder expertise and considered how the evidence base related to how they applied theory and techniques in their practice supporting dementia carers, and to inform the development of C-M-O configurations (Wong *et al.*, 2013).

Data synthesis

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[11] Twenty-five percent of papers were screened by an independent rater and fellow trainee psychologist, Chloe Wheetman, to test agreement and establish validity.

[12] Myself and Sarah Butchard.

The main table of collated evidence focuses on the resources and reasoning identified in included papers: the mechanism. I then synthesised key ingredients in a context-mechanism-outcome framework presented as a series of diagrams to guide service delivery. I shared these models via email with the working reference group, a panel of experts, and a group of dementia carers. Feedback from stakeholders is included in the discussion. We considered the implications and clinical relevance of this model as well as highlighting complexities in service delivery. We also discussed the models in relation to the secondary material identified through the search process.

Dissemination

The review was disseminated virtually via email, at a virtual conference, and on twitter.[13]

Results

Search results are presented in Figure 2. Twenty-five empirical papers were identified through searches. These twenty-five empirical papers, described nineteen different interventions. Characteristics of included studies are presented in Table 1.

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[13] We had submitted to present findings at the FPOP Annual Conference 2020 but this conference was postponed due to COVID-19. This paper was accepted for an oral presentation at the Alzheimer's Society conference 2020 but this was cancelled due to COVID-19.

Figure 2

PRISMA

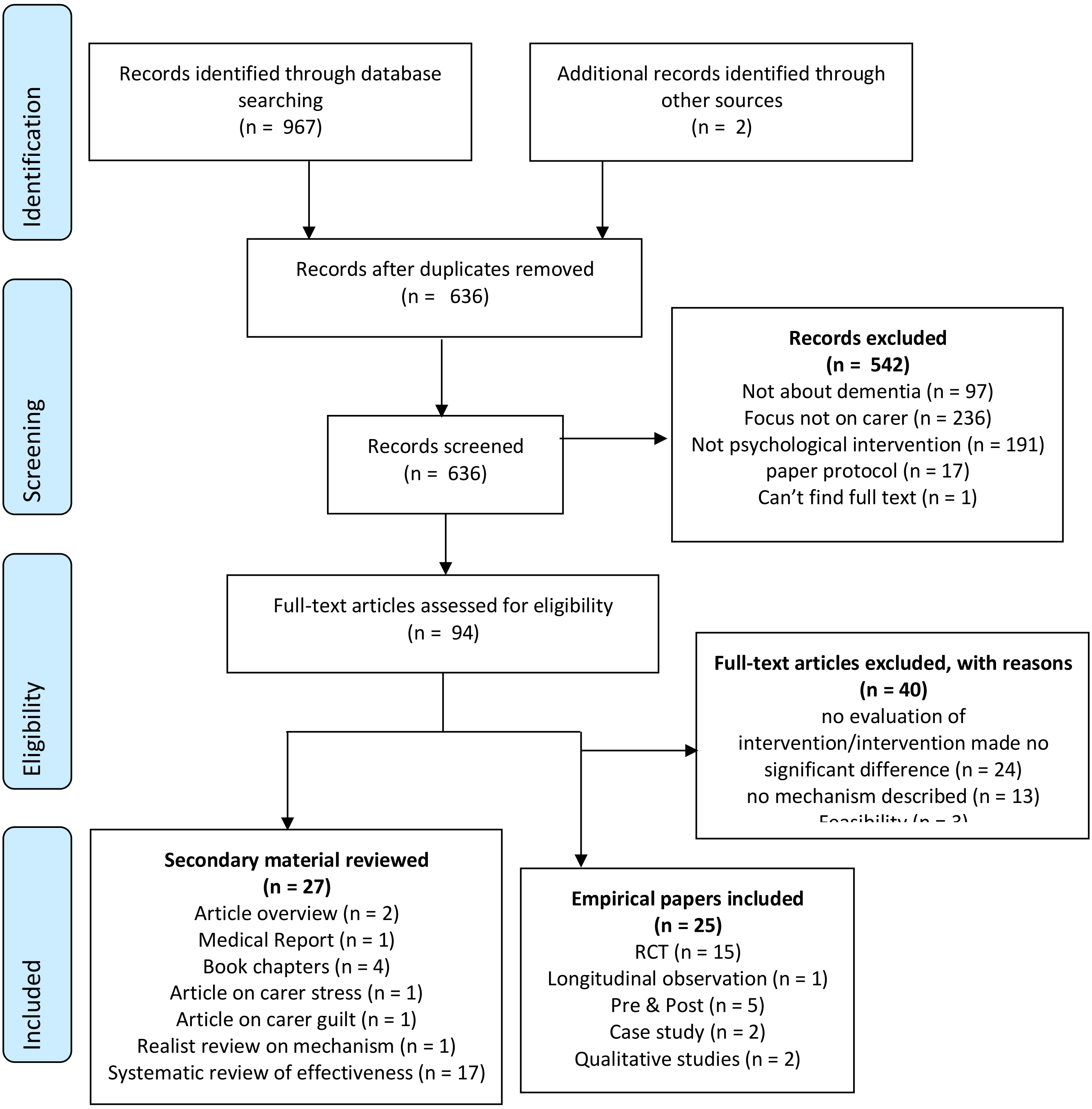


Table 1

Characteristics of included studies

Paper	Country	Method	Intervention	Population Sample	*N*	Duration	Delivered by
Andrén & Elmstahl, 2008	Sweden	Pre & Post	Psychosocial support Group	Community	308	5 weeks & 3-month conversation group	Not specified
Arritxabala et al., 2011	Spain	RCT	Emotional Regulation Groups	Community	52	10 weekly, 2 hour sessions	CBT Psychologists
Cheng et al., 2014	Hong Kong	RCT	1) Psychoeducation + "benefit finding" i.e. looking for positive gains in caring 2) Psychoeducation group	Recruited from psychiatric clinics & senior centres	25	8 weekly, 2 hour sessions	Psychology graduates
Chiverton & Caine, 1989	USA	RCT	Brief educational programme	Spouses in community	40	3 sessions, 2 hours long	Nurse
Coon et al., 2003	USA	RCT	Psychoeducation for anger & depression	Community (just women)	169	8 weekly, 2 hour workshops & 2 booster sessions	Clinical psychologist
Davis et al., 2011	USA	RCT	Telephone support	Care home	53	10 contacts over 3 months	Not specified
de Souza Caparrol et al., 2018	Brazil	Pre & Post	Cognitive stimulation group	Community	17	12 weekly sessions	Research assistant
Farran et al., 2008	USA	RCT	Caregiver skill building intervention	Community	143	5 weekly groups + 7 1-1 t/c contacts. 2 group boosters	Nurses or Social workers
Fung & Wai-Tong, 2002	Hong Kong	Parallel Groups	Mutual support group	Community	52	12 weekly 1 hour sessions	Nurse
Gallagher-Thompson et al., 2008	Germany	Pre & Post	Group CBT intervention	Community	184	13- to 16-week protocol-driven treatment packages.	Post-doctoral fellows or Psychology graduates
Judge et al., 2013	USA	RCT	A strength-based approach	Dyads	118	6 sessions, lasting 90 minutes	Masters level specialist
Kaplan & Gallagher-Thompson, 1995	USA	Case Study	Integrative Therapy (Grief counselling and CBT therapy)	Wife following transition of husband to care home	1	17 sessions of individual therapy	Psychotherapist
Kwok et al., 2014	Hong Kong	Pre & Post	Online counseling	Community	36	9 weeks of back and forth messaging	Clinical psychologists, Social workers, Counsellors
Li et al., 2014; Livingston et al., 2014ab; Sommerlad et al., 2014	UK	RCT	Individual manualised coping strategy programme	Community	260	8 sessions	Psychology graduates supervised by a Clinical psychologist
Mavandadi et al., 2017	USA	RCT	Telephone based care management & telephone education	Veterans	75	Minimum 3 contacts in 3 months Workbook mailed out	MDT Staff
Meichsner et al., 2016, 2017, 2018, 2019	Germany	2 Cases* RCT	Telephone therapy	Mixed	273	12, 50-minute therapy sessions over 6 months	Clinical psychologist
Milne et al., 2014	UK	Pre & Post*	Psychoeducational groups	Community	73	10 weekly, 2 hour sessions	Clinical psychologist + SALT, OT, Admiral Nurse & Carer
Pihet & Kipfer, 2018	Switzerland	Pre & Post*	Psychoeducational groups	Community	18	15 weekly, 2 hour sessions	Nurses and Carer
Wang et al., 2012	China	Parallel Groups	Mutual support group	Community	78	12 weekly, 90 minute sessions	Nurse
Wilz & Kalytta, 2012	Germany	Longitudinal study	CBT Group	Community	178	20, 90 minute sessions	Psychology graduates and guest experts

Quality Appraisal

Results from the quality checklists are available in Appendix 1. Papers of all quality were included, and quality was considered further in the discussion. One of the qualitative papers was considered poor quality as it failed to meet two criteria. All other qualitative studies were high quality. Of the twenty-two quantitative papers; eight papers were appraised as being high quality, eight papers were appraised as being medium quality and six papers were appraised as being low quality.

Context

Interventions were delivered through a range of modalities, including group (*n* = 13) and individual (*n* = 6). Individualised interventions included telephone support (*n* = 2), telephone therapy (*n* =1), face to face therapy (*n* = 2), and online counselling (*n* = 1). Most interventions were delivered to family carers whose relative resided in the community. Two interventions targeted carers after the person they were caring for had moved into a care home. Interventions were led by different practitioners including clinical psychologists, psychology graduates, nurses, and research assistants. Often interventions drew on the expertise of other professionals to deliver specific group content. The minimum intervention duration involved three sessions of two hours; and, the longest duration involved 17 sessions of individual therapy. Interventions were packaged with different aims; most focused on psychoeducation, psychosocial support, emotional regulation and skills, and offering general support.

Mechanisms

Table 2 describes the key components of the intervention, the interactions and processes that underpin change, and the outcomes observed. I will now describe the conceptual models and theories guiding intervention design to explain the “reasoning and resources” involved. Full details of extracted aims, theories and models, techniques and processes can be found in Appendix 2, Table 5.

Changing Thinking and Behaviour

The most referenced theories were cognitive behavioural theories, with thirteen interventions stating they were informed by Cognitive Behaviour Therapy (CBT) (Andrén & Elmstahl, 2008; Arritxabala *et al.*, 2011; Coon *et al.*, 2003; Gallagher-Thompson *et al.*, 2008; Kaplan & Gallagher-Thompson, 1995; Kwok *et al.*, 2014; Meichsner *et al.,* 2016, 2017, 2018, 2019; Milne *et al.*, 2014; Wilz & Kalytta, 2012; Wilz *et al.*, 2018). Two interventions were focused on behavioural change using Zarit, Orr & Zarit (1985) six step model of problem solving (Fung & Wai-Tong, 2002; Wang *et al.*, 2012). One study mentions Meichenbaum's (1977) stress inoculation framework which is CBT informed and involves teaching coping skills to manage stress and anxiety (Milne *et al.*, 2014).

Several studies named techniques commonly used in CBT as successful components of interventions. These included: creating a therapeutic alliance, Socratic dialogue, guiding discovery, monitoring dysfunctional thinking, cognitive restructuring, emotion regulation strategies, assertiveness training, rehearsing skills, increasing pleasant events, progressive muscle relaxation, breathing techniques, roleplaying exercises, generating positive self-talk, searching for strengths, re-evaluating expectations, creating plans, rewarding goals, encouraging self-reflection, and vicarious learning (Arritxabala *et al., 2011;* Cheng *et al., 2014;* Judge *et al., 2013;* Kwok *et al., 2014;* Farran *et al., 2007;* Wilz & Kalytta, 2012; Wilz *et al., 2018*). Where interventions were purely activity based, they improved cognitive functioning, but had no impact on mood or stress (de Souza Caparro *et al.*, 2018).

Reducing Stress

Eleven intervention designs were underpinned by theoretical understandings of stress. The most referenced theory was Lazarus & Folkman's (1984) Transactional theory of stress and coping, which featured in seven interventions (Cheng *et al.*, 2014; Chiverton & Caine, 1989; Davis *et al.*, 2011; Li *et al.*, 2014 & Livingston *et al.*, 2014ab; Mavandadi *et al.*, 2017; Milne *et al.*, 2014; Pihet & Kipfer, 2018). Four other interventions mentioned the Pearlin (1990) Stress model (Arritxabala *et al.*, 2011; Milne *et al.*, 2014; Farran *et al.*, 2007; Judge *et al.*, 2013). Many of the interventions focused on improving coping by better resourcing carers with coping strategies. Sixteen interventions included training on caregiver skills, stress management, problem solving, managing difficult behaviours and finding psychosocial support in the local community (Andrén & Elmstahl, 2008; Arritxabala *et al.*, 2011, Cheng *et al.*, 2014; Chiverton & Caine, 1989; Davis *et al.*, 2011; Farran *et al.*, 2007; Fung & Wai-Tong, 2002; Judge *et al.*, 2013; Kwok *et a*l., 2014; Pihet & Kipfer, 2018; Li *et al.,* 2014; Livingston *et al.,* 2014ab; Milne *et al.*, 2014; Meichsner *et al.*, 2016, 2017, 2018, 2019; Mavandi *et al.,* 2018; Wilz & Kalytta, 2012; Wang *et al.*, 2012).

Several interventions identified specific ways to reduce stress by altering physiology through behavioural activation, mindful breathing, healthy lifestyle, focused breathing, physical grounding, guided imagery, meditation and stretching (Cheng *et al.,* 2014, Kwok *et al.,* 2014; Li *et al.,* 2014; Livingston *et al.,* 2014ab; Wilz & Kalytta, 2012). Therapists and group members also acted as resources to carers, providing support through empathy, validation and reframing (Cheng *et al.,* 2014; Chiverton & Caine, 1989; Davis *et al.,* 2011).

Enhancing satisfaction and self-efficacy

Other interventions discussed increasing the positive byproducts of caregiving. One study referred to Lawton *et al.,* (1991) two-factor model of caregiving (Cheng *et al.,* 2014). Two interventions referenced self-efficacy (Coon *et al.*, 2003; Farran *et al.*, 2007). Ways to increase self-efficacy, include mastery experiences, vicarious experiences provided by social models, social persuasion, modifying self-beliefs of efficacy (Bandura, 1994). Many of the group discussions and cognitive behavioural techniques could also be considered to enhance self-efficacy though this was not mentioned specifically.

Identifying and processing emotions

Other interventions focused on process driven theories and models. Meichsner *et al.,* (2016, 2017, 2018, 2019) referenced Acceptance Commitment Therapy (ACT). Other intervention designs were guided by psychodynamic theories of insight (Kaplan & Gallagher-Thompson, 1995; Milne *et al.*, 2014). Similarly, Coon *et al.*, (2003) referenced Nocaco's (1975) theory of anger and stressed the importance of establishing the cause of the anger and finding a way to relieve the emotion. Moreover, several interventions for dementia carers focused on processing emotions related to grief. Two interventions were guided by Worden's (1991) model of grief (Kaplan & Gallagher-Thompson, 1995; Milne et al., 2014). This model was used alongside CBT strategies: agenda setting, homework, acknowledging ambivalence, building a therapeutic alliance, modifying statements and creating individualised survival guides (Gallagher-Thompson *et al.,* 2008).

Another study referenced Blandin & Pepin's (2015) dementia grief model (Meichsner *et al.*, 2016, 2017, 2018, 2019). In these interventions, the therapist focuses on normalising grief, recognising underling thoughts and emotions, tolerating painful feelings, identifying and restructuring dysfunctional thoughts about grief, providing suggestions of redefining the relationship, encouraging individuals to prepare for death, and activating resources which will help to address future losses (Meichsner *et al.,* 2016, 2017, 2018, 2019).

Altering relational interactions

Other theories looked beyond intrapersonal components and considered wider systems. One intervention was guided by Epstein's (1978) McMaster Model of Family Functioning (Davis *et al.,* 2011). Here, therapeutic change is brought about in family relationships through better responses to problems, more effective communication, shifts in patterns of behaviours and roles, improved responses to feelings and more functional behaviours (Epstein, 1978). Another study referred to Algase's (1996) Need-Driven Dementia-Compromised Behaviours Model, as a way of improving relational interactions and carer's responses to care recipients (Farran *et al.*, 2007). Therapeutic change is achieved when family carers view disruptive behaviours as expressions of unmet needs, changing a carer's appraisal of the situation and their response to a care recipient.

Adapting to change

Davis *et al.,* (2011) discusses psychosocial transition theory (Tyhurst, 1958). In Davis *et al.,* (2011) staff played this role through the provision of telephone support as their family members moved into a care home. This also facilitated adjustment as carers became informed, familiar with staff and orientated to the situation. This was also an identified component of post diagnostic support where carers receive support to overcome the shock and come to terms with reality (Milne *et al.,* 2014).

Learning new skills

Several interventions were underpinned by theories of learning. Coon *et al.*, (2003) and Milne *et al.*, (2014) designed interventions based on Bandura's social learning theory (Bandura, 1971). Chiverton & Caine (1989) refer to education theory (McHugh *et al.*, 1982). Milne *et al.*, (2014) refers to adult learning theory (Gottlieb & Feeley, 2006). Most (ten) interventions focused on improving knowledge offering psychoeducation about dementia and individualised post diagnostic support (Andrén & Elmstahl, 2008; Arritxabala *et al.*, 2011; Cheng *et al.*, 2014; Chiverton & Caine, 1989; Farran *et al.*, 2007; Kwok *et al.*, 2014; Mavandadi *et al.*, 2017; Pihet & Kipfer, 2018; Wilz & Kalytta, 2012; Wilz *et al.*, 2018*).*

Outcomes

Outcomes that demonstrated change were usually reported by the individual. An increase in scores on the following outcomes indicated positive therapeutic change: caregiver satisfaction, positive affect, wellbeing, competence, perceptions of staff, self-efficacy, quality of life, caregiver mastery, understanding and patience. A reduction in scores on the following outcomes indicated therapeutic change: burden, dysfunctional thoughts, stress, anxiety, depression, overload, anger, guilt, emotional distress, emotional strain, relationship strain, role captivity (unwanted strain in role).

Table 2

Mechanisms of change in included studies

Paper	Context	Mechanism		Outcome
		Resources*	**Reasoning****	
Andrén & Elmstahl, 2008	Carers identified from Public Register in the community in Sweden. Face to face groups.	☐ Strategies for: mobilising help, reducing social isolation, coping with and overcoming difficulties, responding to challenging behaviour. ☐ Practical support for future planning. ☐ Education on cognitive changes in dementia. ☐ Group members & interactions.	☐ Strategies and education improves problem solving and enhance perceived coping. ☐ Receiving support enhances networks and improves ability to cope. ☐ Connection with others helps to alleviate emotional distress.	☐ Reduced burden. ☐ Increase in caregiving satisfaction.
Arritxabala et al., 2011	Carers living with someone with dementia in Spain. Face to face groups.	☐ CBT psychologists. ☐ Education on the concept of emotions: definition, functioning, regulation and associated thoughts. ☐ CBT skills and emotional regulation strategies. ☐ Group members & interactions.	☐ Identifying link between emotion and behaviours. ☐ Increases awareness and improves emotional regulation. ☐ Pleasant events improve mood. ☐ Relaxations strategies alleviate stress. ☐ Enhancing assertiveness improves communication and facilitates help seeking. ☐ Problem solving and planning reduces stress.	☐ Fewer dysfunctional thoughts. ☐ Higher positive affect. ☐ Increased wellbeing. ☐ Lower stress.
Cheng et al., 2014	Carers recruited from psychiatric clinics and senior centers in Hong Kong. Face to face groups.	☐ Psychology Graduates. ☐ Group members and interactions. ☐ Education on: dementia, communication skills, stress management and relaxation, balance between self-care and caregiving responsibilities, social support, managing behavioral and psychological symptoms, home-based activities for care recipient, personal care skills for dependencies in activities of daily living, home environmental modification, and community resources.	☐ Interactions enhance awareness of emotional reactions increasing responses to them. ☐ Finding benefits allow experience to be reframe thoughts as positive leading to reappraisal of situation. ☐ Additional support improves resources and reduces caregiving demands. ☐ Upskilling carers improves ability to respond and reduces stress.	☐ Reduced depression in benefit finding group. ☐ Psychoeducation group reduced overload and burden.
Chiverton & Caine, 1989	Cohabiting spouses in the community in USA. Face to face groups.	☐ Nurse. ☐ Psychodeducation on dementia, communication skills and behavioral management, respite care.	☐ Information provided and discussion improves carers knowledge and enhances their perceived coping.	☐ Greater competence.
Coon et al., 2003	Women over 50 identifying as primary carer in USA.	☐ Clinical psychologist. ☐ Information about anger management. ☐ Depression management skills.	☐ Generating positive self-talk and increasing pleasant events improves mood. ☐ Monitoring dysfunctional thinking	☐ Reduced anger. ☐ Improved self-efficacy.
Davis et al., 2011	Carers whose loved one resides in a care home in USA. Over telephone.	☐ Telephones. ☐ Staff and family interactions. ☐ Signpost to community resources.	☐ Normalizing, empathy, validation help to process emotions and facilitate adjustment. ☐ Positive reframing improve mood. ☐ Knowledge of community resources enhances network and improves perceived coping. ☐ Contact facilitates trust & builds relationships.	☐ Reduced guilt. ☐ Improved perceptions of staff.
de Souza Caparrol et al., 2018	Carers cohabiting in community visited at home in Brazil.	☐ Research Assistant. ☐ Activities.	☐ Cognitive stimulation.	☐ Improved cognition.

