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Facilitating social coping-'seeking emotional and practical support from others'-as a critical strategy in maintaining the family care of people with dementia

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Abstract

The aim of this study was to identify how the family care of people living with dementia could be supported to make reliance on family care sustainable in the long term despite the impact of stress. A Realist Evaluation (Pawson & Tilley, 1997) was conducted to investigate this aim. An initial review established 'coping' as a primary means of mediating stressors associated with caregiving. However, there was a need to specify which coping approaches/strategies are most effective. In-depth interviews were conducted with a purposive sample of family carers ($n = 18$) in a suburb in North East England from 2016 to 2017. Analysis of the data revealed 'social coping' (SC) that included an emotional support component as a critical mediator of family carer stress. Several key hindrances to the utilisation of SC, including underpinning causal factors, are explicated. Ways in which these hindrances might be overcome are discussed and guidelines introduced for how family carers, formal providers and practitioners can facilitate SC as a critical coping strategy in sustaining the family care of people with dementia over the long term.

KEYWORDS

coping strategies, dementia, family carers, Realist Evaluation, social coping, sustaining family care

1 | INTRODUCTION

Estimates indicate the number of those affected by dementia in the United Kingdom (UK) will rise to one million by 2025 and over two million by 2051 (Prince et al., 2014). This alarming trend is reflected globally with a predicted 135.5 million diagnoses of dementia by 2050 (Prince et al., 2013). Presently, there is critical reliance in the UK, as well as more globally, on family carers of people with dementia (hereafter referred to as 'carers') to provide the bulk of care. In