Paper	Context	Mechanism		Outcome
		Resources*	**Reasoning****	
Farran et al., 2008	Carers in the community in USA. Face to face group.	☐ Nurses or Social workers. ☐ Group members and processes. ☐ Education on behavioural symptoms & interventions.	☐ Increased awareness of care receivers needs and interventions improve caregiving response. ☐ Improved ability to self-regulate.	☐ Reduced emotional distress.
Fung & Wai-Tong, 2013	Carers recruited from senior centers in Hong Kong. Face to face group.	☐ A nurse. ☐ Group members and processes. ☐ Information about resources & problem solving.	☐ More able to identify the problem, find alternatives, execute and evaluate plan.	☐ Reduced distress. ☐ Improved quality of life.
Judge et al., 2013	Caergiving dyads recruited through social services in USA. Face to face with one deliverer, two participants.	☐ Post-doctoral fellows or psychology graduates. ☐ Education on dementia, communication, managing memory, staying active and recognizing emotions and behaviours.	☐ Information assists with planning. ☐ Time improved connection and relationship. ☐ Validating and reframing improved mood. ☐ Adaptations & adjustments negated problem.	☐ Reduced emotional health strain, dyadic relationship strain, role captivity. ☐ Higher caregiving mastery. ☐ Fewer symptoms of depression and anxiety.
Kaplan & Gallagher-Thompson, 1995	Wife following transition of husband to care home in USA. One to one therapy.	☐ Masters level specialist. ☐ Therapeutic alliance. ☐ Discussing the four tasks of grief.	☐ Normalising and naming grief, improving awareness. In vivo exposure helped processing. ☐ Reframing negative thoughts and experiences improved mood. ☐ Pleasant events and establishing social relationships improved mood. ☐ Adjustment helps move on.	☐ Reduced depression and anxiety.
Kwok et al., 2014	Carers whose loved one used day care in Hong Kong. Online.	☐ Clinical psychologists, social workers, counsellors. ☐ Online counselling. ☐ Strategies for responding.	☐ Cognitive restructuring changes unhelpful thoughts. ☐ Mindful breathing improves self-awareness. ☐ Improved caregiving skills increase competency.	☐ Reduced distress.
Li et al., 2014; Livingston et al., 2014; Sommerlad et al., 2014	Carers recruited from NHS dementia services in UK. One to one, face to face, manualised sessions delivered in own home.	☐ Psychology graduates supervised by clinical psychologist. ☐ START manual. ☐ Education on dementia, carer stress and relaxation management. ☐ Information about common decisions. ☐ Relaxation CD with strategies.	☐ Promoting emotion focused coping helped alleviate distress along with challenging negative thoughts and increasing relaxation. ☐ Improved ways of responding to behaviours. ☐ More information and support. ☐ Increased planning and assertive communication more achievement of goals.	☐ Reduced depression and anxiety. ☐ Improved quality of life.
Mavandadi et al., 2017	Carers of veterans with dementia receiving care from Veterans Affairs Medical Centre (Primary Care) in US. Over telephone.	☐ MDT Staff. ☐ Telephones. ☐ Education on communication skills, behavioral management techniques, stress management and coping skills, long-term planning.	☐ Changing appraisals of and responses to common stressors through psychoeducation. ☐ Training in emotion- and problem-focused coping skills and problem-solving techniques. ☐ Improving psychosocial support.	☐ Improved coping. ☐ Improved caregiving mastery.

Paper	Context	Mechanism		Outcome
		Resources*	**Reasoning****	
Meichsner et al., 2016, 2017, 2018, 2019	Carers who are living with person living with dementia in Germany. Individual telephone based therapy.	☐ Clinical psychologist. ☐ Telephones. ☐ Psychosocial resources.	☐ Recognising and accepting painful thoughts and emotions reduces secondary strain. ☐ Identifying and restructuring dysfunctional cognitions. around grief and normalising it facilitates processing. ☐ Activating resources improves management of stress ☐ Sharing strategies improves coping.	☐ Higher wellbeing.
Milne et al., 2014	Carers of someone open to NHS dementia services in UK. Face to face course.	☐ Clinical psychologist, Speech And Language Therapist, Occupational Therapist, Admiral Nurse & carer group processes and group members. ☐ Information about managing behavior problems, stress management, emotion regulation, orientating to the positives, coping with change and loss, carers own needs. Directed to respite services.	☐ Processing emotions and acceptance reduces secondary strain. ☐ Improved knowledge and increased awareness. ☐ Stress reduction techniques reduce stress.	☐ Greater understanding and patience.
Pihet & Kipfer, 2018	Carers recruited by Alzheimer's Association, daycare and memory clinics in Switzerland. Face to face group.	☐ Nurses and carer. ☐ Discussion regarding appraisal of stressful situation and coping strategies. ☐ Education on how dementia affects communication and relational behaviour.	☐ Identifying what is stressful and distinguishing between what can and can't be modified conserved energy and reduced secondary strain. ☐ Using strategies to better solve problems and cope with emotional consequences.	☐ Reduced burden and distress. ☐ Improved self-efficacy.
Wang et al., 2012	Carers recruited from services and respite care centres in China. Face to face groups.	☐ Nurse. ☐ Information about dementia, emotional impact of caregiving, self-care, support outside of the group, home care skills and ways to improve the relationship.	☐ Identifying what is stressful and distinguishing between what can and can't be modified conserved energy and reduced secondary strain. ☐ Using strategies to better solve problems and cope with emotional consequences.	☐ Reduced distress.
Wilz & Kalytta, 2012	Carers recruited through dementia services in Germany. Face to face groups.	☐ Psychology graduates. Guest experts. ☐ Information about dementia, problem behaviours, problem solving, self-care, loss and caring skills.	☐ Information modifies stress inducing assumptions regarding behaviour. ☐ Strategies to cope with and respond to emotions.	☐ Reduced depression & anxiety. ☐ Delayed nursing home placement.
Wilz et al., 2018	Carers whose loved one was receiving dementia services in Germany. Over the telephone.	☐ Clinical psychologists. ☐ Telephones. ☐ Information. ☐ Education on strategies. ☐ Therapeutic alliance.	☐ Problem analysis and problem solving. ☐ Guided discovery enabled cognitive restructuring, reduced distressing thoughts beliefs. ☐ Emotion based coping and acceptance reduced secondary strain. ☐ Planning activities and pleasant events improved mood. ☐ Reviewing goals & making future plans enabled progress.	☐ Improved emotional well-being. ☐ Fewer symptoms of depression & ill health. ☐ Improved coping with care situation and behaviour of the care recipient.

***** The components of the system, i.e. what you need to make it work.**

***** The relationship between those components and the processes and interactions through which the components and relationships generate the outcome, i.e. how it is thought to work.***

Context-Mechanism-Outcome configurations

We have developed four configurations to guide the application of psychological interventions for dementia carers, presented as follows:

1) Improving understandings and resourcing carers.
2) Coping with loss and processing grief.
3) Improving mental health.
4) Supporting transitions.

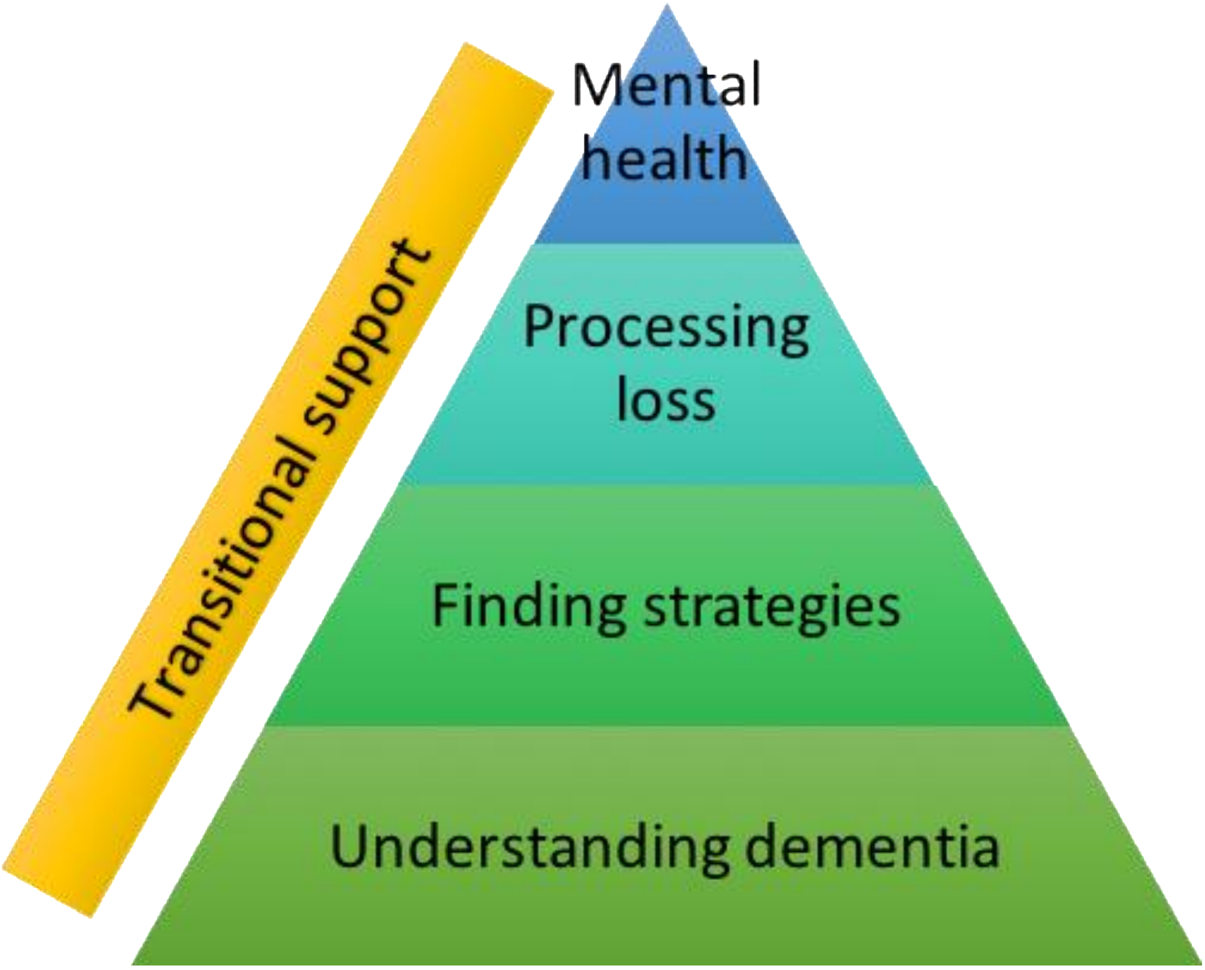
C-M-O configurations were developed on mechanisms described in evidence-based interventions. Feedback from the reference group will be presented alongside models in a text box to guide implementation in practice. Clinical psychologists working in the field of dementia carer support feedback that the models would be useful in practice.

These models can be thought to work together within a stepped model of care (Figure 3), where carers may benefit from these interventions at different times during their experience of supporting someone living with dementia. We expect that all carers will need to understand dementia, a large number of carers will need support expanding their resources to cope with caring, many will experience grief, and a smaller number of carers will require targeted mental health support. Carers will likely experience different transitions throughout their caring experience, and would benefit from transition support at any time during their caring experience. Finding strategies and understanding dementia will be presented within one model as they involved the same mechanisms.

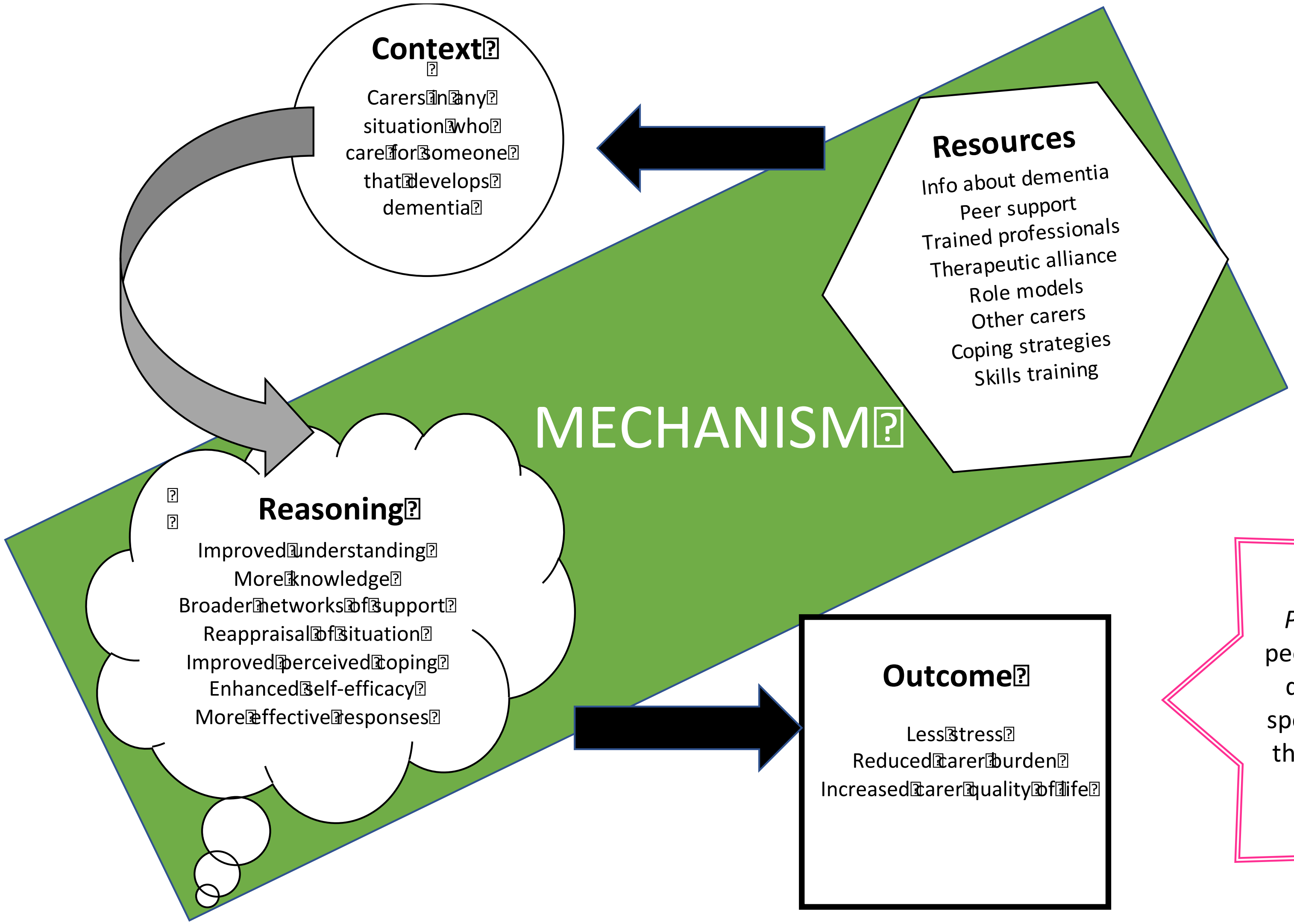
Psychologists agreed that the mechanisms could be accessed interchangeably in practice. One professor of health psychology said that he thought they would be helpful in guiding services in the third sector, which are needed as health services alone struggle to meet the needs of family carers. Several carers described agreeing that the models fit with their perspective of what is helpful in therapeutic support. One carer described finding the models easy to understand, which they thought would help them understand how services can help. Another pointed out that the models are focused on service delivery and could be adapted in a way that would help carers consider how they might help themselves.

Figure 3

Stepped Care Model



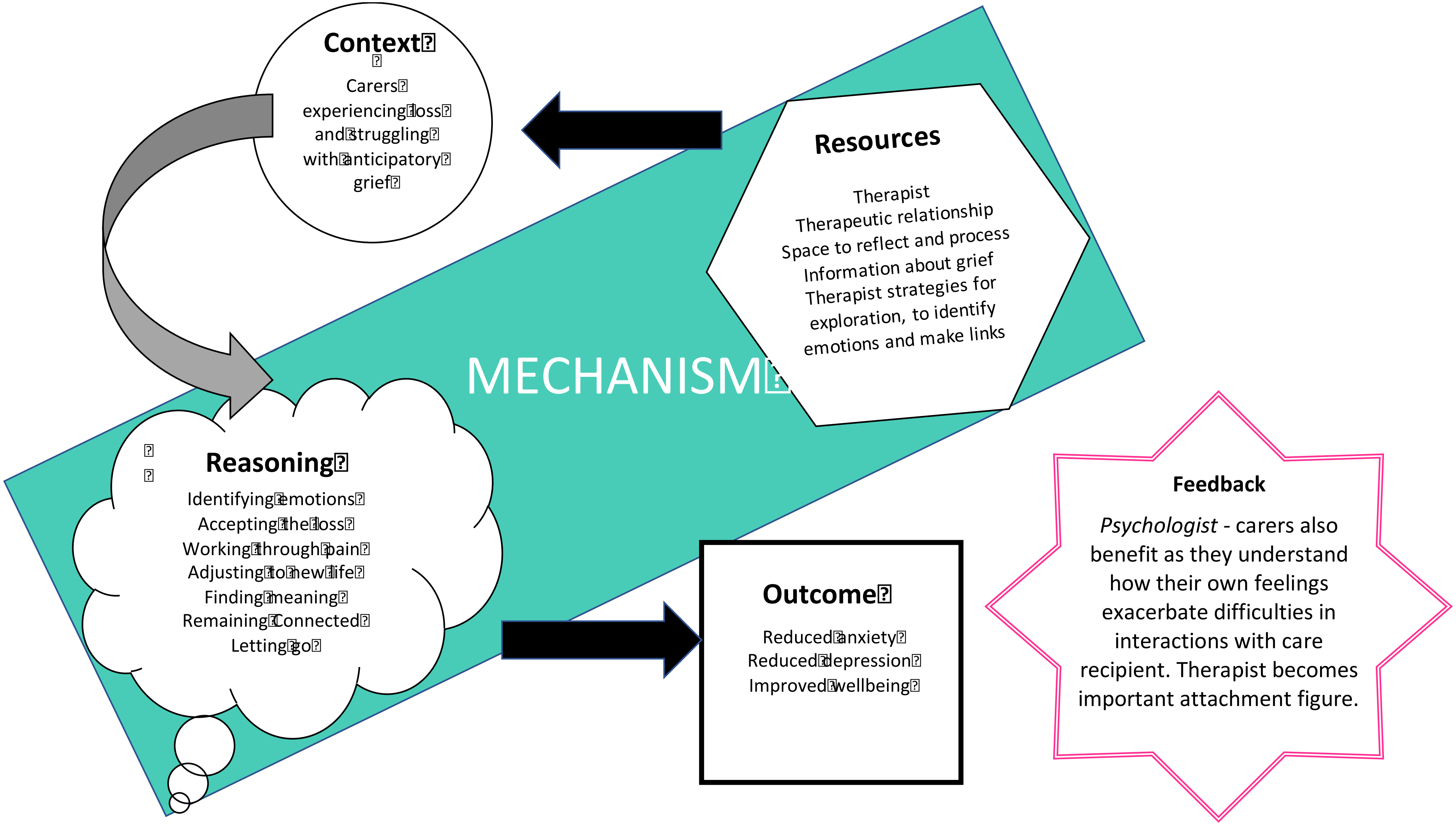
Improving understandings and finding strategies



Feedback

Psychologist - carers of people with rarer forms of dementia benefit from specialist intervention but this is often not available in practice.

Coping with loss and processing grief



Context

Carers experiencing loss and struggling with anticipatory grief

Resources

Therapist
Therapeutic relationship
Space to reflect and process
Information about grief
Therapist strategies for exploration, to identify emotions and make links

MECHANISM

Reasoning

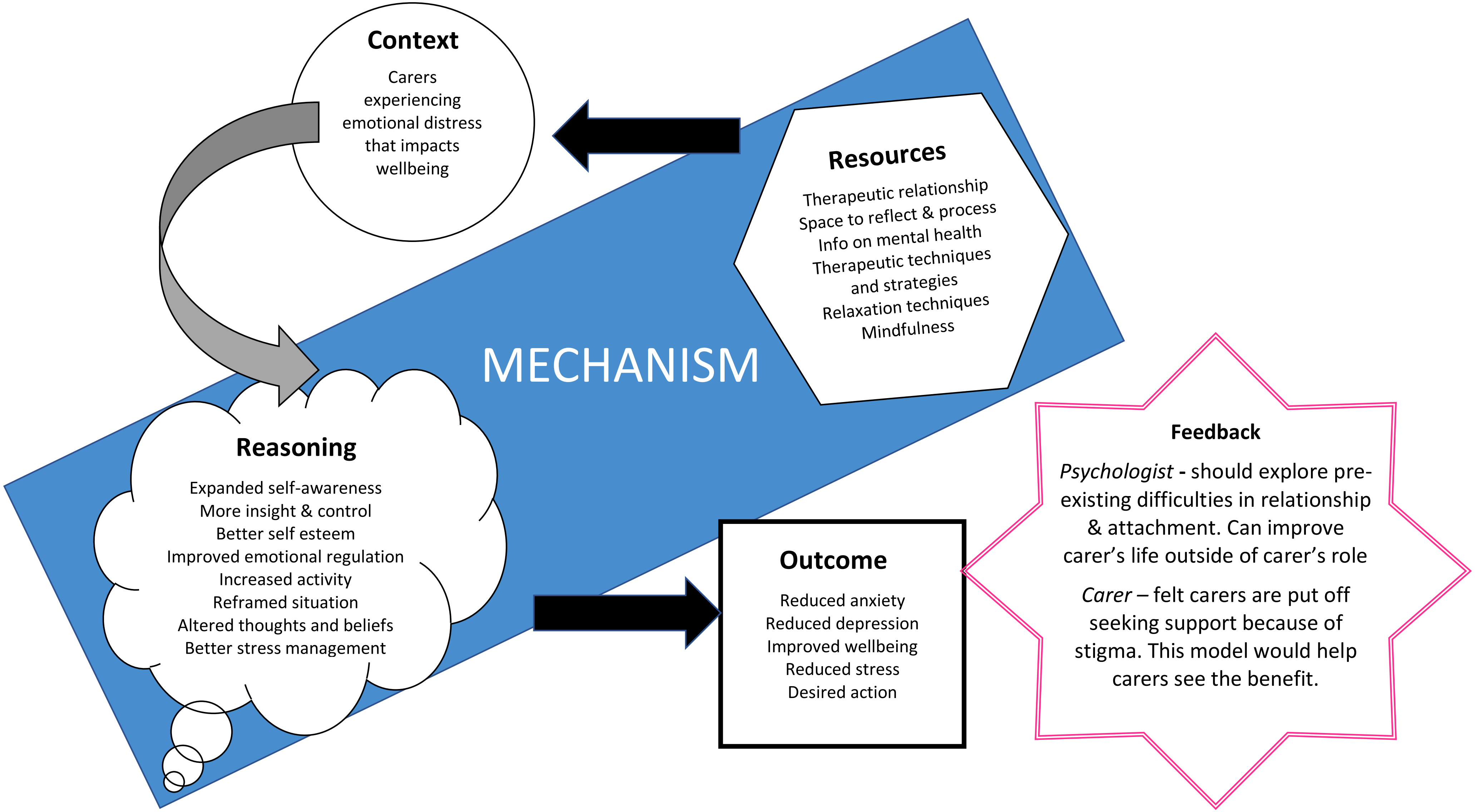
Identifying emotions
Accepting the loss
Working through pain
Adjusting to new life
Finding meaning
Remaining Connected
Letting go

Outcome

Reduced anxiety
Reduced depression
Improved wellbeing

Feedback

Psychologist - carers also benefit as they understand how their own feelings exacerbate difficulties in interactions with care recipient. Therapist becomes important attachment figure.



Context

Carers experiencing emotional distress that impacts wellbeing

Resources

Therapeutic relationship
Space to reflect & process
Info on mental health
Therapeutic techniques and strategies
Relaxation techniques
Mindfulness

MECHANISM

Reasoning

Expanded self-awareness
More insight & control
Better self esteem
Improved emotional regulation
Increased activity
Reframed situation
Altered thoughts and beliefs
Better stress management

Outcome

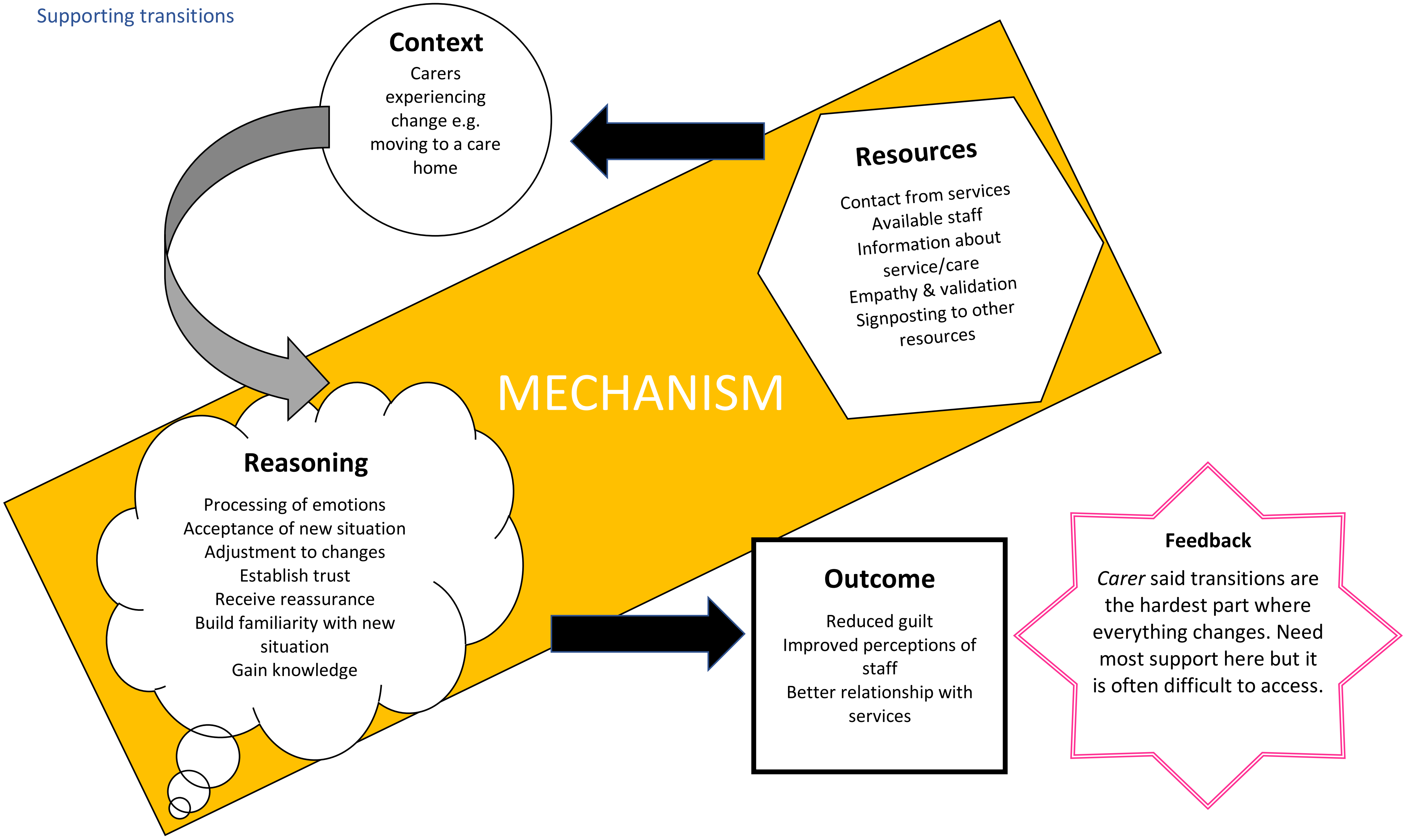
Reduced anxiety
Reduced depression
Improved wellbeing
Reduced stress
Desired action

Feedback

Psychologist **-** should explore pre-existing difficulties in relationship & attachment. Can improve carer's life outside of carer's role

Carer – felt carers are put off seeking support because of stigma. This model would help carers see the benefit.

Supporting transitions



Context

Carers experiencing change e.g. moving to a care home

Resources

Contact from services
Available staff
Information about service/care
Empathy & validation
Signposting to other resources

MECHANISM

Reasoning

Processing of emotions
Acceptance of new situation
Adjustment to changes
Establish trust
Receive reassurance
Build familiarity with new situation
Gain knowledge

Outcome

Reduced guilt
Improved perceptions of staff
Better relationship with services

Feedback

Carer said transitions are the hardest part where everything changes. Need most support here but it is often difficult to access.

Discussion

Many interventions used the same techniques but described different theoretical underpinnings. Techniques involving changing carers' perceptions, and altering their responses, were common to all interventions. Depending on the presenting problem, different mechanisms were hypothesised to exist. There is considerable theoretical overlap in described mechanisms of change. This might account for some of the heterogeneity in intervention design and targeted outcomes.

I will begin by expanding on the theoretical underpinnings of the C-M-O configurations, to better understand the mechanisms described in models. Theories and evidence discussed below were extracted from papers included in this review. I will then reflect on support for the configurations, before discussing the applications of these models in practice and making clinical recommendations. Finally, I will consider the strengths and limitations of this review before making suggestions for future research.

Theoretical underpinnings of C-M-O configurations

Improving understandings and finding strategies

Carers feel less stressed when they understand dementia better, and have the resources to cope with the demands of caring. Lazarus & Folkman's (1994) theory of stress states that stress is a relationship between the person and the environment that is appraised as taxing, or exceeding their resource; and, endangering to their wellbeing. Stress thus involves two important phases: 1) cognitive appraisals; and, 2) coping. Providing accurate and helpful information about a diagnosis of dementia and offering support, can help carers reappraise a situation as less harmful, less threatening or less challenging. Accurate information is a way to challenge stigma, rationalise catastrophic interpretations of events and provide carers with effective strategies to cope. Dementia is the most feared and stigmatised disease in the UK (Saga Populus Poll, 2016). Research has found that family carers usually experience fear and are uncertain about the cause, timeline and controllability of dementia (Quinn *et al.*, 2017). Providing accurate information can shape illness representations held by family members, influencing their understanding of what is happening to the person, and the best ways to respond and provide support (Quinn *et al.*, 2017). Health care professionals may help guide caregiver responses using models of problem solving. For example, Zarit's

(1985) six step model was described which involves: 1) identifying the problem, 2) generating alternative solutions, 3), selecting a solution after reviewing pros and cons, 4) cognitive rehearsal, 5) carrying out the plan, and, 6) evaluating the plan. These tools have an impact on wider systems and successful interventions often resolve problems within a family unit (Miller *et al.,* 2000; Lough *et al.*, 2007).

In Pearlin's (1990) model, caregivers' stress is a consequence of multiple varying interrelated conditions; including, the socioeconomic characteristics and resources of caregivers, and the primary and secondary stressors to which they are exposed. Primary stressors are hardships and problems anchored directly in caregiving. Secondary stressors are the strains experienced in roles and activities outside of caregiving, and the intrapsychic strains involving diminishing self-concepts. Providing social support, referring to other agencies and supporting carers to get financial support can intervene at multiple points along the stress process by reducing primary or secondary stressors (Pearlin *et al.*, 1990). Previous research suggests a carer's perception of their resources is a more important predictor of their distress than the nature and presentation of the person living with dementia's illness (Donaldson *et al.*, 1998; Crespo *et al.*, 2005; Coon *et al.*, 2003; Rinaldi *et al.*, 2005; Cherry *et al.*, 2013).

Carers also experience therapeutic gains in this model by developing self-efficacy. Self-efficacy describes people's beliefs about their capabilities, which determine how they feel, think, motivate themselves and behave (Bandura 1986, 1997, 2001; Zeiss *et al.*, 1999). A strong sense of self-efficacy enhances human accomplishment and personal wellbeing, as people approach threatening situations with assurance, they can exercise control over them (Bandura, 1994). Some evidence suggests, *perceived* knowledge of dementia may influence carers' subjective burden more than their *actual* knowledge, suggesting building confidence around knowledge is important to enhance wellbeing (Schindler, 2012). The stress-buffering effects of social support may be attributable to the self-esteem boosts people obtain from their supporters (Thoits, 2013).

Lawton *et al.,* (1991) two-factor model of caregiving proposed that caregiving experiences can have differential impacts on well-being, with caregiving satisfaction resulting in positive affect and caregiving burden resulting in negative affect. Connecting with others and finding meaning in caring improves the likelihood that carers experience positive consequences of caring (Cherry, *et al.*, 2013). An important resource that enables these mechanisms, are other people. Bandura's social learning theory postulates that new behaviours can be acquired by observing and imitating others (Bandura, 1971). Bandura stated that learning is a cognitive process that takes place in a social context, and can occur purely through observation or direct instruction (Bandura, 1964; Eysenck, 1964). In this model, learning takes place through a collaborative partnership where the learner is active and shares responsibility, applying their knowledge and capabilities to understand and manage their problems, and work towards goals that are meaningful to them (Gottlieb & Feeley, 2006). In this way, coping can be improved through the provision of information and instructions (McHugh *et al.*, 1982).

Coping with loss and processing grief

In this model, carers experience less anxiety and depression through processing grief and loss. Several theories focused on processing emotions, accepting loss and finding meaning. Psychodynamic theory postulates that therapeutic change is achieved through enhancing insight into the problem and processing the emotional consequences (Molnos, 1995). These ideas guided the development of two models of grief, guiding evidence-based interventions. Worden's (1991) model of grief involves four tasks: 1) accepting the reality of the loss; 2) working through the pain of grief; 3) adjusting to the environment where the person is missing; 4) finding an enduring connection with the person and embarking on a changed life. Blandin and Pepin (2015) developed a model of grief in dementia and stated that predeath grief cycles through three states: 1) separation – caused by the disease trajectory; 2) liminality – being in between the previous situation and a new one; and, 3) re-emergence – adapting to change. These interventions work by supporting carers to acknowledge their feelings and tolerate difficult emotions. Movement through these states can be inhibited through resistance, a lack of recognition or denial (Blandin & Pepin, 2015). Here the therapist can assist by providing space to process the emotions, psychoeducation on grief and offering therapeutic insights.

Similarly, ACT is informed by cognitive and behavioural theories, but is process driven. ACT focuses on altering cognitive fusion and experiential avoidance, through commitment and behaviour-change strategies which increase psychological flexibility (Hayes, 2016). Therapeutic change is not achieved by removing problematic thoughts or feelings, but instead through promoting acceptance and mindfulness. A modern CBT approach, Acceptance and Commitment Therapy (ACT) has been found to be particularly beneficial for carers experiencing high levels of anxiety (Kishita, 2018). ACT is likely to help carers who cannot change or control their experiences as dementia is a neurodegenerative illness that inevitably involves loss.

Improving mental health

The mechanisms described in the above two models, would also improve mental health as stress and loss are highly predictive of depression and anxiety (Kessler, 1997; Kendler, *et al.* 2004*;* Treadway *et al.,* 2013). There may, however, be a subgroup of carers who would benefit from targeted therapeutic techniques that improve anxiety and depression more generally. Here, within the context of a therapeutic relationship, carers receive targeted techniques and strategies to address negative-based thinking which alters during successful treatments (Lorenzo *et al.,* 2015). Alongside changes in thoughts and behaviours, it is likely that factors such as client's expectations of improvement and their acceptance of the therapeutic rationale affect the mechanisms through which therapeutic change occurs (Frank, 1982). Moreover, recent evidence suggests that building hope could be a transdiagnostic mechanism of change (Gallagher *et al.,* 2020).

Supporting transitions

Psychosocial transition theory (Tyhurst, 1958) states that change itself invokes disturbances to mood and functioning arising from uncertainty, unfamiliarity, and disorientation. Tyhurst (1958) suggested others can be supported by someone else who can help them define the new situation, and provide what they need to cope in the changed circumstances. Research consistently finds that transitions are a stressful time for dementia carers and carers are often unprepared for changes (De Silva & Curzio, 2009; Ray *et al.*, 2015). Adjusting to change is challenging and results in increased feelings of helplessness, loneliness, loss of control and being undervalued; and associated distress can be alleviated by good communication between clinicians and the carer (Bloomer *et al.,* 2016). Carers can be supported through regular contact, transparent communication, clear new information and empathic support from staff to come to terms with, and cope with change. Involving caregivers at key transitional points can also improve the care provided for people living with dementia (Ray *et al.*, 2015).

Support for C-M-O models

Rationale for separate models

Interventions with different designs have the potential to reduce depression, stress, and physical and emotional overload; in addition to acquiring skills and knowledge about dementia (dos Reiss, 2018). However, different resources and reasoning are required to produce therapeutic outcomes in different contexts. Education by itself will do less than education combined with strategies to improve the psychological wellbeing of dementia carers (dos Reiss, 2018). There are instead, active processes involved in cognitive restructuring which may target carers' beliefs about their responsibilities; beliefs about their own need for support; and, their beliefs about the care recipient's behaviour. Similarly, while cognitive reframing can reduce anxiety, depression and stress; it does not affect carers' coping or sense of burden alone and carers need additional resources to cope with the demands of caring (Vernooiji-Dassen, 2011). Carers should be able to access support for their own mental health as it impacts their experience of caring (McCabe *et al.,* 2015). Many studies achieve significant outcomes in reducing distress from behavioural problems, but it is more difficult to improve depression levels (Lopez, 2007). Carers would likely benefit from evidence-based interventions for depression from therapists with an understanding of dementia.

Some interventions will be relevant to all caregivers, but in addition, a minority might require more intensive psychological support. Evidence suggests everybody would benefit from understanding dementia (Chambers, *et al.,* 2001; Haapala *et al.,* 2019). However, not everybody will be involved in providing practical support and caregiving. Those that are, would benefit from tools and strategies to cope with caring and additional training and financial support. Not everyone will need support with grief or mental health, but more intensive psychological interventions may benefit carers experiencing clinically significant depression or anxiety. Carers may be at higher risk of experiencing mental ill health, but they still may not receive this from secondary mental health services, and delays in accessing support might negatively impact carers and the care delivered. Fewer than 20% of people seeking help for depression and anxiety disorders receive cognitive-behavioural therapy (CBT) (Flynn & Warrens, 2014).

Identifying the right time

Likewise, different C-M-O configurations will be helpful for carers at different points in their journey. For example, providing information and strategies to cope, as soon as possible, would help to maximise the involvement of people with dementia (Orgeta, 2019). It is also likely that all carers would benefit from all models at different time points and that mechanisms could be accessed interchangeably within one intervention. A superordinate organisational concept may be helpful, such as case/care management, which meets the needs of all with timely, responsive and tailor-made interventions (Mantovan, 2010). Moreover, more complex, challenging and multifactorial problems require an equivalent level of intervention; only multicomponent interventions reduce the risk of institutionalisation (Pinquart, 2006).

Modes of delivery

Our findings suggest that these mechanisms can be active across different modes of delivery including online, face to face, over the phone. Most of the evidence for improving understanding and building resources were face to face; whereas, grief therapy and transitional support were also offered over the phone. This fits the work of a previous review focused on effectiveness, which found that psycho-education-skill building group interventions delivered face-to-face better impact on reducing burden than those delivered remotely (Kishita, 2018). This review offers insight into why this might be the case, as carers are learning through adult to adult learning relationships collaborative partnerships with observed modelling from others. Carers may better develop self-efficacy in the presence of others and reinforcement that builds self-esteem and confidence. Moreover, the psychotherapeutic interventions underpinned by Cognitive Behavior Therapy (CBT) models have strong empirical support for treating anxiety and depression and these effects were not affected by the mode of delivery (i.e. face-to-face vs. technology) (Kishita, 2018).

Feedback on models

The models received positive feedback from health care professionals, researchers and those currently caring for an individual with dementia. Psychologists indicated that some interventions could be therapeutic for some carers, but not others. It raises an interesting point about who is expected to gain through psychological interventions for dementia carers: the care recipient or the carer? Psychologists suggested further enriching the models by including relational aspects and dynamics relating to attachment difficulties. However, this depth of understanding was not usually considered in empirical studies. It is likely an important context that should be considered in clinical practice. Several dementia carers fed back positively saying they found the models helpful in themselves, making it more transparent how change may be achieved in therapeutic interventions and helping carers consider what they could do for themselves.

Figure 4

Clinical Recommendations

Clinical Recommendations

- There are specific ingredients of change in evidence based psychological interventions for dementia carers.
- Carers of people living with dementia need access to psychological interventions that are designed to support dementia carers.
- Health services and community organisations could better support carers by developing a package of care for carers with multiple mechanisms.
- There are four models of carer support which are evidenced based and can be accessed interchangeably:
    1. **Reframing experiences and changing beliefs can help carers regulate difficult emotions and improve their mental health.**
    2. **Coping with loss and processing grief reduces anxiety and depression.**
    3. **Responsive contact and information can support transitions, relieving guilt and building positive relationships with services.**
    4. **Improving knowledge and providing caring strategies reduces carer stress.**
- Learning strategies and improving knowledge is more likely to take place in face to face contexts with other individuals present.
- Carers may benefit from targeted support for their mental health, but may not meet criteria for mental health support. Older adult services should consider offering therapeutic intervention to carers at the time they need.
- Carers can still benefit from positive change from psychological interventions delivered over the phone or internet.

Strengths

The methods in this review are in line with the quality standards for realist reviews (Pawson, 2005). We included a wide variety of interventions from studies across the world. We systematically reviewed secondary material to situate a review with a theoretical focus, alongside the existing empirical evidence base. Throughout the process, we have sought external feedback from stakeholders to make sure that the paper is useful to those trying to implement research into practice. We have produced four models to guide service delivery and a suggested framework to consider allocating resources to interventions in practice.

Limitations

The papers included in the review were of mixed quality. As we focused on papers that included information about mechanisms, we have a variety of evidence. In some ways, there was a tension between rigour and relevance as larger RCTs sometimes provided less theoretical or conceptual information, whereas studies with this detail often featured fewer participants. Moreover, mechanisms, are only hypothesised as they are not observable: they are ‘underlying’ and ‘invisible’ (e.g., Bhaskar, 1997; Pawson, 1989). Reduction of mechanisms to the interaction of resources and reasoning may be insufficient to explain change as each level of a system has its own ‘powers and liabilities’, which may cause effects on higher or lower levels of the system. This will likely be the case for interactions occurring at ‘lower’ levels of systems (for example, chemical and electrical interactions that ‘are’ the processes of thought within individual humans) and potentially at very high levels of systems (for example, interactions between political and economic systems) (Emmel *et al.,* 2018). Even where some aspects of an interaction can be observed (e.g., communication between two humans), other levels cannot (e.g., the unconscious drivers of responses within that communication) (Emmel *et al.,* 2018). Moreover, research focused on 'active ingredients' within a package and the 'therapeutic dose' of those ingredients is difficult to determine as it is hard to separate specific techniques from generic therapeutic factors, which consistently predict good outcomes (Charlesworth & Stanton, 2006).

Suggestions for future research

There remains substantial heterogeneity between studies and methodological flaws, meaning that the grade of evidence is very low (Brooks, 2018). Many caregiver intervention studies have been atheoretical, arising from pragmatic or opportunistic evaluations, rather than either social or psychological theory (Charlesworth & Stanton, 2006). Greater attention to theory would facilitate intervention selection, clarify intervention aims and guide the choice of outcome measures (Charlesworth & Stanton 2006; Benbow *et al.,* 2014; Lopez, 2007). Interventions could be developed based on the models outlined above which would provide further scope to develop and evaluate the context-mechanism-outcome configurations in practice.

Conclusion

This realist review offers insight into the mechanisms of change in evidence based psychological interventions for dementia carers. There appear to be different therapeutic mechanisms active in different contexts. The evidence supports four distinct models of carer support: one focused on improving understandings and learning strategies; another on processing loss and grief; a more general model for improving mental health; and, a fourth model focused on additional support at times of transition. These mechanisms can be interchangeable in a wide variety of interventions. This review strengthens the application of psychological theory in practice and provides causal webs that can be recreated in a diverse range of service delivery contexts.

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Chapter 2: What is it like to care for a parent living with dementia from a distance?

I prepared this paper for submission to *Social Science & Medicine*. This journal publishes narrative studies and focuses on “material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and organisation”. This study uses methods widely used in social sciences, to explore an aspect of mental health and make recommendations for policy and clinical practice; therefore, I hope the journal will be interested.

Abstract

Background

Geographical distances are growing between generations. However, we know very little about long distance caregivers. We used narrative inquiry to hear the stories of long distance dementia carers. Through these stories, we can understand their unique emotional, psychological and social needs.

Methods

We recruited 12 people who identified as long distance dementia carers from London and Liverpool via Twitter and local carers groups. Data was collected using the Biographical Narrative Interpretative Method. Participants were asked a single question to share their story and then prompted using individual questions based on their response. Questions explored details of the events that took place and their meaning to carers. Participants provided feedback on their summary stories.

Results

For many, being a carer was a key part of their identity which was often overlooked. Carers described practical challenges of engaging with services and logistical challenges of coordinating care. Many relied on networks and experienced altered dynamics within family systems. Caring involved draining journeys and increased financial pressures. Carers described feeling isolated, frustrated and torn between worlds. Emotional responses were shaped by the distance. Carers described heightened anxiety as they were less able to respond to or acclimatise to stressors. For some, becoming a carer provided an opportunity to connect more and experience closeness.

Conclusions

Stories of long distance carers provide insight into their needs and experiences. With these insights, we can consider tailor interventions to overcome challenges and optimise the chance of experiencing caring as positive.

Background

Dementia carers

There are an estimated 885,000 people in the UK living with dementia, and the prevalence is expected to increase (Wittenberg *et al.,* 2019). Objective seven of the National Dementia Strategy acknowledges that 'family carers are the most important resource available for people with dementia' (Department of Health, 2009). Family carers are also essential to social and healthcare systems, making the largest contribution to the cost of dementia care, equivalent to £11.6 billion (Prince *et al.*, 2014; Giebel *et al.*, 2016; Farre *et al.*, 2016; Michalowsky *et al.*, 2015).

Taking on a caring role for a person with dementia is extremely stressful (Brodaty, 2009; Cassie & Sanders, 2008). Carers can experience high levels of anxiety and depression (Li *et al.*, 2014; Cooper *et al.*, 2008), with many also experiencing anticipatory grief (Farina *et al.,* 2017; Robertson *et al.,* 2020). The NICE quality standards for dementia (NICE, 2010) recommend carers are offered an assessment of emotional, psychological and social needs and appropriate tailored interventions (Quality statement 6). Carers are also entitled to an assessment of their own needs, including the sustainability of the caring role and the wishes and aspirations of the individual outside of the caring role (Department of Health, 2014). Despite policy emphasising the importance of support for carers, existing support is extremely patchy and inconsistent.

Caring for a parent

Not all caring experiences are the same, suggesting we need to learn more about the experience of carers in different contexts (Robertson *et al.,* 2019). Children experience care differently to spouses: typically balancing numerous roles, such as adult child, parent, and employee (Bastawrous *et al.,* 2014); using more informal support (Pinquart & Sörensen, 2011); and tending toward managing care than providing hands-on assistance (Brodaty & Donkin, 2009; Kjällman-Alm *et al.*, 2013; Hwang *et al.*, 2017). For spouses, caring for an individual is often considered a marital duty and involves an extension of existing roles and responsibilities (Conde-Sala *et al.*, 2010). While children may also care out of duty, they are more likely to experience clashes with other roles and responsibilities and often have to put their own life on hold to care for a parent (Kjällman-Alm *et al.*, 2013). Adult children are more likely to experience existential shifts, experiencing feelings of powerlessness, loneliness in their responsibilities, loss and guilt (Høgsnes *et al.*, 2016). The negative perception of adult children is associated with greater caregiver burden, and more negative evaluations of the care recipient's quality of life (Conde-Sala *et al.,* 2010; Robertson *et al.*, 2018, 2019; 2020).

The rise of distance carers

Many individuals move from the region that they grew up in and where their parents reside. Such geographical mobility has a large impact on sociological factors in a community (Bonin, 2008) and trends suggests that distances between generations are expanding: people are increasingly likely to live further away from their parents (Hoff, 2015). However, we know very little about the experiences of people caring from a distance. Long distance caring is usually defined by living more than one hour away from the care recipient (Cagle & Munn, 2012). Research into carers of people with cancer found that long distance carers report more distress than those living within an hour of care recipients (Cagle & Munn, 2012). Caring may be more stressful, as out-of-pocket expenses are higher for long-distance carers (Rainville, Skufca & Mehegan, 2016). Moreover, carers are likely to have moved away for work and face work related stressors. Most carers (40%) care for their parents or parents-in-law and are of working age (Carers UK, 2015). In the last six years, there has been a twelve percent increase in the number of people quitting work to care for older relatives (Carers UK, 2019).

There may also be differences in positive dimensions of caregiving, with specific contributors to resilience for adult children living at a distance. Living at a distance may be protective as cohabitation is associated with fewer opportunities for respite care (O'Rourke & Wenaus, 1998). The opportunity for respite influences subjective burden, coping and resilience (Svanber, Stott & Spector, 2010; Kupferschmidt, 2009); particularly in adult children (Conde-Sala, 2010; Cherry *et al.*, 2013).

The need for research

With geographical distances growing between generations, and the prevalence of dementia increasing, there will be more children caring for their parents from a distance. It is likely that caring for someone living with dementia and access to support is uniquely shaped by the experience of distance. However, we know very little about the experience of distance carers and it is, therefore, important to explore. Hearing the stories of this potentially isolated group can help us understand their unique emotional, psychological and social needs. Information about the needs of long distance carers could inform assessment criteria for carers and provide insight into tailored interventions.

Aims

1. To explore the stories of children that care for their parents living with dementia from a distance using narrative inquiry.
2. To build an understanding of the timeline of events and critical incidents to inform recommendations about what distance carers need, and when this might be helpful.
3. To gain insight into the lived experience of dementia carers. This includes the emotional and psychological processes, along with the meaning they attribute to events.
4. To use these insights to consider interventions to improve psychological and emotional wellbeing when caring from a distance.

Methods

Study Design

I used narrative interviewing and narrative analysis to explore the stories of people caring for their parents from a distance. To inform the methods, I undertook training on a course provided by the National Centre for Research Methods and completed the module on narrative inquiry at the University of Liverpool.

Procedures

I gained ethical approval from the University of Liverpool's committee of research ethics (CORE) in December 2018 (Reference 3852). We[14] recruited 12 people self-identifying as long distance carers for a parent with dementia. Recruitment procedures are outlined in Figure 1. The information sheet is available in Appendix 3, and the information sheet is available in Appendix 4. We identified carers through existing research networks and carers groups, online and in person; in the north of England and in London. I received support and advertising from: Together in Dementia Everyday (TIDE), Service User Reference Forum

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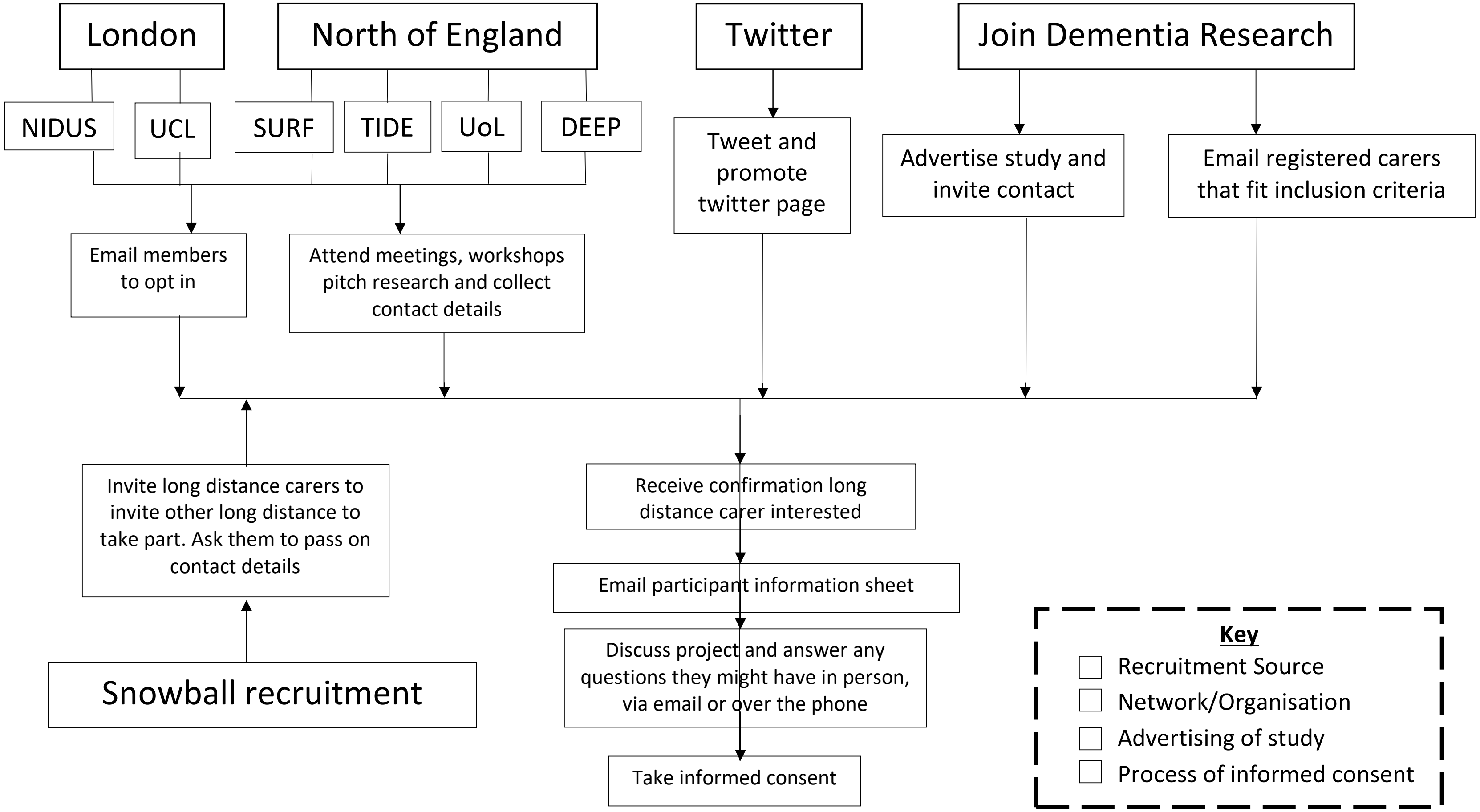
[14] I had one supervisor attached to the University of Liverpool (UoL) and one at University College London (UCL) who helped with recruitment.

(SURF) and Dementia Engagement and Empowerment project (DEEP). The study was also aligned with NIDUS, Alzheimer's Society Centre of Excellence for independence at home based at University College London (UCL). I used social media to set up and run a twitter page for the study and registered the project with Join Dementia Research (an online research participation matching service) (see Appendix 5 for flyer). Through these initial sources, I sought further participants through a process of snowball recruitment; whereby respondents recruit others themselves, starting a process analogous to a snowball rolling down a hill (Wasserman *et al.*, 2005). Snowball sampling overcomes many of the recruitment challenges associated with inviting difficult-to-reach communities to join health-care research (Sadler *et al.,* 2010)

Figure 5

Recruitment procedures



Narrative Inquiry

Narrative research begins with the premise that we tell stories about our lives (Marks & Yardley, 2014). Ricoeur (1980) argued that since we live in a temporal world, it is necessary to make sense of life in narrative form, imposing a sense of order and meaning. Research participants will inevitably provide accounts that take on a story structure (Hiles & Cermak, 2007). Narrative inquiry has roots in social constructionism, whilst also including a more inclusive view that incorporates *both* a rich description of the socio-cultural environment *and* the participatory and creative inner world of lived experience. In this respect, narrative data always carries a 'double signature', i.e., social constructionist and phenomenological (Hiles & Cermak, 2007). The focal point of narrative theory is narrative emplotment (Frye, 1957; Mattingly, 1994); an active and temporal process of constructing a plot. Storytellers depict how characters, events, interactions, and outcomes are related (Holloway & Freshwater, 2007; Kierans, 2005; Mattingly, 2007; Lapum, 2010). Narrative analysis provides a vantage point that allows other to analyse how the storyteller constructs meaning (Keirans, 2005; Lapum, 2010).

Interview Procedure

Narrative interviews are a participative activity in which a person can author (and re-author) their lived experience, their understandings of reality, and their place in that reality (Mishler, 1986a, 1999; Hiles & Cermak, 2007). Individual interviews allow an in-depth exploration of the factors that underpin participants' stories: their values, past experiences, circumstances, reasoning, feelings opinions and beliefs (Ritche *et al.*, 2014).

I used a topic guide split into two parts: 1) a set of demographic questions, to contextualise the participants; and, 2) a narrative interview. I first recorded the age, sex, ethnicity, and location of the parent living with dementia. I then conducted a narrative interview using the format suggested by Wengraf (2013), called the Biographical Narrative Interpretative Method (BNIM)[15]. BNIM starts with a single question aimed at inducing personal narrative (SQUIN) and follow up question prompts called particular incident narratives (PINs). The follow up questions are unique to the individual and request further information about answers given to the first

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[15] Biographical Interpretive method was first developed by German sociologists to produce accounts of the lives of Holocaust survivors and Nazi soldiers. The main theoretical principle in the method is that there is a whole story which is a sum of its parts (individual interviews). The task is to elicit the meaning frame of that experience.

question (Wengraf, 2013) (see Appendix 6 for SQUIN and example PIN sequences). Interviews lasted between 60-120 minutes and were recorded on an encrypted IPad before they were transcribed and anonymised. After each interview, I completed field notes reflecting on my emotional responses and possible meanings communicated within the interview (Nicholson *et al.,* 2012). I transcribed six interviews and outsourced the transcription of the other six to an approved transcriber within the university.

Analysis

I undertook analysis in two phases: 1) analysis of narrative; 2) narrative analysis (Polkinghorne, 1995). In stage one, narratives are analysed to produce categories; the meaning-making through story construction and interpretation, first happens between the narrator (person who had the experience) and the listener (researcher). These categories are analysed to produce a story (Polkinghorne, 1995, p. 6; Savin-Baden & Van Niekerk, 2007). In stage two, this process is re- enacted on a different level (one that might be understood to be less personal in nature); the researcher assumes the role of narrator whilst the listener will be the consumer/reader of the published research (Savin-Baden & Van Niekerk, 2007).

My analysis was informed by both structural and thematic traditions of narrative inquiry. Thematic narrative analysis involves identifying common thematic elements across the events reported and the action taken, whilst keeping the story intact for interpretative purposes (Reissman, 2008). Structural narrative analysis focuses on providing a timeline or sequence of events, generating an insight beyond the content of what is said (Reissman, 2008; Labov, 1967, 1982).

Stage one: Analysis of narratives

First, I inductively generated a set of themes from each narrative and used NVivo to organise stories within stories. Next, I produced a summary story of each narrative interview; synthesising the key components of a story in the order it was told and highlighting key themes at the end. I adapted Braun & Clarke's (2006) guidelines for thematic analysis proceeding through the process of: familiarisation, coding, creating themes, reviewing themes, and interpreting themes. Analysis is often undertaken in narrative inquiry by examining the epiphanies[16] and metaphors inherent in the stories (Savin-Baden & Van Niekerk, 2007). All epiphanies are viewed as transformational and significantly change people's lives. I used metaphors at an early stage as a way of formulating the data and seeing what is being said that is not obvious (Savin-Baden & Van Niekerk, 2007). Consequently, stories are created and re-created in the interview and then negotiated through the exchange of summary stories. When more than 10 interviews are undertaken, starting with an analysis of narratives and producing summary stories is a way to write a coherent analysis that does not fragment individual voices (Savin-Baden & Niekerk, 2007). Each summary story was sent back to participants as a letter. Writing letters in first person allows the differentiation of one's own interpretations and personal stances (Savin-Baden & Niekerk, 2007).

Stage two: Narrative Analysis

After completing all interviews, I undertook a narrative analysis, which involved moving from individual data gathered to the construction of a meta-narrative; integrating data from each story (Polkinghorne, 1995). This involved looking at what is distinctive about each story and what is missing (Kramp, 2004). At this point, I employed techniques from structural narrative analysis to focus on complicating actions (events which occur, the plot, crises and turning points) and evaluations (comments on the meaning of events, "the soul" of the narrative) (Reissman, 2008). I mapped aspects of each summary story into columns of actions, participant's evaluations, and my subsequent interpretations. I then created a meta-narrative; editing and reshaping what was told, and turning it into a hybrid story, a 'false document' (Reissman, 2008).

The results section will focus on presenting work from stage two of the process: the meta-narrative. I will begin by highlighting key themes and then I will outline a timeline of events. Finally, I will tell the story of long distance carers, providing quotations to support

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[16] The notion of epiphany has been developed in various ways but in interpretive research Denzin has proposed four different types of epiphany:

1. Cumulative epiphany: an event that is symbolic of profound changes that may have been going on for a number of years or be a turning point in one's life caused by the accumulation of numerous related experiences.
2. Illuminative epiphany: a point in time or particular experience that reveals insights; or an event that raises issues that are problematic.
3. Major epiphany: such as an event or experience that is so traumatic or challenging that its meanings or consequences are immediate.
4. Relived epiphany: an event or issue that has to be relived in order to be understood.

interpretations.

Ensuring Rigour

I used Lincoln & Guba's (1985) trustworthiness criteria and techniques to refine stories, ensure rigour and quality, and prevent bias (Loh, 2013). Every summary story was sent to the participant to be 'member –checked', offering an opportunity to provide further context and an alternative interpretation (Patton, 2002, p. 561). A small number of participants clarified details surrounding specific incidents described in their story, where it had not been clear to me in the original interview. Every participant thanked me for their story, and most fed back that they found the process insightful, and therapeutic to take part. This informed my reflections on the therapeutic potential of stories. A smaller number of participants extended their story, and themes from these extensions were integrated in the meta-narrative. For example, having further challenges with services that they wanted to make sure were described. I kept records of the conversations with participants and used my reflections on this process to inform the discussion within this thesis. I also sought *peer validation* from my supervisors as scholars familiar with the interview themes and the context of caring (Kvale, 2007). I had planned to present my work in a number of forums, facilitating a process of *audience validation* from primary intended users and readers (Patton, 2002). This included the FPOP 2020 conference, the Alzheimer's Society 2020 conference, a public lecture in a seminar series on ageing, and the University of Liverpool's annual conference. These events were postponed or cancelled due to COVID-19 and I have created opportunities for virtual dissemination where possible. For example, I produced a blog based on these findings for a virtual platform, *Mobilise*, supporting carers online (See Appendix 7).

Reflexivity

To further ensure rigour, I have held in mind how my own positioning shaped the process and I will reflect on this in the discussion. Here, I will outline relevant aspects of my identity to support the reader's interpretation of my analysis. I have experienced a loved one developing dementia, completed a previous PhD on carer experiences, and worked as a trainee psychologist in older people's services. Through reflective introspection and discussion with my supervisors, I considered how this might shape the process. Experiences are infused with meaning which are beneath and around what we are immediately aware of, and are communicated through the feelings engendered when encountering another (Caper, 1988;

Nicholson *et al.,* 2012). I kept a log of my own feelings and discussed these with my supervisors to aid analysis. I also considered how aspects of my identity might influence how participants related to me. I was mindful of whether I disclosed aspects of my identity, and if I did, when and how so. As I recruited participants from twitter, I interviewed three people that I knew and had encountered through professional spheres. I also considered how this connection and our familiarity with one another might shape the process.

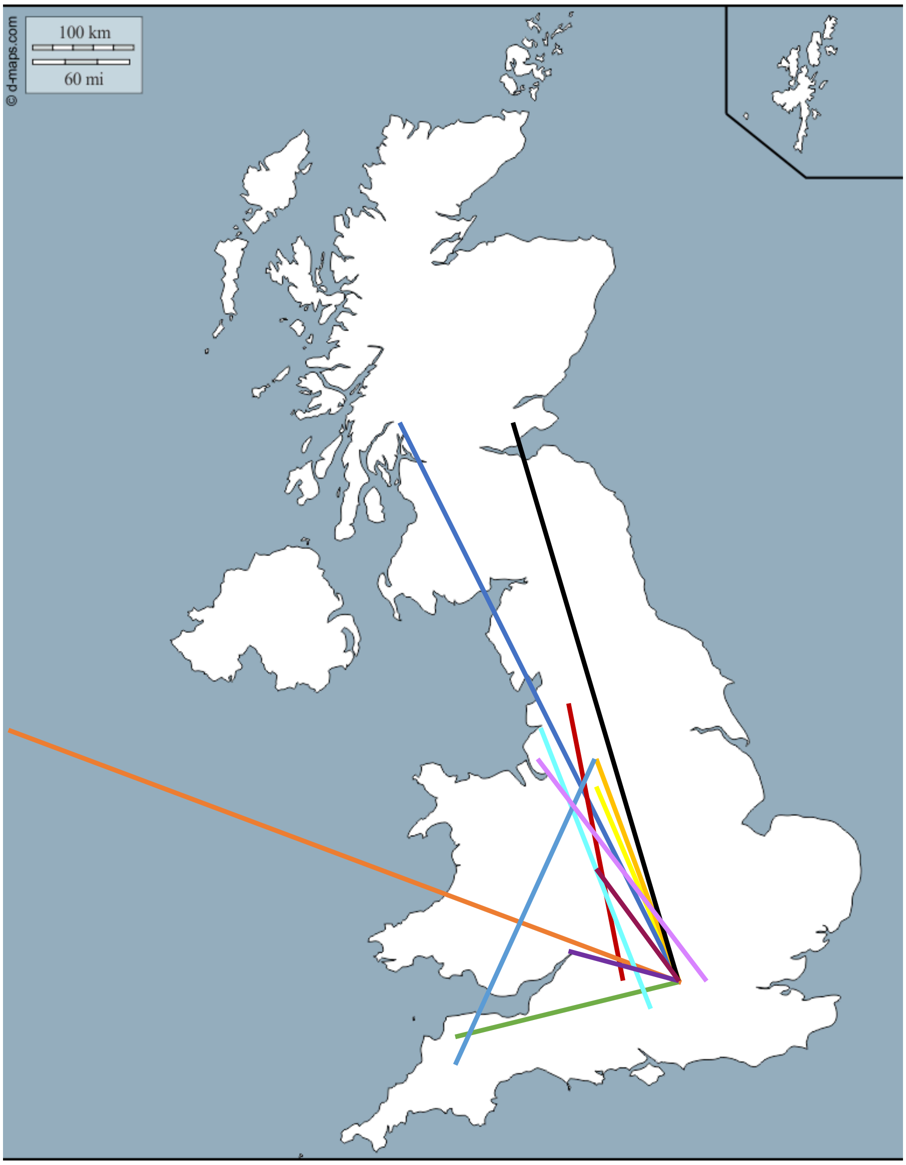
Results

Participant Demographics

I recruited twelve participants from various sources: Twitter (*n* = 4), Join Dementia Research (*n* = 2), TIDE (*n* = 1) and UCL networks (*n* = 5). Nine were women and three were men. The mean age of participants was 52, with the youngest being 30 and the eldest 67. Nine participants were White British, two were Mixed Race and one was South Asian. Eleven were in employment, representing: two clinical psychologists, one doctor, a clinical academic, an academic researcher, a social worker, a guitar teacher, a journalist, an author and a marketing manager. Nine participants were recruited within an hour of London and three participants were recruited within an hour of Liverpool. Figure 2 shows the range of locations that participants lived and their respective journey to their parents. Participants were at different stages in their story from a recent diagnosis of dementia to their relative's death. Two participants had parents that had died within the last two years. Three participants experienced the death of their parent during this process. These participants wished to remain part of the project and opted to see their summary stories to provide feedback.

Figure 6

Distances represented on Map



Feedback from participants

All participants were sent copies of their summary stories after agreeing to receive them and provide optional feedback. Ten out of twelve opted to provide feedback. Some small details were changed to more accurately reflect the detail of events for two participants. Most participants commented on the emotions that were evoked through the experience and expressed a gratitude for the opportunity to take part.

The story of long distance dementia carers

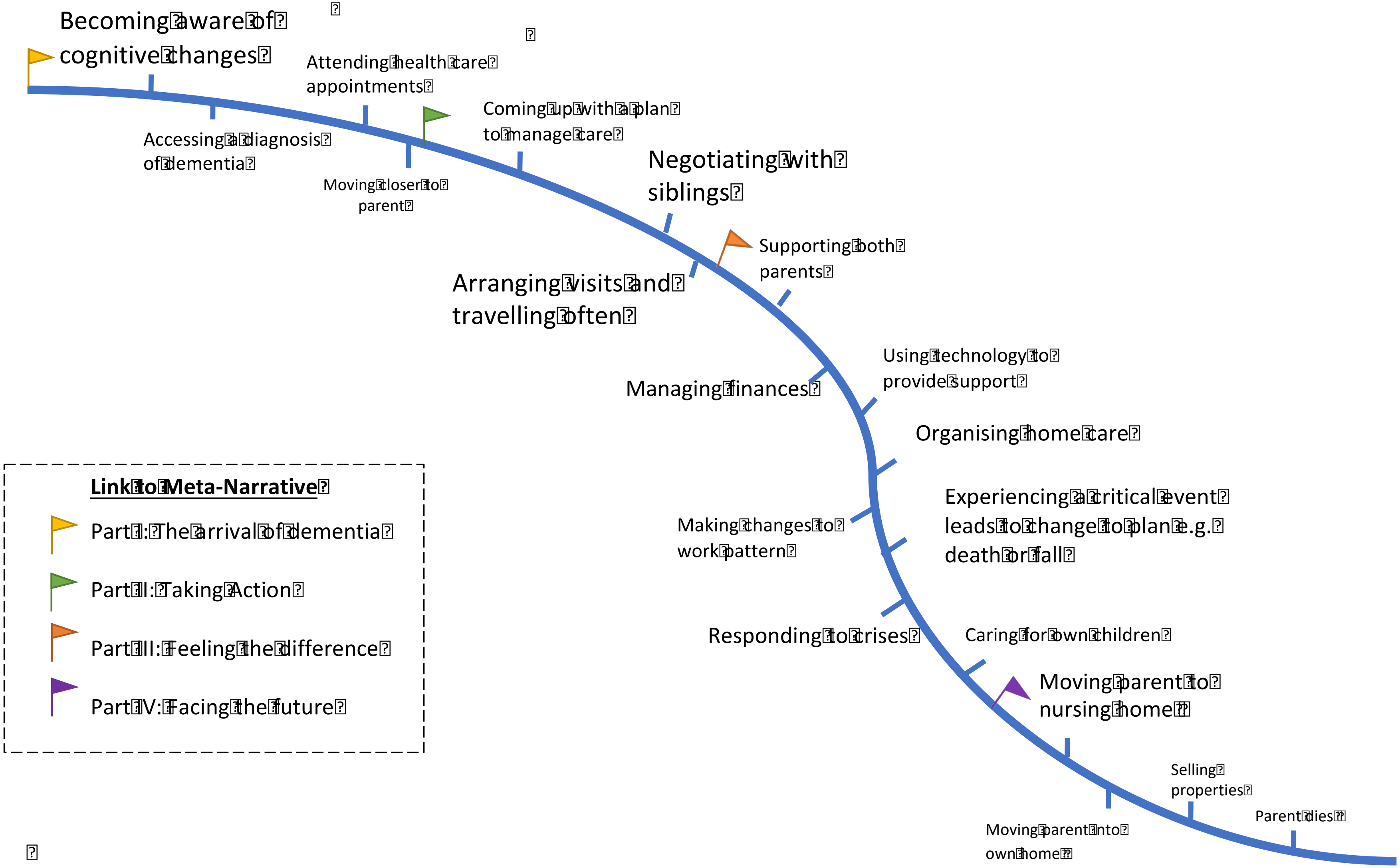
The experience of long distance carers will be shared in three ways: 1) highlighting key themes, 2) outlining a timeline of action and events, 3) the telling of a meta-narrative. The outputs were derived in stage two of the analysis: narrative analysis. Stage one informed the themes, timeline and meta-narrative. The process that facilitated the transition from stage one to stage two is a process of narrative mapping (See Appendix 8 for an excerpt). Themes were derived from participant's evaluations and my interpretations, and the timeline was a synthesis of the actions and events described. Key themes identified across stories are presented in Table 1 and provide insight into landscapes of meaning. An approximate timeline of key actions and events is presented in Figure 3 and provide insight into landscapes of action. Here, the size of event correlates with number of mentions.

Table 3
Overview of themes

Themes	Subthemes from stories	Transcripts referenced
Emotional Experiences	Shock	1,3,10
	Aloneness	1,3,4,6,8,9,10,11,12
	Stressful dilemmas	1,2,3,6,8,9,10,11,12
	Activates attachment experiences	1,2,3,6,7,8,9,12
	Uncertainty	1,2,5,6,7,10,11,12
	Grief	1,2,4,5,6,7,8,9,10,11,12
	Fearing developing dementia in future	4,9,11
	Increased suspicion of services	4,8,11,12
	Amplified emotional responses	3,5,6,7,8,9,10,11,12
	Triggers past traumas	6,7
	Burnout	9,12
	Feeling suicidal	12
Logistical Challenges	Juggling work	1,2,3,5,6,8,9,10,11,12
	Distance differently demanding	1,2,3,4,5,6,8,9,10,11,12
	Managing relationships	1,2,5,6,9,12
	Other caring commitments	1,2,3,5,9,12
	Inadequate support from services	1,2,4,5,8,10,11,12
	Needs of ethnic minorities not met	8,12
	Increased isolation	3,4,5,6,8,9,11
	More risk	3,4,6,8,11
	Financial implications	3,4,6,8,9,10,11,12
	Journey	4,5,6,8,9,11,12
Matters of Identity	Dual professional/personal identity	1,2,3,5,6,9
	Holding many roles and responsibilities	1,2,3,4,8,9,10,11,12
	Being a parent and child	1,3,4,5,6,8,9,10,12
	Not being recognised/feeling invisible	3,4.5,6,8,11,12
	Attached to role	8,9,12
	Relational roles changed	2,3,5,6,8,9,10,12
Protective Aspects	Acceptance	1,3,9,10
	Finding meaning and purpose	1,3,4,8,9,10
	Partner support	2,10
	Connecting through caring	1,2,3,5,9
	Compartmentalising	5,6,10
	Channeling experience to do good	8,9,12

Figure 7

Timeline of events



I will now present the meta-narrative, telling the story of long distance carers in four parts.

Part I: The arrival of dementia

Becoming aware of cognitive changes

Most carers began their story talking about changes they observed in their parent's behaviour and presentation, before they received a diagnosis. Often carers observed these changes remotely through long distance conversations, or they relied on their parent to report incidents to them. These changes included their parents becoming repetitive, getting 'muddled up' in conversations, acting out of character, withdrawing from activities, seeming depressed, and becoming suspicious of family members. For some, these changes were most memorable if they presented potential risks:

> *She would take a taxi into town and then not have any money, and then not be able to remember her PIN to get anything out. Erm, she would lock herself in or out of the house.*
>
> *Daughter 06*

> *He was driving to the supermarket, very familiar crossroads at traffic lights, he told me "I got to the traffic lights, the lights turned green and I hadn't a clue where I was."*
>
> *Daughter 07*

Three carers discussed finding out later that their parent had been a victim of financial abuse and several others talked about money unaccounted for.

> *At that point, I didn't have an online account or anything… Unbeknown to me, she was sending a lot to India, helping charities in the village and praying for herself. All part of dementia.*
>
> *Daughter, 12*

Some carers reported not knowing whether these changes warranted concern, but said with hindsight they evidenced the onset of dementia.

> *You couldn't really convince him it was a bit of a weird thing to do. In hindsight, you are like that is probably "something".*
>
> *Daughter 02*

Some carers reflected that their parents masked their difficulties over the phone but conveyed a developing vulnerability that prompted carers becoming more involved in their parent’s lives. During this time, many carers talked about naturally and intuitively stepping in to help their parents.

> *She stopped doing things like sending her grandchildren birthday cards... So, I sent them for her.*
>
> *Daughter 09*

In this way, there was no clear “moment” children became carers, as many gradually took on more responsibilities as their role evolved with the progression of dementia.

Finding out about dementia

Approximately half of participants played a key role in facilitating a diagnosis of dementia. Several attended appointments, and provided collateral information to support the diagnostic process:

> *I said to her, maybe her memory wasn’t as good as she thought and would she like to go to a memory clinic, and she said no. And then about 6 months later she agreed to go…*
>
> *Daughter 09*
>
> *Mum was diagnosed… following me speaking to the GP saying hold on a minute, something is not quite right with mum.*
>
> *Daughter 12*

Of those that were involved in the diagnostic process, some found support from the memory service helpful. Others struggled to access post-diagnostic support from a distance. Health care professionals were more likely to describe being involved in the diagnostic process. One participant described that she felt it was her responsibility to notice the onset of dementia and intervene:

> *I told her I would tell her [when she got dementia]. And maybe that is not fair, maybe I should not have said that in the first place…I just thought I would know if she gets it… not ever thinking that that would happen… you don’t realise when it’s your family.*
>
> *Daughter 05*

The diagnostic process presented issues for some carers, which further complicated issues they faced at a distance. For example, a parent declining to know the outcome of the assessment:

> *I went to the memory clinic and they come and do the assessment… and my Mum didn't want to know she had dementia… so we are in this bizarre situation where she… we don't say she's got dementia.*
>
> *Son 06*

This made it difficult for a carer to discuss plans about the future and gain agreement for additional care at home. When their parent became more vulnerable, this placed more pressure on the carer, who was less able to respond at a distance. Others faced similar difficulties when their parent did not accept the diagnosis:

> *My mother wouldn't accept that as a diagnosis. "Nothing wrong with me, stop fussing."*
>
> *Daughter 10*

More than a third of carers were not involved in the diagnostic process, and could not identify when the diagnosis took place. These carers missed out on opportunities to receive support or learn about dementia, perhaps increasing their sense of distance or disconnection in the caring relationship:

> *I could see he [GP] had got possible dementia on his screen, and I was terrified that she [mum] was going to see that and think that I had told him that... So I felt so, erm stressed by that whole experience.*
>
> *Daughter 08*
>
> *I have honestly no idea when she got diagnosed.*
>
> *Daughter 11*

Being less likely to receive support with understanding dementia at a distance, carers struggled to make sense of the observed changes, which left them feeling uncomfortable, unloved and unsafe:

> *I would feel quite frightened with her to be honest… I would catch her looking at me in a very nasty, antagonistic, malevolent way… I would think, what have I done, why is she looking at me like she wants me to die, and now I know that was because she didn't know who I was… I thought I've got to be careful because she might do something horrible to me.*
>
> *Daughter 08*

Responding to dementia

For many, a diagnosis of dementia brought with it shock and anxiety. Carers were more likely to receive the news in a remote context, without support. For one carer, the news of a diagnosis prompted them to re-evaluate their current positioning and relationship:

> *The most emotional aspect was that diagnosis … I remember like that is like a flashbulb memory… I was crying… the physical sensation was I can't breathe… what happened when I read that email is I suddenly had that recognition that my father is human, my father's going to die, this is a horrible disease… I decided that if I was going to get over the hatred and move beyond the hatred, towards him, and build a real relationship with him, I needed to be there… I had a lot of panic attacks leading up to my move, erm, but I did it, and I don't regret it.*
>
> *Daughter 03*

Many talked about trying to manage their anxiety by having control:

> *When it first happened, I almost thought the absolute worst… how on earth would we do this? That was partly because of the distance and I sort of set of on this kind of trail of trying not to allow any problems to happen and so trying to be completely proactive and completely pre-emptive… it was too much a sense of trying to control everything.*
>
> *Daughter 05*
>
> *You love this person very much, you want to… I quite happily, easily can micromanage situations and I suppose I can be a bit of a control freak… I want to make sure everything's ok… there's a huge amount of risk there, and I think probably for myself too much risk.*
>
> *Son 06*

Many found technology, like skype and facetime enabled them to maintain contact, keep an eye and seek reassurance. A few carers put cameras in place to monitor the situation and struggled with boundaries:

> *I remember in the early stages you need to be there… I was getting up in the middle of the night looking at my camera. I was glued to my camera but now I am not.*
>
> *Daughter 12*
>
> *I saw this [camera] in Curry's, and got it and stuck it in… I should've asked the carers if they were alright with this, but to be honest, I didn't care.*
>
> *Son 04*

Finding a workable routine

Most carers established a workable routine, usually this involved daily phone calls and visiting on a weekly, fortnightly or monthly basis. Every carer recognised that they were a limited resource and they struggled to determine when to use that resource, how to best use it and which events warranted overcoming the distance:

> *After a while it's a bit like, (pause) do you know the story about Peter and the wolf?… it was like that… after a while I was thinking "ok measure yourself. Talk to the doctor, find out from the hospital, talk to the care agency, can you talk to the social worker?". Trying not to be too knee-jerk, because at first, I was very knee-jerk, and I was up and down.*
>
> *Daughter 10*

> *The appointments in particular is one of the real challenges I think for me... It is just me trying to work out what is important and what is not.*
>
> *Daughter 05*

Part II: Taking action

Building networks

Negotiating with family

Every carer mentioned their family network in providing support. Some people were caring for both parents. This involved coordinating care and coming to a workable arrangement for everybody. Carers discussed how proximity to their parent was not the determining factor for involvement. Other factors included: availability, financial position, other caring demands and motivation to care. Negotiating these factors put pressure on relationships with rich histories. Many had to build a better relationship to provide care and for some was a long arduous process:

> *We [brother and I] don't trust each other (laughing)… maybe that's too harsh. But we, we don't get on particularly well… When I came to London at seventeen… he had to grow up very quickly… he has a bit different relationship… so we do fall out you know.*
>
> *Son 06*

Gender seemed relevant in influencing who took up what roles and when:

> *Yeah, my brother is not very supportive… it's me and my sister, classic – its fallen on the girls who are doing a lot.*
>
> *Daughter 02*

> *My brother's kind of helpful but not very.*
>
> *Daughter 01*

Negotiation was more likely to take place over virtual platforms because of the distance. Carers discussed aggravation experienced in “family WhatsApp groups” arising from perceived pressure and passive aggressive messaging. At its best, sibling relationships evolved over time, improved through assertive communication and a shared purpose:

> *Maybe her dementia, partly my dad’s dementia, partly brought her grandchildren and children more and more together because we all had a mission to make sure that they were alright.*
>
> *Daughter 09*
>
> *Saying to my brother, "come on brother, can you help here?" or "I really can't get there, you've really gotta get your finger out because I'm doing X and Y."*
>
> *Daughter 01*

At its worst, negotiating roles impacted relationships and caused irreparable damage.

> *I have to park it because that frustration when it consumes you, you just want to hit someone. It’s like how dare you, my mum has sacrificed so much for so many people and where are you all? In her hour of need.*
>
> *Daughter 12*
>
> *It puts pressure on the dynamic between us as siblings about who is doing what. Who wants to step up to the plate? Who wants to step away? Who feels resentful that someone is doing this or not doing that?... I know that caused a powerful rupture in family relationships.*
>
> *Daughter 10*

Within stories, there was a recognition that the size of your family shaped your resource:

> *It’s difficult in a small family… I've got one brother and erm, most of the older rellies are dead, my brother's gay, I'm gay, so we have no children…*
>
> *Son 06*
>
> *I think that is the other thing that I realise how lucky I am to have brothers and sisters…It makes all of the difference to have a wider network.*
>
> *Daughter 09*

Organising care at home

Carers also talked about other formal and informal networks that could provide care at home.

> *I am really lucky with is she has got a close friend who is a walking encyclopedia on dementia… So, mum has got support on a day to day basis which is why she is still living independently*
>
> *Daughter 05*

One challenge to building this network was weighing up the costs and benefits, and gaining agreement from their parent to accept involvement:

> *You want her… to be as independent for as long as possible… you take those things away, you can't really introduce them again… my Mum made that argument.*
>
> *Son 06*

Some relied upon agency care. For many, this service was not satisfactory:

> *We're on our second care agency now because the first one we were on went into administration… the standard of carers is very variable.*
>
> *Daughter 10*

Anger, sometimes directed at health and social care professionals was perhaps heightened by carer's own sense of frustration at their distance from and lack of power over the situation:

> *The carers' managers are pretty damn stupid, went about with no brain power.*
>
> *Son 04*

Several overcame issues with agencies by flexibly managing boundaries:

> *I mean honestly, we break the rules... I text her direct, she texts me… the agency don't know this, she would get into trouble… but we've come to a working arrangement like that because it works for us both.*
>
> *Daughter 10*

Trusting a care worker was vital, some carers recruited the person they felt they could trust the most into independent working. Other carers started their search for support independently and became recruiters, employers and managers. These carers described not knowing their responsibilities or legal duties. Finding trusted paid care workers was even harder for family carers who wanted input from members of the same minority community. Care workers almost became a proxy for family members, but this usually meant overstepping professional boundaries and breaking rules. The relationship between care workers and family is likely intensified because of the distance.

Getting support from services

Carers also talked about seeking support from health and social services. Carers described patchy service provision:

> *I had only heard of admiral nurses this week... there are actually none anywhere near where they live… I told them they should get involved in the local hospice… my mum tried, and it was like it's just for people with much more advanced illness.*
>
> *Daughter 02*

Many perceived the offer as inadequate, leaving carers fending for themselves, attempting to provide care without adequate training:

> *The Welfare system, let us down… we don't need them to pay for it… there are budgetary restrictions… I bought the damned hoist myself … I'm guessing that they were afraid to give advice… I think they were afraid of the liability that they would incur by giving advice, woah, it's a problem.*
>
> *Son 04*

Others faced difficulties in accessing care and acknowledged the challenges of accessing support through a GP, from a distance:

> *You speak to one GP and then because different GP models aren't the same you don't speak to the same person… you have to fully explain the context again and they don't have time.*
>
> *Daughter 07*

Others remarked on the division between services as confusing and unhelpful:

> *There is no handbook to say by the way the agency staff won't cut your mums fingernails so you need to sort that out another way. You turn up and they are great big long fingernails… these small things are dignity actually… I also had no idea of this separation between NHS and social care. I had no idea. No idea. You don't know. You kind of assume it is together.*
>
> *Daughter 11*

Carers from a minority group discussed their frustrations at not being accommodated by services:

> *I said it has got to be female and can I have a translator because whilst mum speaks a bit of English it is not great it is not ideal… We got the appointment… and were met by two men… I couldn't believe it.*
>
> *Daughter 12*

Many people spoke of matters that they wished they had known sooner:

> *Eventually we learnt that we should've been getting carer's allowance… nobody in the system actually said.*
>
> *Son 04*

Struggling and feeling marginalised

Many of the issues carers faced with services were exacerbated by the distance. For example, the lack of continuity of care which some imagined were worsened by austerity:

> *Liaising with the Social Services… and with the GP… the lack of continuity is quite difficult as a carer long distance to be honest… I do absolutely accept that erm budgets are strapped.*
>
> *Daughter, 10*

Being at a distance appeared to enhance a sense of physical and psychological fragmentation. Many carers reflected on the way the distance limited the amount of support they felt entitled to as a carer:

> *There is almost an exclusivity at carer networks. There can be a status attached to that level of commitment. I mean those people have made a huge sacrifice… it is then really hard to entertain that there may have been another way of doing things*
>
> *Daughter 05*

For many, this issue arrived in the beginning and got worse over time:

> *We have zero support now; we are on our own.*
>
> *Daughter 11*

Everything changing

Responding to crises

Many carers recounted critical events after which arrangements became unworkable. For some carers, this was the death of the other parent. When this happened, carers usually had to act into the caring role of the spouse, whilst experiencing grief. These carers were often disadvantaged as they were not socialised to the role or familiar with their parent's needs. Others, described how a fall altered their parent's abilities to cope independently:

> *And then my mum had a fall… that was just a nightmare. An absolute nightmare… what I still struggle to get my head around is that from being relatively, relatively independent with support. Within a day of that fall she was just massively confused, became doubly incontinent and incredibly dependent.*
>
> *Daughter 01*

When loved ones were in hospital, carers recalled doubting the capacity of hospital staff to respond to, and meet the needs of someone living with dementia. Some booked into hotels during this time, incurring extra financial strain. Sometimes, when care needs could not be managed, the person living with dementia had to move into a care home. When carers were not present at a best interest meeting, they did not fully understand those decisions and became suspicious with services.

> *They were far too keen to get her into a nursing home, far too keen and she was so determined never, ever to go into a nursing home.*
>
> *Son 04*

Transitioning to a nursing home was often considered a last resort, a feared outcome and was experienced as a difficult transition.

Learning to sit with uncertainty

Carers described experiencing limited control which could be uncomfortable. This made it more difficult to make decisions about care:

> *I felt like if I knew that this was going to be 6 months or something then I would take 6 months off work and I would just be there. But I don't know this could be years… and it was, years and years and years.*
>
> *Daughter 09*

Many carers tried to ascertain the right time to make decisions such as trying to implement more care support at home, or moving a parent to a care home. Even where carers were informed about dementia, the nature of the illness meant that people could not predict timings:

> *It is just so unpredictable what her needs are and how the dementia is going to manifest and also that academic knowledge that you think you have isn't actually necessarily what is going to happen to you and your family.*
>
> *Daughter 05*

Managing the impact on life

Juggling work

Most carers talked about how caring impacted their work. Those with full time jobs were spending time travelling outside of working hours, feeling tired, stretched and "knackered" all the time:

> *It is quite a long drive from here it takes about four and a half hours… I do work full time so I have got to then get up and drive home for four hours after having had no sleep so you know it can be a strain.*
>
> *Daughter 11*

Several carers spoke about managing the strain by reducing their working hours. One carer gave up their job completely, following what they described as a "breakdown" they attributed to burnout. For those that received it, support from employers was greatly valued.

Two carers were working freelance, which had its own unique costs and benefits. These carers could work flexibly and remotely and control their own time. However, it also meant they had no provision for paid leave. Carers that worked freelance suffered financially and experienced different strains:

> *I went freelance as a writer, so I had kind of more flexible time… that's ok in theory, but what I hadn't realised of course is that when you are freelance, you have no support system and you have no safety net… so it's very high pressure and very stressful.*
>
> *Daughter 08*

Tiring from travel

Over time, carers generally increased the amount of time they were visiting their parents. For many, the journey itself was worrying, exhausting and potentially risky:

> *It was snowing, I remember… scary, my eyes were closing once… as you get further North, the distance between the service areas gets bigger and bigger and eventually, there were no service areas, full stop.*
>
> *Son 10*

> *I had to go in an emergency at night… there is always that stress of thinking whether I will get there before she dies, erm [chokes up], there is always a danger to me that I might put myself in danger, so I'm always having to balance the impetus to get there with the necessity to look after my own physical wellbeing.*
>
> *Daughter 08*

Another demand of frequent travel was the cognitive load incurred by organising logistics and planning travel:

> *It is hard. And I got tireder and I would do ridiculous things. I remember one airport they said to me "right airline, right time, wrong airport"... You just sort of begin to lose the plot slightly as to what you are actually doing and I think it was hard.*
>
> *Daughter 09*

Experiencing financial ramifications

Almost every carer discussed the costs incurred by long distance caring. To avoid the demand of driving and minimise time travelling, carers often took trains and planes which were expensive and required advanced planning.

> *I felt torn, I arranged to go, I bought tickets two months in advance I mean the amount of money that we gave to EasyJet… it is stunning... I constantly felt torn I should be there more, I should do more.*
>
> *Daughter 09*

The cost also limited the frequency of visits:

> *I can't just jump on a train, unless I want to pay a hundred and fifty quid and I've got five hours to get down there, I can't do that, you know.*
>
> *Son 06*

The combined cost of travel and reduced working hours left several carers in dire straits:

> *I'm earning nothing now, I'm a freelance person who lives hand to mouth… this has had a massive impact on my life, in every respect. Mentally, emotionally, psychologically, financially, in terms of pension… it has been huge.*
>
> *Daughter 08*

Caring affecting relationships

Many talked about how caring impacted their romantic relationships. Partners' support varied, some felt well supported, but others did not:

> *Don’t get me wrong he [husband] is great but he just can’t handle it and throws it back in my face… he sees me putting my mum first.*
>
> *Daughter 12*

All parents talked about the tension in providing for their children at the same time:

> *And I was crying there all of the time… my husband didn’t really get it either he said I was neglecting our daughter so yeah just everything... I had the burnout melt down.*
>
> *Daughter 12*

> *I think what I remember of that time is just being really busy at work… I have got three kids, so you know just juggling all of that. Just being knackered all of the time.*
>
> *Daughter 01*

Surviving the stress

Carers talked about how managing the impact on their lives was incredibly stressful. This stress was shaped by the distance. Carers felt powerless:

> *I think it is very stressful being far away in that feeling like something is going wrong you just have this really strong urge to just go and to be there.*
>
> *Daughter 02*

While carers were removed from the situation, for some it felt constant:

> *When I started to think about it, it is incredibly stressful all this… it bubbles along in the back of your mind all the time, no matter what you're doing. Is Mum ok?*
>
> *Daughter 10*

> *It feels very tense…. for about ten years I always had my phone with me and on 24 hours a day waiting for it to go off and it did… you are always in the wrong place at the wrong time.*
>
> *Daughter 09*

A thread across all stories was the sense that there was no limit to what can be done, making it very difficult to ascertain when you had done enough:

> *It's an unfillable pot, isn't it, really?... you can just throw as much into it as you can really, erm, while try and maintain your own life.*
>
> *Son 06*

Part III: Feeling the difference

Experience of distance

Feeling protected

Carers described aspects of being at a distance that made their experience easier. Some discussed being able to compartmentalise their experience, enjoy their lives and get some respite from caring:

> *That's the challenge I suppose is distance, erm, but I suppose it also gives us some, er, respite in a way… you can't help but have a sense of relief that when you come back… you can sort of put it sort of behind you.*
>
> *Son 06*

> *There are benefits from being at long distance because it means that I can, selfishly, although she's buzzing along in the back of my head most of the time… I can have a life… as long as I know she's safe.*
>
> *Daughter 10*

Missing out on connection

Whilst being at a distance meant that carers were less likely to be involved, this was not always experienced positively. Many longed to be closer and grieved for missed opportunities which occupied imagined, alternative realities:

> *In the fantasy… I would see her regularly and it would be easy to see her for a cup of tea or go to the pictures or go to a group and then take her back home… we would have a better quality relationship.*
>
> *Daughter 05*

Carers spoke about feeling like they were missing out on final moments of connection

> *I don't want to forego the possibility that there is a moment of connection, or at least some moment where I can make (pause) make it known to her that I do love her.*
>
> *Daughter 08*

Feeling torn

As the demands increased, carers contemplated the distance, and many weighed up whether to move closer:

> *I did spend quite a lot of time looking at properties online… I had no work that I could do there, I had no friends or support network… I'm so glad I didn't do it because within a couple of years of making that decision she did have to go into a home, and I would have lost absolutely everything.*

Daughter 08

Several people sought therapeutic support for their internal conflict. Two carers wished that their counsellors better understood dementia.

For one carer, this internal conflict and increasing anxiety led them to impulsively take action, driving through the night and driving their mother home the next day, after she had a fall in a care home:

> *I was so, so angry at that… my Mum crying for help… and nobody came, nobody came… we had to get her out of there, couldn't leave her there.*
>
> *Son 04*

Frustration

Carers described mounting frustration that issues arouse because they were at a distance. They imagined that if they were closer, they would be able to provide smaller input, more frequently and avoid problems:

> *So yeah, it is really hard not being there and not being able to do the simple things… it has to be more of a crisis before you can do things.*
>
> *Daughter 09*

Experience of visits

Heightened anxieties

For many carers, visiting evoked anxiety. The absence of regular contact raised the stakes and meant that carers did not acclimatise to the experience:

> *At a distance every visit counts, erm, every visit is loaded with significance, because every time I go there I think this might be the last time I see her alive… everything has to be more concentrated, it's like a drink isn't it?*
>
> *Daughter 12*

Many carers described facing this alone to minimise the disruption for their family:

> *I do everything by myself… rarely have I been with my husband and kids … my experience has been it being very lonely and very anxiety provoking… I would never know, never know what to expect. And I remember driving on the motorway just praying, please let her be having a good day. Please let her be having a good day, because I just felt so… I'm sorry I'm going to get a little bit upset [crying] I just felt so awful.*
>
> *Daughter 01*

Amplified losses

Seeing their parent less often meant that the deterioration in their presentation seemed more stark:

> *I probably mark the changes more, whereas if I was there every other day, erm, maybe I wouldn't see them so clearly*
>
> *Daughter 10*

> *I would imagine it's more pronounced, in a away, because if I was down there every day it would become normalised… because I'm down there every four weeks, I get jolted into that again*
>
> *Son 06*

For some, witnessing these changes felt difficult, meaning carers visited less, perpetuating the problem:

> *Increasingly, I see the absence of him, rather than the presence of him, and, and I feel awkward about going… that's probably indulgent on my part or, selfish or self-protecting, you might say, he's your Dad, just go see him.*
>
> *Son 07*

Revisiting the past

The emotional aspect of visiting was often embellished by what it meant to be *returning home*. Revisiting the place of their childhood, often meant revisiting experiences which may have been left behind for a reason:

> *I've gone back to my childhood… I live right in the centre of London as well so, you can guess I have a slight aversion to suburbia… I need to be out of it… the suburbia of my childhood, I have no warmth towards it… it takes me back to those first seventeen years of my life where I didn't wanna be there… they're deep seated memories that get triggered when you go back.*
>
> *Son 06*

Saying goodbye

Many carers discussed how living at a distance forced "endings" to process, when they said goodbye.

> *I feel really sad leaving her because she's upset... you just feel ghastly really, you feel like you need to stay… it's an enhanced feeling of what's there normally I suppose but when you are saying goodbye, leaving her… those emotions are heightened.*

Son 06

Altered Identities

The influence of a professional lens

Several carers I interviewed were health or social care workers. Many talked about the cumulative demand that arouse from caring inside, and outside, of work. People recognised that professional expertise was very useful, though at times increased the expectations carers felt from themselves and others:

> *You're trained, as a counsellor, social worker, licensed practitioner, all these things, where you should know better, you know. But when it comes to your family, and your nearest and dearest, you do stupid things.*
>
> *Son 06*

> *Because I have got professional knowledge and things I am better at solving things than most people… it was clear to everyone in my family that because I am the only girl and I am the only doctor and I am the only person that knows about dementia that I was the lead.*
>
> *Daughter 09*

Dual roles

Several carers reflected on the challenge shifting between identifying as a parent and a child at the same time:

> *I think I get baffled as to whether I'm being my boys' Dad or my Dad's son (pause) and they don't quite mesh in the moment of being with my Dad?*
>
> *Son 07*

For some carers, these dual identities were all consuming, perhaps limiting their own identity and wishes:

> *I Felt as if… I have looked after my kids… now I am looking after my parents, you shouldn’t think this and it is selfish, but will there a time when my life is for me? For trying that.*
>
> *Daughter 09*

Becoming a carer and no longer a child

Many carers talked about an existential shift they experienced when they identified with being a carer:

> *Caring means the buck stops with you… I'm a carer, yeah.*
>
> *Son 06*

For some, this involved gaining membership to a collective identity:

> *When you talk to people like at visiting time at the hospital, everyone's going through it. Women of my age particularly… we're the carers.*
>
> *Daughter 10*

Many felt unsure of the conditions they had to satisfy to be a "carer". Without a diagnosable illness or recognition from others, many minimised their role and dismissed the impact that their parent's dementia was having on their life:

> *If you don't have a diagnosis… you don't feel you can call yourself a carer, you don't realise that that's what you are.*
>
> *Daughter 08*

Their lack of visibility from a distance meant that they were less deserving of the status as a carer. For some, services reinforced this through their lack of flexibility:

> *I think number one that would help dementia distance carers is for people to acknowledge that distance carers exist… I cannot get myself identified as a carer in my own local authority… the first question it asks you is are you looking after a person in THIS BOROUGH? And no I'm not.… you don't exist unless you are living with the person in the same local authority.*
>
> *Daughter 08*

The impact of culture and ethnicity

Two of the carers related how their identity as a carer was shaped by their culture and ethnicity. One of them described a cultural legacy and expectation that motivated them to care for their parents. Overcoming the distance felt more important in the context of these expectations:

> *I thought bloody hell they must have come across so much racism but they have never complained… I feel owe it to them... Sikhism is about giving and looking after the elderly and giving them that respect.*
>
> *Daughter 12*

For another, being an ethnic minority left them feeling further alienated and even further distanced in complex and profound ways:

> *We were the only family of mixed race… now she had no concept of that… there was part of me that began to wonder, what does she think of me when she looks, because, I'm not a totally white person… does she have any concept of my Dad?*

Daughter 08

Part IV: Facing the future

Letting go

Several carers talked about going on a journey with their emotions and arriving at a place where they had learnt to take care of themselves, by letting go of any struggles within their control. One carer referenced Acceptance Commitment Therapy (ACT) as a specific therapeutic model that had helped them:

> *… it [ACT] has really helped me in terms of thinking about not struggling with how I want things to be but actually just meeting her wherever she is and that being OK… I don't know if it is less painful but there is less of a struggle with it.*
>
> *Daughter 01*

Other carers discussed how connecting with the moment in the present helped. Sometimes this meant focusing on their parent's experience:

> *He does not complain and he still loves being alive… It's pretty admirable.*
>
> *Daughter 03*

Other times it was a way to shift focus away from the uncertainties:

> *I have realised I don't know what we will do but whatever it is, it doesn't need to be sorted out at the moment so I have stopped thinking about it.*
>
> *Daughter 05*

Holding on

Other carers talked about remaining connected to their parent, which often meant holding on to their identity. Gaining from connection helped carers get something from caring

> *I don't care if I have to go through all that to get that little two minutes of lucidity with my mum then fucking brilliant, I will take it.*
>
> *Daughter 12*

Making changes to bridge the gap

Some experiences of distance came to an end when carers moved their loved ones closer to them. This involved stressful transitions, finding a new home and selling old properties. Overcoming this provided a turning point where carers overcame difficulties and built a new closeness:

> *I found it less stressful. Not at the very beginning when she was miserable but once she had settled… I would go to the local hospital in the middle of the night and all these people could come to see her in a way that they just couldn't have… she was very delighted that they came even if she wasn't quite sure who they all were.*
>
> *Daughter 09*

Finding meaningful connection

For carers that remained at a distance, creating rituals on visits helped with them to cope with their feelings and foster connection:

> *Sharing the things and putting the flowers in the vase, talking to her about them… Little things. They are little points of connection I think that aren't dependent on memory.*
>
> *Daughter 01*

Many carers fostered deep connections with their parents through caring. Often it was easier to draw on these connections after events or transitions and create narratives of meaning retrospectively:

> *In some ways, it is a gift to be able to spend that time and give back something, even though it was really hard, and really stressful, and really tiring.*
>
> *Daughter 09*

> *It [caring] allowed me to build a relationship with him… That gives me a deep sense of erm, purpose, and being, yeah, the person that I wanna be.*
>
> *Daughter 03*

Some found meaning in sharing their stories, reinvesting their energy in campaigning and research, to make a positive difference to others:

> *The only way I deal with my grief now is campaigning because that helps me if I can help someone else like me in underserved communities… I have found my voice through that.*
>
> *Daughter 12*

Saying goodbye

Death featured in most stories. For some, envisaging death was daunting and a source of anxiety:

> *I do know that I have to prepare myself for when she dies, there is going to be a huge hole because so much of my life has been revolving around this.*

> *Daughter 08*

For others, they anticipated relief at the end of the road:

> *Sometimes you feel really despairing and just think, oh bloody hell, hurry up and die, and it's awful to feel like that, because you just feel so tired and fed up with it, and physically and emotionally, worn out with it.*
>
> *Daughter 10*

Two of the carers I spoke to had experienced their parents dying at the time of interview. Whilst this may have been the end of their caring role, it was not the end of their story, as the events impacted their life as they storied their experience of bereavement:

> *I was very conscious that I would try and do everything I could while she was alive… I thought I have done this, it is not a surprise to me this is happening… being conscious I was gradually losing them, that should be fine… But it wasn't… last weekend I went to their graves… and they were so alive and they were so dead.*
>
> *Daughter 09*

Fearing dementia

Many carers looked towards the future fearing the same fate. Many had children living at a distance from them, and feared another cycle of long distance caring:

> *I'm concerned about my son, erm, because eventually, I hope, he will look after me, erm and if I get dementia, err, he's screwed.*
>
> *Son 10*
>
> *It is just such a horrible horrible disease and it gets me and my sisters really worried… you are like: ok, this is genetic then! That's good. I'm looking forward to that, which one of us is going to get it?*
>
> *Daughter 11*

For carers without children, the idea of facing dementia alone was even more frightening:

> *I'm looking at that and I'm thinking this is taking up my entire life, who does that for people who don't have anyone? Nobody.*
>
> *Daughter 08*

Discussion

Despite living at a distance, carers[17] were actively involved in their parent's lives and their caring role was shaped by an individual's experience of distance. Carers supported their parents with: accessing a diagnosis of dementia, managing finances, providing hands on care, setting up networks of support, advocating for their parent's health and social needs, and providing emotional support. Caring extends beyond hands-on care to include anticipating future support needs, monitoring and supervising, and preserving the individual's sense of self (Farina *et al.*, 2017).

I will begin by discussing the logistical and practical challenges described by long distance carers; before discussing the psychological and emotional consequences. I will then apply the models of care and support that I developed and presented in chapter one to this context and then I will outline the clinical recommendations in Figure 4. Finally, I will consider the strengths and limitations of this work, before reflecting on the overall process and concluding.

Logistical and practical challenges

Much previous research has identified carer burden as linked to behaviours that challenge exhibited by the person living with dementia (Chiao *et al*., 2015). However, in this synthesis, the negative and stressful experiences were more often externalised and attributed to the practical aspects of caring, less-than-ideal care by others, loss, and, the distance. I did not directly identify themes relating to the impact of the cognitive or behavioural changes caused by dementia itself, although, this is implicit through when considering the challenges that carers experienced in meeting the needs of a parent living with dementia. It may also be that distance carers are less likely to experience carer burden relating to sustained exposure to behaviours that challenge, as they have more breaks from providing hands on care. It may also be that carers felt this experience was less relevant to my question as I prompted them to talk about their experiences of caring from a distance.

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[17] My supervisors and I reflected on what to call participants. Whether to refer to them as carers, people or participants? We felt our own uncertainty mirrored theirs and chose to call them carers as they identified with the label enough to come forward for this project. The complexity of the construct of being a "carer" will be discussed later.

Dealing with disconnection

Distance carers often live on the periphery of their parents' lives and face challenges arising from disconnection. Not seeing a parent regularly, carers are less likely to be aware of the onset and progression of dementia. Despite a lack of opportunities to observe changes, carers can still notice social changes through remote contact which can indicate the onset of dementia (Singleton, 2017). While distance carers can still provide helpful collateral to services, they are less likely to be engaged with diagnostic services. Many distance carers described "navigating in the dark" without a diagnosis or access to support. Illness representations influence family understanding of what is happening to the person, and how they respond and provide support (Quinn *et al.*, 2017). Long distance carers may be more likely to struggle to make sense of interactions and meet the needs of dementia carers.

Carers also faced a disconnect between their caring responsibilities and daily lives. Many carers described competing responsibilities across time and place. There is an increasing prevalence of 'sandwich carers' who are looking after children whilst caring for older parents (Carers UK, 2014). Distance carers are less likely to be socialised to the environment of their parents and providing day to day care. This placed immense pressure on carers when they had to step into a more "hands on role" after a critical incident or event, such as a fall or death of the other parent. Carers struggled to integrate their parent's needs into their own lives and felt torn between localities. At times of crisis, this was most demanding for carers. People living with dementia are more at risk of hospital admissions (Shepherd, 2019), but understandings of dementia are limited in acute settings and individuals benefit from carers advocating for them (Sampson *et al.,* 2011). However, each new care setting is another physical location a carer feels distanced from, increasing their sense of fragmentation and displacement.

Incurring costs

The additional costs carers incurred travelling shaped carers visiting patterns and added additional stress to their experience, as economic factors affect mental health (Friedli, 2009; Wolpert *et al.*, 2014; Gruebner *et al.*, 2017). While the government aims to provide financial support to carers with carer's allowance, it remains unclear if long distance carers would qualify for this support. One carer discussed how living in a different borough prevented them from accessing for carer support. Additional financial support can mitigate at multiple points along the stress process by reducing primary or secondary stressors for carers (Pearlin *et al.*, 1990). Parallel to this, carers struggled to manage work commitments in a different location. Employers must offer certain legal rights to carers; including, the right to ask for flexible working and time off in emergencies (Citizens advice, 2020), but carers may struggle to access this if their roles are not recognised. Several carers sought to manage the difficulty by working freelance, but these carers took personal risks and faced different costs. Carers may require further support to weigh up the costs and benefits of taking occupational risks to facilitate flexibility. Zarit's (1985) six step model of problem solving may help assist carers in making occupational choices.

Coping with complexity

Carers faced further complexities when making decisions and managing risks. The absence of a diagnosis made it hard for carers to make shared decisions about future care. Family carers are often relied on to negotiate choices and make stressful healthcare decisions in dementia (Lord *et al.*, 2016). Decision making with a person living with dementia is complex, requiring negotiation and nuanced communication (Miller, Whitlatch, & Lyons, 2016). Long distance carers are left trying to manage these conversations remotely or scheduling difficult conversations in short periods of time, which can be detrimental to relationships. Distance carers also described a lack of continuity in care and issues with case management. Services may struggle to have the resource to flex and adapt to the needs of distance carers, particularly in the context of austerity.

Carers overcame difficulties with the distance by creating strategies to monitor their parent's health, and finding ways to maintain contact and connection. Video calling over skype and facetime was helpful but may not always be feasible as people's cognitive abilities may limit their ability to operate this technology. Often carers monitored their loved one through one-directional video surveillance, which may provide an economic and efficient means to help people with dementia maintain independent living (Mulvenna *et al.,* 2017). However, there are ethical concerns in capturing and storing media of people living with dementia and formal care staff without their consent (Dewsbury & Ballard, 2013). Professionals and people living with dementia tend to prioritise living well and promote positive risk taking (Rapaport *et al.*, 2020). However, family carers may prioritise avoiding harm, and often feel they are left holding the risk (Rapaport *et al.*, 2020). There is a tension in balancing autonomy and risk in living well with dementia and this tension is further exacerbated by distance; as carers may more heavily rely on technology or care at home to manage risk. Carers may have fewer opportunities for a direct assessment of risk, relying on “snapshots” of functioning or only becoming aware at real crisis points. Distance carers are likely to find risk difficult to control risk or coordinate a response to it, making them more reliant on technology or the input of paid carers. Often, when something went wrong with care, carers felt let down and their anxieties were heightened.

Psychological and emotional consequences

Fragmented identities

Despite playing a vital role in their parent’s lives, many carers felt unacknowledged and disconnected, as if distance caring did not fit the mould. There is no legal definition of a “carer”; and the NHS defines a carer as anyone who looks after a family member or a friend with an illness (NHS England, 2020). However, many people do not see themselves as carers; and, it takes an average of two years for carers to acknowledge their role as a carer (NHS England, 2020).

At a distance, carers may be even more likely to minimise, or underestimate the role they play because of their remote positioning. Carers may also be less likely to be positioned as carers if they are not engaged with services. Self-conceptions and self-evaluations are socially derived and socially sustained (Tomm, 1984; Thoits, 2013). The carers I interviewed were less likely to be seen “performing” caring acts and may have less opportunity to take up caring duties that are recognised and valued by others in society. Without membership to a community, distance carers may struggle to understand their experience and find an identity. Long distance carers may face issues integrating aspects of their identity as they are disconnected in space and time. Such fragmentation could leave carers without a coherent sense of self and an unstable self-image is a risk factor for depression (Thoits, 2013). If distance carers are only left with ‘thin’ descriptions of caring they may be at risk of forming ‘damaged identities’ (Adams-Wescott *et al.,* 1993). It is likely that ‘thickening’ the plot, in line with the aims of narrative therapy, to encompass the experience of distance dementia carers would be therapeutic (Freedman & Combs, 1996; Morgan, 2000).

Some participants identified two distinct and separate dimensions of caring: 1) providing hands on care, and 2) caring about. It is unclear which of these dimensions is more demanding; however, discourses often focus on the needs of “hands on carers”, as if their experience is more significant because it is “productive”. It is likely these dimensions have different emotional and psychological consequences, which warrant independent recognition, exploration and support. If carers feel they are excluded from “caring” because they are not providing hands on care, they may feel themselves diametrically positioned as “not caring”, which has the potential to do psychological harm. One participant described gaining benefit from carer support groups, and carers groups should seek to include distance carers and validate the emotions connected with these distinct dimensions of caring.

Amplified emotions: heightened anxieties, internal conflict and multiple losses

A diagnosis is more likely to be received remotely, increasing the chance that carers could be struggling alone with their reactions. This means carers risk lacking confidence in their knowledge (Schindler, 2012), and are less likely to benefit from the stress-buffering effects of social support attributable to the self-esteem boosts people obtain from their supporters (Thoits, 2013). Distance carers also face the additional emotional load of existential anxieties prompted by the diagnosis. Being at a distance, carers described feeling constantly torn, as if they were always in the wrong place at the wrong time. Such internal conflict has a negative impact on mental health (Thoits, 2013). Carers should be supported to find workable solutions and connect with their agency to prevent feelings of powerlessness which negatively impact carer wellbeing (Quinn *et al.*, 2015). Adult children experience existential shifts when caring for a parent (Robertson *et al.*, 2020), which are further complicated by the distance.

Carers also described the ways in which seeing their parent less often made the deterioration in their functioning more obvious. Dementia carers experience normal phases of bereavement in advance of the loss of a significant person (Garand *et al.,* 2012). It is likely that distance shapes the bereavement process. Participants interviewed described grieving for abstract losses including closeness that had never been felt, and opportunities for a different relational experience which they felt the distance prevented. Accepting the reality of these losses and working through this grief may help carers process this grief (Worden, 1991). It is also important to understand the nature of a person’s attachment to their parent, as yearning and searching may shape their experience of grief (Bowlby & Parkes, 1970). A growing body of evidence supports the link between attachment style and complicated grief (Chang, 2016).

Drained by the demands and facing it alone

The physical and emotional journey was experienced as an additional demand. Major life events and chronic strains in people's lives have *nonspecific* impacts which negatively affect physical health and/or mental health (Thoits, 2013). Carers spoke of feeling exhausted, drained and tired. Many managed the demands of caring alongside many other commitments. Carers are likely to experience high levels of stress when the relationship between person and their environment is appraised as taxing, or exceeding their resource and endangering to their wellbeing (Lazarus & Folkman, 1994). Carers that wanted to avoid the costs of expensive travel tickets, drove to their parents. Often this meant, driving in highly emotional states whilst feeling fatigued, facing an increased risk of accidents on the road (European Commission, 2018). Carers are also more likely to experience abstract transitions on the journey as they travel to and from different places and spaces. For some, this means travelling home and revisiting a time in their life which may have been difficult and left behind for a reason. This may trigger uncomfortable emotions and difficult memories.

Due to the nature of distance caring, carers are more likely to be "going it alone", leaving friends and family behind. Carers may feel more anxiety and stress without their support system around them (Rodakowski *et al.,* 2012). A carers perception of their support may be more relevant than actual received support (del-Pino-Casado *et al.*, 2014), and distance carers may be more likely to feel alone as they described feeling disconnected and isolated. Aloneness may affect a carers sense of self-efficacy which affects their beliefs about their capabilities (Bandura 1986, 1997, 2001; Zeiss *et al.*, 1999). Carers were more reliant on family networks placing a huge importance on familial interactions. These negotiations often resulted in family conflict, which negatively impact dementia carers (Livingston *et al., 2010).* Assertiveness training can reduce conflict, promote satisfaction in relationships and reduce psychological distress (Speed *et al.,* 2018). Clinicians could consider how to adapt this training to include remote forms of communication to aid long distance carers to feel less alone and better supported. Strategies for Relatives (START) is a training package that includes assertiveness training and is clinically and cost effective (Li *et al.,* 2014).

Compartmentalising and creating connection

Carers experienced several positive consequences in caring at a distance. They described an ability to disconnect from the demands of the caring role, and return to their own life. It is possible that distance also provides a therapeutic vantage point, where carers can reflect on their experience whilst experiencing safety and normality. Sometimes, carers were critical of themselves and made moral judgements about their ability to disconnect. Carers would benefit from permission to acknowledge all aspects of their experience and find ways to value the disconnect. The psychological impacts of stressors depend on their *meanings* to the individual (Brown & Harris 1978; Harris *et al.,* 1989). Working with carers to construct a cohesive narrative may help them benefit from caring. Compartmentalising experiences, carers may struggle with ambivalent emotions and fragmented experiences. Narrative therapy explores how language can shape the meaning we make of past experiences, and could be one avenue to expand on the therapeutic value of stories (White & Epston, 1990). Many carers described a process through which caring enabled them to feel more connected by finding a new closeness. Reciprocating caring behaviours received from their parents in the past can help carers find meaning in caregiving and increase positive affect (Cherry *et al.*, 2013; Lawton *et al.,* 1991). Some carers who moved their parents closer to them, found it easier to attain this. Distance carers could be supported by others acknowledging their role, helping them to connect with *meaning* and reducing and interpersonal or intrapersonal stressors.

Applying models of psychotherapeutic support to distance carers

Improving understandings and finding strategies

Evidence suggests that any individual that cares about someone living with dementia will be less stressed if they receive support understanding the illness and are equipped with strategies for caring. Unlike psychotherapeutic interventions, evidence suggests psychoeducation and skills training is more effective face to face (Kishita, 2018). One of the reasons that this might be is because of the learning that takes place in adult-to-adult collaborative relationships (Gottleib & Feeley, 2006). While distance carers can access information online, they are likely to struggle without peer support and contact with individuals with expertise who they can bond with and learn from. Finding a way to create groups virtually would help distance carers to learn more, expand their networks of support, enhance their self-efficacy and improve their perception of coping.

Coping with loss and processing grief

Evidence suggests that carers experience less anxiety and depression when they have therapeutic support to process their grief. Distance carers may experience loss differently, in more abstract ways or grieve for “what never was” or “could never be”. Therapists should consider this in therapeutic interventions for distance dementia carers and find ways to help them identify these emotions, accept the loss, work through the pain and adjust to life. Distance carers may require additional support for finding meaning and remaining connected as distance enhances feelings of disconnection. Finding space to reflect and process may be more difficult for long distance carers.

Improving Mental Health

Psychotherapeutic support is not affected by remote delivery, producing more options for services in supporting distance carers (Kishita, 2018). However, distance carers may face unique challenges in accessing support as they live outside of the postcode for dementia carers. If distance carers can access a therapeutic relationship, space to reflect and process their emotions, alongside strategies for managing their mental health, they are likely to experience: greater insight and control, better self-esteem, improved emotional regulation, increased activity and a more positive appraisal of the situation. Mental health support for carers could help to improve their wellbeing and cope with the additional demands of distance caring.

Supporting transitions

Change can invoke disturbances to mood and functioning arising from uncertainty, unfamiliarity, and disorientation (Tyhurst, 1958). Distance carers would benefit from specialist support and clearer communication from trusted others to help them define the new situation, and provide what they need to cope in the changed circumstances (De Silva & Curzio, 2009; Ray *et al.,* 2015; Bloomer *et al.,* 2016). More contact from services and inclusion of distance carers would improve the knowledge of distance carers, establish trust, facilitate adjustment and build familiarity. This could help carers feel less guilty and have better relationships with staff and services.

Figure 8

Clinical Implications

Clinical Implications

For society

- Travel companies could reduce carer burden by offering discounts on travel for carers. For example, "a carers rail card" for long distance carers.
- Creating virtual communities of support could help widen support networks for isolated individuals and connect long distance carers so that they feel heard.
- Employers should offer more flexibility to long distance carers who face unique demands arising from the burden of travel.
- There should be a shift in the public perception of distance carers to recognise the importance of their role.
- Communities should consider how to share caring responsibilities with distanced generations. More health interventions do not always lead to better outcomes (Mulley, Richards & Abbasi, 2015) and may be financially unsustainable (Wolpert *et al, 2016).*

For Service Delivery

- Dementia services should make every effort to include long distance carers and offer flexible post-diagnostic support to carers remotely.
- Clinicians should avoid making assumptions about the level of involvement dementia carers have based on proximity.
- Carers assessment should include questions about the impact of the distance, costs incurred and seek to offer specific interventions to distance carers. These include:
    - More support with technologies.
    - More financial support.
    - Support in coordinating networks of care.
- Therapists should consider stories as therapeutic opportunities. Carers can be helped to form an identity, make sense of their experiences and find meaning.
- When critical events occur (e.g., the loss of the other parent, a fall or change in physical health) distance carers would benefit from more support to meet caring needs. Specialist dementia support should be available in crisis not just at diagnosis.
- Distance carers would likely benefit from psychotherapeutic interventions that explore their emotions and help to process them. For example, Acceptance Commitment Therapy.

For long distance dementia carers

- Seek to recognise own stress and manage accordingly.
- Validate own emotions and reflect on journey.
- Reflect on additional anxiety felt from a distance and find workable solutions in person with dementia's interest, avoid overcompensating.
- Use boundaries to benefit self and permit respite from stressful experiences.
- Avoid judgment and offer self-compassion.
- Be flexible, pragmatic, and learn through trial and error.
- Adjust expectations and let go of aspects outside of own control.
- Assert self in family negotiations and create sustainable routines.
- Maintain own life in face of demands.
- Stick with experiences as they unfold in the present.
- Connect with meaning in role and seek connection.

Reflections

During this analytic process, I was struck by several observations I wish to share. Firstly, the orientation and tone of carer's narratives appeared to me to be shaped by the chapter they were experiencing in their lives. Individuals whose parents had recently been diagnosed spoke a lot more about the future: their fears and a sense of overwhelming anxiety. Those that were actively experiencing crises, struggled more with weaving a cohesive structure which conveyed the level of distress they were experiencing. Those who had been caring for years, even decades, spoke a lot more about an anticipated ending and the arrival of death. One of the carers that I interviewed, who had experienced bereavement, was better able to retrospectively connect with the meaning they gained through the experience. The other participant I spoke to, whose mother had died, referred to their parent in the present tense throughout the whole interview which inferred to me some of the complexity of grief. Continuously, I held an impression of the abstract nature of these emotional ties and depth of the experience of distance carers.

Asking individuals to openly tell their stories evoked a level emotion that I had not experienced before in semi-structured interviews or anticipated. I wonder if the open-ended nature of the methods worked in a way resembling psychoanalytic free-association. Perhaps meeting strangers off the internet permitted anonymity, which encouraged openness. I worked to offer compassion and containment nonverbally, holding silence in line with the interview method. I feel I gained a privileged insight into people's lives, and I felt moved by the content. At times, I felt a tension between my role as a researcher and as a developing therapist. I felt aware of the therapeutic potential of reflecting back and reframing stories. I strove to demonstrate compassion and kindness, whilst adhering to the content of what was shared to maintain research integrity. At times, I mirrored carers' feelings of aloneness and impotence, working in a research capacity, without the connection to services and permission to help.

My identity shapes the orientation of the paper, and the aspects of the meta-narrative I have chosen to highlight. I am most interested in improving the experience of carers, and so I have focused on insights that relate to clinical implications, and have naturally found it easier to consider these from a psychological stance due to my orientation in training. While I was expecting aspects of my personal and professional identity to shape my experience of this project, I perhaps underestimated the depth of connection I would feel when identifying with participant's stories when I considered my own relationship with my parents, my experiences caring, and my time living at a distance from my family. During lockdown of COVID-19, the outputs on this work developed on new relevance as we experienced disconnection from others, and many of us became people caring about others living at an enforced distance.

Strengths & Limitations

To our knowledge, this is the first in-depth exploration of the stories of distance dementia carers in the UK. This narrative project provides insight into key actions and events, along with the meaning they have for carers. We recruited a diverse range of carers across the UK through a variety of networks. Rigorous narrative analysis was undertaken with carers who were actively involved in constructing their stories and providing feedback on the analysis paper.

As a significant proportion of the recruitment took place through twitter, samples may have been limited to smaller networks which are relatively closed. Issues of representativeness historically apply to representativeness, as theorised by statisticians (Seale *et al.,* 2004). In qualitative research, sampling can be bottom-up, socially informed and practically driven. The concept of generalisability in qualitative research needs to be based on the idea of social representativeness (Seale *et al.,* 2004). The sample also represent a subsection of dementia carers. While most of the sample are women, this is likely representative as 60-70% of dementia carers are also women (Alzheimer's Research UK, 2015). The vast majority of individuals interviewed were in relatively well paid jobs, were highly educated and three quarters of the sample lived in London. This is likely to be socially representative of distance carers as educational attainment correlates highly with geographical mobility (Bonin, 2008), class, and living in London (Hect *et al.,* 2020). However, not all distance carers are from a privileged socioeconomic background. It is likely that the nature of caring at a distance for those who have less access to funds, or who may be less educated is even more challenging. Moreover, while doctors and health care professionals may experience economic and educational privileges, they are not invulnerable from the demands of caring and still have emotional and psychological needs. Health care professionals are often more at risk at experiencing mental ill health due to hesitancy in seeking support because of mental health related stigma (Knaak *et al.,* 2017).

Conclusion

Stories of long distance carers provide insight into their unique needs and experiences. Caring from a distance presents specific logistical and practical challenges. Carers incur additional costs, experience more isolation and juggle multiple competing demands in separate locations. As a result, distance carers are more likely to feel alone, experience acute and intense periods of anxiety, be more burdened by travel, and experience loss in many different ways. Carers would likely benefit from interventions which are tailored to their needs at a distance. The insights gained through this work provide insights into ways to overcome challenges and optimise the chance of a positive experience of caring.

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Appendices

Appendix 1 Quality Appraisal Checklists

Table 4

Quality Checklist for Qualitative Studies

Study	**Was there a clear statement of the aims of the research?**	**Was a qualitative methodology appropriate?**	**Was the research design appropriate to address the aims of the research?**	**Was the recruitment strategy appropriate to the aims of the research?**	**Were the data collected in a way that addressed the research issue?**	**Has the relationship between researcher and participants been adequately considered?**	**Quality***
Milne et al., 2014	Yes	Somewhat	Yes	Yes	Yes	No	Low
Meichsner et al., 2017	Yes	Yes	Yes	Yes	Yes	Yes	High
Meichsner et al., 2016	Yes	Yes	Yes	Yes	Yes	Yes	High
Kaplan & Gallagher-Thompson, 1995	Yes	Yes	Yes	Yes	Yes	Yes	High

* High = 6; Medium = 4-5; Low = 0-3

Table 5

Quality Checklist for Quantitative studies

Paper	Were participants appropriately allocated to intervention and control groups? (Was randomisation independent?)	Were patients and clinicians, as far as possible, 'masked' to treatment allocation?	Were all patients who entered the trial accounted for and an intention-to-treat-analysis used?	Were all participants followed up and data collected in the same way?	Was a power calculation carried out, based on one of our outcomes of interest?	Were outcomes relevant, valid and reliable?	Quality*
Andrén & Elmstahl, 2008	No	No	No	No	Can't Tell	Yes	Low
Arritxabala et al., 2011	No	No	No	Yes	Yes	Yes	Low
Cheng et al., 2014	Yes	Yes	Yes	Yes	Yes	Yes	High
Chiverton & Caine, 1989	No	No	Yes	Yes	Can't Tell	Yes	Low
Coon et al., 2003	Yes	Yes	Yes	Yes	Yes	Yes	High
Davis et al., 2011	Yes	Yes	Yes	Yes	Can't Tell	Yes	Medium
de Souza Caparrol et al., 2018	No	No	No	Yes	Can't Tell	Yes	Low
Farran et al., 2008	Yes	Yes	Yes	Yes	Yes	Yes	High
Fung & Wai-Tong, 2002	Yes	Can't tell	Yes	Yes	Can't Tell	Yes	Medium
Gallagher-Thompson et al., 2008	Yes	Yes	Yes	Yes	Yes	Yes	High
Judge et al., 2013	Yes	Can't tell	Yes	Yes	Yes	Yes	Medium
Kwok et al., 2014	No	No	Yes	Yes	Yes	Somewhat	Low
Li et al., 2014; Livingston et al., 2014ab; Sommerlad et al., 2014	Yes	Yes	Yes	Yes	Yes	Yes	High
Mavandadi et al., 2017	Yes	No	Yes	Yes	Yes	Yes	Medium
Meichsner et al., 2018	Yes	No	Yes	Yes	Yes	Yes	Medium
Meichsner et al., 2019	Yes	No	Yes	Yes	Yes	Somewhat	Medium
Pihet & Kipfer, 2018	No	No	Yes	Yes	Can't Tell	Somewhat	Low
Wang et al., 2012	Yes	Yes	Yes	Yes	Yes	Yes	High
Wilz & Kalytta, 2012	Yes	No	Yes	Yes	Yes	Yes	Medium

*** High = 6; Medium = 4-5; Low = 0-3**

Appendix 2 Full detail of extracted data relating to mechanisms

Table 6

Full details of extracted data

Paper	Stated aims	Content in intervention	Specified theories and models	Techniques and processes	Outcomes	Results
Andrén & Elmstahl, 2008	To use psychosocial intervention to help carers better cope with their emotional states and problem solve	Strategies for: mobilising help, reducing social isolation, coping with and overcoming difficulties. Advice about challenging behaviour. Practical support for future planning. Education on cognitive changes in dementia. Ego therapy in conversation group.	Cognitive, behavioural and social mechanisms of action. Ego therapy.	General education and increased social support. Ego therapy supports and develops resources the individual had provided since birth.	Caregiver burden, Caregiver satisfaction, Caregiver health.	Lower strain and disappointment. Increased satisfaction
Arritxabala et al., 2011	To train in skills and strategies that help modify emotions through simple theoretical explanations.	Education on the concept of emotions: definition, functioning, regulation and associated thoughts. Train on CBT skills and emotional regulation strategies.	CBT. Beck and Ellis rational emotional therapy. Pearlin stress model.	Identifying the link between emotion and conduct. Behaviour modification and cognitive restructuring. Rewarding activities. Progressive relaxation and breathing. Problem solving. Emotional modification by identifying irrational thoughts. Assertiveness training. Roleplaying help requests. Identifying and analysing problem behaviours. Providing behaviour management skills. Increase pleasant activities. Plans.	Dysfunctional thoughts. Psychosocial support. Positive and negative Affect. Satisfaction with life and care. Well-being. Emotional states. Depressive symptoms. Stress.	Higher positive affect and increased well-being. More emotional regulation and satisfaction with care. Lower stress and negative affect. Fewer dysfunctional thoughts.
Cheng et al., 2014	To use benefit finding to reduce depression and burden.	Psychoeducation on dementia. Communication skills. Stress management and relaxation. Balance between self-care and caregiving responsibilities. Social support. Managing behavioural and psychological symptoms. Home-based activities for care recipient. Personal care skills for dependencies in activities of daily living. Home environmental modification, and community resources.	Two-factor model of caregiving (Lawton, Moss, Kleban, Glicksman & Rovine, 1991). Folkman (1997) theory of stress.	Identify emotional reactions and reappraise thoughts to be positive. Positive re-appraisal introduced with the thought-emotion-behaviour triangle.	Depression, Overload, Depressive symptoms.	Benefit finding reduced depression. Psychoeducation reduced overload and burden.
Chiverton & Caine, 1989	To increase perceived coping through education	Psychoeducation on dementia. Explore change in roles and responsibilities and related feelings. Communication skills and behavioural management. Respite care. Problem-solving.	Education Theory. Lazarus and Folkman theory of stress.	Educating spouses and discussion.	Coping.	Greater competence.

Paper	Stated aims	Content in intervention	Specified theories and models	Techniques and processes	Outcomes	Results
Coon et al., 2003	To develop skills to reduce anger and depression and improve perceived coping.	Two separate interventions. 1) information about anger management 2) depression management skills.	Anger (Novaco, 1975, 1985 & Feindler and Ecton 1986). Depression management - social learning theory and CBT. Self-Efficacy (Bandura, 1997; Zeiss et al., 1999).	Teaching skills: generating positive self-talk, monitoring dysfunctional thinking, assertiveness training in role play, rehearsing skills, increasing pleasant events, self-monitoring, problem-solving.	Caregiving self-efficacy, Anger, Hostility, Depression, Ways of coping.	Reduction in anger and hostility and self-efficacy improved in both groups. Increase in positive coping strategies in anger group only.
Davis et al., 2011	To facilitate adjustment to a transition and improve mood by increasing perceived coping.	Emotional adjustment. Caregiver-staff interaction. Family functioning. Health. Social support. Role change. Emotional adjustment. Family communication. Health behaviours. Community resources/support. Review of progress. Reinforce coping strategies	Psychosocial transition (Tyhurst, 1958), transactional stress and coping (Lazarus and Folkman, 1984). McMaster Model of Family Functioning (Ryan et al., 2005).	Provide emotional support, direct to appropriate resources and teach strategies to cope. Empathy, giving permission, normalising, validation, or venting, bibliotherapy, interpretation, positive reframing, problem solving, and resources.	Guilt about nursing home placement. Depression. Burden. Hassle. Satisfaction.	Reduced guilt and more positive perceptions of interactions with staff compared to standard care.
de Souza Caparro et al., 2018	To use cognitive intervention to reduce overload and stress.	25 activities. E.g., "complete the sentence", "find the error", "tell the story", "sudoku", "amend history".	Cognitive Stimulation.	40 minutes weekly activities practiced in and out of researcher presence.	Cognitive functioning. Stress. Burden.	Improvement in cognition. No improvement in stress or overload.
Farran et al., 2008	To increase caregiver skill to reduce stress.	Potential causes of behavioural symptoms; and, prevention of behavioural symptoms during personal care, particularly verbal and physical aggression; management of restless behaviours, hallucinations, delusions, and paranoid or suspicious behaviours.	The stress process model (Lawton & Pearlin). Self-efficacy theory (Bandura, 1986, 1997, 2001). Person–environment interaction (Hellen, 1998; Kielhofner, 2002). The need-driven, dementia-compromised behaviour model (Whall & Kolanowski, 2004).	Appraising care receiver abilities, inabilities, and needs; and increasing caregiver repertoire of interventions in response to care receiver behavioural symptoms. Self-regulation, behavioural rehearsal, reciprocal determinism, self-reflection, and vicarious learning strategies (Bandura, 1986, 2001).	Problem Behaviours. Distress with behavioural symptoms. Behaviour management skill.	Skill building intervention more effective than information and support comparison condition in reducing emotional distress.
Fung & Wai-Tong, 2002	To reduce caregiver distress, improve quality of life and reduce mental health service use.	Sharing feelings, education in dementia, information about community resources and problem-solving strategies.	6-step model of problem-solving suggested by Zarit, Orr, and Zarit (1985).	Offering support. Six steps: defining the problem, generating alternatives, examining and evaluating each alternative, cognitive rehearsal of action plan, execution of the plan as homework, and evaluation of outcomes.	Caregiver distress. Quality of Life.	Reduced distress. Improved quality of life. No change in service use.
Gallagher-Thompson et al., 2008	To reduce stress and depression. To begin to understand mechanisms of change.	Discuss plans for future transitions and ideas for pleasant activities between caregiver and care-recipient.	CBT	Cognitive-behavioural principles; it is a skills-learning based approach. Practice and personalising material. Creating plans and increasing pleasant events.	Depression. Stress. Conditional Bother. Skill Utilisation.	Fewer depressive symptoms, reduced overall life stress and reduced caregiving stress.

Paper	Stated aims	Content in intervention	Specified theories and models	Techniques and processes	Outcomes	Results
Judge et al., 2013	To use a strength-based approach to offset caring stresses and reduce intrapsychic pain.	(1) Education regarding dementia and memory loss and introduction to strength based approach, (2) effective communication, (3) managing memory, (4) staying active, and (5) recognizing emotions and behaviours.	The Stress Process Model. Combines education skills and cognitive rehabilitation skills training.	Action Plans. Strength based inventory. Practice and acceptance reflecting, personalising, compromising, challenging self, rephrasing, connecting with others. Using memory aids. Validating and reframing, re-evaluating expectations. Substituting behaviours adjusting the environment, relaxing.	Caregiver mastery. Emotional and Physical Health Strain. Self-efficacy. Role captivity. Relationship strain. Depression. Anxiety. Quality of life and self-esteem.	Reduced emotional health strain, dyadic relationship strain, role captivity. Higher caregiving mastery. Fewer symptoms of depression and anxiety.
Kaplan & Gallagher-Thompson, 1995	To use therapy to treat clinical depression in spousal caregiver.	Therapy focused on identifying, challenging, and modifying the cognitive and behavioural factors underlying depression. Discussing the four tasks of grief.	Beck's CBT theory and Worden's model of grief counselling (Lewinson). The notion of disturbed self-regard (Freud 1957). The Palo Alto model of individual time-limited (C/B) therapy for treatment of late-life depression is based on Beck (Beck et al., 1979) and Lewinsohn (Lewinsohn et al., 1986).	Therapy tools; agenda, cues, expectations therapy, homework. Dysfunctional though records, search for evidence of danger. Naming emotional pain in context of anticipator grief. Invivo exposure to emotions. Building of therapeutic alliance. Semantic method to modify statements. Pleasant events. Normalising and supporting efforts to learn financial management. Role playing establishing social relationships. Build relationships with others. Creating a survival guide for individuals. Acknowledging ambivalent thoughts and feelings. Clients find a place for their partner in life whilst living.	Beck Depression Inventory. Hamilton Depression Rating Scale. Hopelessness Scale. State-Trait Anxiety Index form.	Reduced depression and anxiety.
Kwok et al., 2014	To reduce caregiver distress arising from BPSD by improving perceived competence	Activity arrangement, handling of BPSD, such as combativeness and confusion, and communication with care recipient; in addition, healthy lifestyle, grief, and relaxation also concerned the caregivers.	CBT	Training on caring skills, stress reduction, grief handling, and healthy lifestyle maintenance. Worksheets to identify and modify any maladaptive beliefs. BPsD and validation techniques. Cognitive restructuring. Behaviour management and PCC model. Positive psychology and caregiving. Meditation. Mindful breathing. Self-recognition	Neuropsychiatric symptoms. Self-efficacy.	Reduced distress.
Li et al., 2014; Sommerlad et al., 2014; *Livingston et al., 2014ab*	To use a manualised individual therapy to improve anxiety, depression and reduce costs to services.	Dementia and its symptoms. Carer stress and relaxation exercises. Behavioural management. Changing unhelpful thoughts. Assertive communication. Promoting emotion-focused coping strategies. Future care needs, information about care and legal planning, and information leaflets about making common decisions. Planning pleasant activities. Plans for maintaining skills.	Stress process theory (Lazarus et al., 1984).	Relaxation (CD), identifying triggers and reactions to challenging behaviours, and identifying and challenging negative thoughts. Homework and manual. The relaxation techniques used were signal breath, focused breathing, physical grounding, guided imagery, meditation and stretching. Behavioural activation.	Anxiety and depression. Coping. Burden. Neuropsychiatric symptoms.	Reduced depression and anxiety. Improved mental health. Better quality of life. The most psychologically distressed changed their coping style, while those who were less distressed benefited from the intervention through other mechanisms.

Paper	Stated aims	Content in intervention	Specified theories and models	Techniques and processes	Outcomes	Results
Pihet & Kipfer, 2018	To understand how strategies are affective to gain and understanding of the change process.	Discuss the appraisal of stressful situations and the coping strategies.	Lazarus and Folkman transactional theory of stress and coping.	1) appraisal: taught to break down a global situation into specific ones, identify more precisely what is stressful, and distinguish between situations or aspects of it which can be modified and those which cannot. 2) coping strategies: trained to choose an appropriate strategy depending on whether the situation can be modified (problem solving 7 step procedure) or not (reframing) and to seek social support. Education on how dementia affects communication and relational behaviour. The program uses a combination of information provision, group discussions, work on personal stressful situations, and exercises at home.	Burden. Problem behaviours and related distress. Psychological distress. Daily Life measures.	Reduced burden. Improved psychological distress and self-efficacy. The qualitative results emphasised the benefits of a group format: Participants felt understood by peers, could build new social bonds and experienced reduced social isolation. More use of strategies, particularly reframing.
Wang et al., 2012	To use support to reduce caregiver distress, improve quality of life.	Information about client's condition. Discuss emotional impact of care-giving; Information about self-care. Discuss ways to improve interpersonal relationship. Support outside the group. Home care skills.	6-step model of problem-solving (Zarit, Orr, and Zarit, 1985).	The six steps included defining the problem, generation of alternatives, examining and evaluating each alternative, cognitive rehearsal of action plan, execution of the plan as homework, and evaluation of outcomes.	Caregiver distress. Quality of Life.	Reduced distress.
Wilz & Kalytta, 2012	To increase psychological wellbeing and prevent adverse effects by modifying stress-inducing assumptions regarding behaviour	Information about dementia, problem behaviours, problem solving skills, self-care, loss and skills for everyday situations.	CBT	Individualistic post diagnostic talk, relaxation imagery, psychoeducation, processing, cognitive restructuring and emotion orientated interventions.	Anxiety and Depression Scales. Mental and Physical quality of life.	Lower symptoms of depression and anxiety and delayed nursing home placement.
Wilz et al., 2018	To help caregivers cope with the challenges of caregiving by managing behaviour problems of the care recipient, managing own stressful emotions.	Managing behaviour problems. Stress management and regulation of emotions. Creating value oriented positive activities. Recognising the limits of in-home care. Coping with change, loss, and grief.	CBT	Creating a therapeutic alliance, problem solving, providing information, problem-analysis, problem-solving training, Socratic dialog, guided discovery, cognitive restructuring, emotion based coping, acceptance of the illness and its resulting changes, positive activities, creating health-promoting activities, planning activities. Emotional regulation strategies. Normalising emotions. Reviewing achieve goals and planning for the future.	Depression. Emotional Wellbeing. Burden. Body Complaints.	Improved emotional well-being. Fewer symptoms of depression and fewer physical health symptoms. Improved coping with care situation and behaviour of the care recipient.

Appendix 3 Information Sheet

Title: What is it like to care for a parent living with dementia from a distance?

Version Number 1: 16.10.2018

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

What is the purpose of the study?

The number of people living with dementia is projected to increase in our ageing population. Geographical distances are growing between generations and we expect more children to be living at a distance from their parents. Little is known about the way that distance impacts on the caregiving experience. We want to understand more about what it is like to care for a person living with dementia, from a distance. For this reason, we would like to hear the stories of people who have lived experience of caring for a parent living with dementia from a distance.

Why have I been chosen to take part?

You have been invited to take part because you have identified that you have experience of caring for a parent living with dementia from a distance.

Do I have to take part?

No. Participation is voluntary and you are free to withdraw participation at any time, without explanation and without incurring any disadvantage.

What will happen if I take part?

If you agree to take part, a researcher, Sarah Robertson, will ask you to share your story in a one-to-one interview in a location of your choice. You will be invited to begin wherever you like and Sarah will ask follow up questions about different events or experiences you describe. The interview will be audiotaped and anonymously recorded. We expect the interview to last around 90 minutes.

How will my data be used?

Your data will be anonymously transcribed. Any information that may identify you or your parent will be deleted and replaced with an anonymous alternative.

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator / Supervisor acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Sarah Butchard, butchard@liverpool.ac.uk.

Further information on how your data will be used can be found in the table below:

How will my data be collected?	Voice recording on encrypted device.
How will my data be stored?	Password protected files.
How long will my data be stored for?	Audio recorded data will be stored until October 2020. Anonymised data will be stored until 2028.
What measures are in place to protect the security and confidentiality of my data?	Data will be kept on password protected devices. Audio data will be transcribed and then anonymised.
Will my data be anonymised?	Any information that could identify you or somebody else will be replaced.
How will my data be used?	Data will form part of Psychology Doctorate project looking at long distance caregiving.
Who will have access to my data?	Only members of the research team will have access to your data.
Will my data be archived for use in other research projects in the future?	Anonymised data will be kept. No identifiable information will be shared.
How will my data be destroyed?	Identifiable data will be deleted when the project finishes in October 2020. All anonymised data will be deleted by Dr Butchard in 2028.

Are there any risks in taking part?

We do not expect there to be any risks involved. It may be that after sharing your story you wish to seek further support or advice about dementia. You can contact the Alzheimer's

Society helpline on **0300 222 1122** or the Admiral Nurse Dementia Helpline on **0800 888 6678**.

Are there any benefits in taking part?

We do not expect you to directly benefit from the research but we hope the results of the research will benefit others in the same situation in the future. Some people have reported finding it therapeutic to tell their stories.

What will happen to the results of the study?

Results will be written up for a doctoral thesis and may be shared with the wider research community in presentations and publications. You will not be identifiable in any study results. If you would like to receive a copy of the results please let Sarah Robertson know at the time of interview.

What will happen if I want to stop taking part?

You can withdraw their participation in the study at any time, without explanation. Contact Sarah Robertson, sarah.robertson@liverpool.ac.uk to withdraw from the study.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Dr Sarah Butchard, butchard@liverpool.ac.uk, **0151 7945530/34** and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling **0303 123 1113.**

Who can I contact if I have further questions?

Please contact Dr Sarah Butchard

Dr Sarah Butchard, Clinical Psychologist
School of Psychology, University of Liverpool
0151 7945530/34

Appendix 4 Consent Form

UNIVERSITY OF LIVERPOOL

Participant consent form

Version number & date: 1 16.10.2018
Research ethics approval number:
Title of research: What is it like to care for a parent living with dementia from a distance?
Name of researcher: Sarah Robertson

Please initial box

1. I confirm that I have read and have understood the information sheet dated 16.10.2018 for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves an audio recorded interview which will later be typed up and anonymised. ☐
3. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
4. I understand that I can ask for access to the information I provide and I can request the destruction of that information if I wish at any time prior to June 2020. I understand that following I will no longer be able to request access to or withdrawal of the information I provide. ☐
5. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the archive for sharing and use by other authorised researchers to support other research in the future. ☐
6. I understand that signed consent forms and audio recordings will be retained in the School of Psychology until October 2020. ☐
7. I agree that my anonymised information can be quoted in research outputs such as posters, publications and oral presentations. ☐
8. I agree to take part in the above study. ☐

___________________________	__________	_______________________
Participant name	Date	Signature
___________________________	__________	_______________________
Name of person taking consent	Date	Signature

Principal Investigator
Dr Sarah Butchard, Clinical Psychologist
School of Psychology, University of Liverpool
0151 7945530/34
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Student Investigator
Dr Sarah Robertson, trainee clinical psychologist
School of Psychology, University of Liverpool
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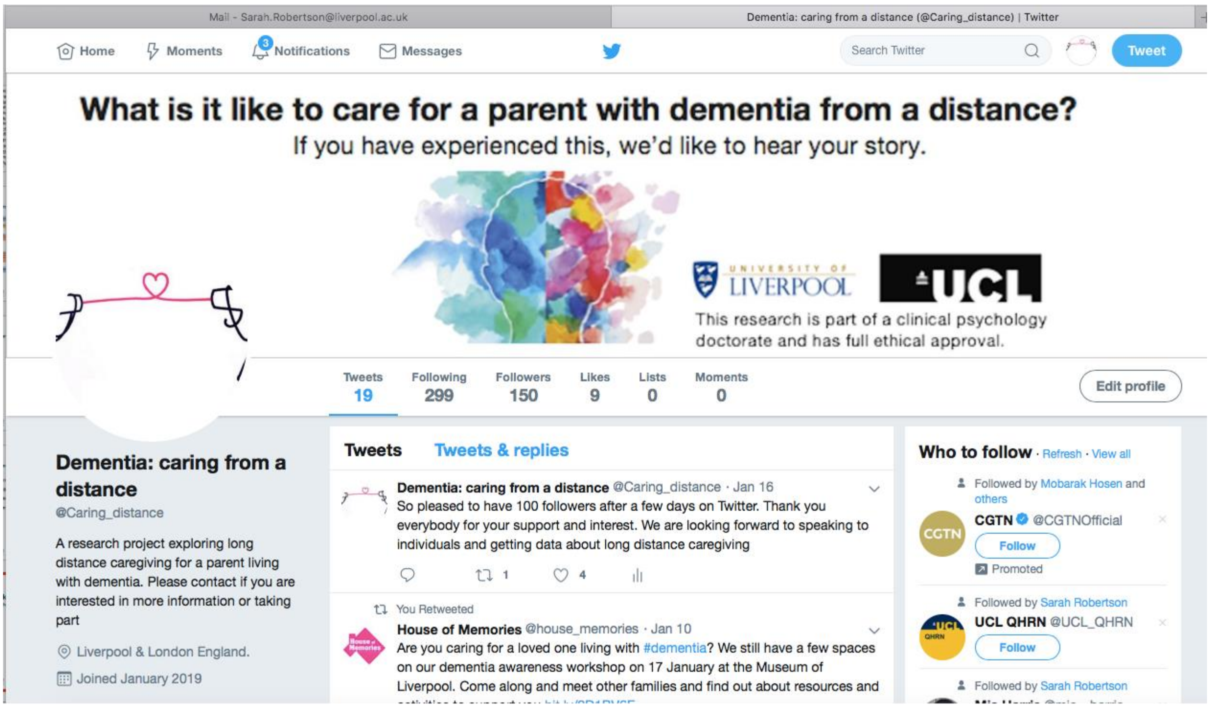
Appendix 5 Recruitment tools

Figure 9

Twitter Page



What is it like to care for a parent with dementia from a distance?

If you have experienced this, we'd like to hear your story.

This research is part of a clinical psychology doctorate and has full ethical approval.

Dementia: caring from a distance

@Caring_distance

A research project exploring long distance caregiving for a parent living with dementia. Please contact if you are interested in more information or taking part

Liverpool & London England.

Joined January 2019

Dementia: caring from a distance @Caring_distance · Jan 16

So pleased to have 100 followers after a few days on Twitter. Thank you everybody for your support and interest. We are looking forward to speaking to individuals and getting data about long distance caregiving

House of Memories @house_memories · Jan 10

Are you caring for a loved one living with #dementia? We still have a few spaces on our dementia awareness workshop on 17 January at the Museum of Liverpool. Come along and meet other families and find out about resources and

Followed by Mobarak Hosen and others

CGTN @CGTNOfficial

Followed by Sarah Robertson

UCL QHRN @UCL_QHRN

Followed by Sarah Robertson

Figure 10

Join Dementia Research Flyer

What is it like to care for a parent living with dementia from a distance?

If you have experienced this, we'd like to hear your story.

Geographical distances are growing between generations but we know little about what it is like for long distance caregivers. We want to better understand this experience to learn about the needs of people caring in this unique context. Please email sarah.robertson@liverpool.ac.uk if you are interested in taking part. A research project undertaken as part of a Clinical Psychology Doctorate with full ethical approval.

Have you been providing care for a parent over a long distance?

We would love to meet with you and hear about the events and experiences important to you

Take part in a single, open ended interview

Recruiting within an hour of Liverpool and London

Dr Sarah Robertson
School of Psychology
University of Liverpool
Twitter: @Caring_Distance

sarah.robertson@liverpool.ac.uk

Appendix 6 Narrative Interview Topic Guide

Narrative Interview

Stage 1: Single Question Aimed at Inducting Narrative

Interviewer: *I'm interested in your story. You can begin wherever you like and I may ask you further questions about things you say and take some notes to help me do that. Can you tell me about your experiences caring for somebody living with dementia from a distance? The events and experiences that are important to you.*

Stage 2: Particular Incident Narratives

Below are examples. Information from stage 1 will be inserted into the gaps provided by […] in the sequence it is brought up:

Interviewer: *You said […]. Can you remember a particular time that happened?*
You told me about […]. Can you tell me more about how it felt at the time?
Earlier you mentioned […] What was important about that?
Before you said […] What was that like for you in that moment?
You told me […] What did that mean to you?

Appendix 7 Narrative Mapping

Table 7

Excerpt from narrative mapping

Transcript	Described Action/Event	Participant's Evaluation	My interpretation
1	Becoming aware of some changes. Mum becoming forgetful and repeating stories.	Not knowing if it was something "to worry about". Starting worry.	As mum behavior changed, carer started to perceive vulnerabilities and fear future. This is when role changed and began carer. Dementia itself altered course.
	Mum received a diagnosis of dementia from GP. Mum attended CST.	Felt services were initially good. Experienced assessment as odd as related to own professional experience. Diagnosis a relief but felt mum had no reaction to it.	Dual identity (professional and personal) shaping experience. Diagnosis provided validation but also expectation there would be duties to fulfil and uptake. Disconnect in experience.
	Contact with memory service ended post diagnosis.	Felt unsupported after discharge.	Services helped but support was not maintained. Services were focused on diagnosis.
	Began providing care from a distance alongside work. Travelling up every week or fortnight.	Felt tired, stretched and overworked. "Knackered" all of the time. Felt on the periphery of family life.	Caring was a demand in conflict with existing commitments. Made a choice to protect family consequence was loneliness. Had to juggle roles and responsibilities.
	Problem-solving care arrangements and coming up with a plan.	Felt was active in the early stays. Sense was not calm and unsteady.	Being active was protective, may have helped with anxiety as provided evidence was doing something. Unintended consequences of feeling chaotic as held responsibility to respond.
	Dividing responsibilities with siblings, coordinated care and took up roles. Siblings had power of attorney.	Felt in conflict, angry and annoyed. Felt resentful of siblings living closer as attempted to do the same amount. Brother appeared useless. Felt motivated to be there for mum and observed relationship to be different.	Everybody reactive and defending against the idea they were not doing enough. Maybe overcompensated as living at a distance. Perhaps felt further distance by not having involvement as power of attorney. Tried to make an equal contribution despite additional personal costs from distance. Attachment relationships affected involvement in care. Differences of being at a distance were not recognized.

Appendix 8 Blog

What is it like to be caring from a distance?

Across the UK, there are many people now experiencing an enforced distance from their loved ones. How might this feel? What might help? Here to share some insights is Dr Sarah Robertson. Sarah's current research is focusing on the experience of long distance dementia carers.

My work has focused on people who find themselves taking on caring responsibilities for their parents, from a distance. I interviewed long distance carers, to hear their stories and better understand what they needed. This work seems to have taken on a new relevance, with many more people caring remotely in the context of COVID-19.

Carers are now limiting the contact they have with their loved ones and focusing on essential visits only. Many carers report feeling torn in the balancing act of providing enough care to ensure wellness and safety, whilst minimizing the risk associated with COVID-19. Divided by location, long distance carers are used to struggling with balancing commitments with work and family life in one place, and the needs of their parent in another. Caring involves establishing routines and patterns, but often the unexpected make them unworkable.

Long distance carers rely heavily on carefully coordinated networks of support. With all of society stretched in one way or another, carers will now be impacted by a reduced capacity in the networks they rely on. Many more will find themselves setting up networks remotely, relying on technology and coming up with creative strategies to cope with the distance.

Due to COVID-19 there has been unprecedented and unimaginable change in society. Psychosocial transition theory (Tyhurst, 1958) states that change itself invokes disturbances to mood and functioning arising from uncertainty, unfamiliarity, and disorientation. Tyhurst (1958) suggested individuals could be helped by having time to understand the new situation, adapt and being supported with the tools to cope.

On top of this, carers will be experiencing the impact of enforced distance. My work with carers uncovered the psychological and emotional consequences of distance caring. Carers described heightened anxieties and fewer avenues for reassurance. Many described feeling alone as they struggled to manage high levels of uncertainty. Others talked about a sense of loss. Distance results in lost opportunities. Many carers will also be grieving for losses in their own lives; e.g., planned holidays, parties or social connections. Now, more than ever, carers face additional stress whilst running the risk of an empty tank.

Our research suggests that distance carers may find the following strategies helpful:

- identifying and managing stress
- not minimizing the role that can be played remotely
- letting go of expectations and guilt
- accepting choices
- validating emotions
- communicating assertively with others and asking for help when it is needed
- remaining open and flexible. Trying not to control what is impossible to control

Many of the carers we spoke felt better when they felt heard. Distance carers are, in fact, not alone. These emotions are normal and they will pass. Just like COVID-19.

Some of the carers we spoke to said they found strategies from Acceptance Commitment Therapy (ACT) helpful. ACT aims to help people cope with strong emotions when they arise, focusing on the present and moving towards a valued direction. ACT released COVID-19 strategies for people who may be feeling overwhelmed.

These can be summarised as:

F = Focus on what’s in your control
A = Acknowledge your thoughts & feelings
C = Come back into your body
E = Engage in what you’re doing

C = Committed action

O = Opening up

V = Values

I = Identify resources

D = Disinfect & distance

For carers interested in more psychological strategies for managing anxiety, restoring sleep or practising self-care some worksheets can be found here.

Dr Sarah Robertson is a trainee psychologist and researcher in dementia care at the University of Liverpool. Her research focuses on living well with dementia and supporting carers. Currently she is supervised by Dr Sarah Butchard at University of Liverpool and Dr Penny Rapaport at UCL. You can follow her work on Twitter @1SarahMae.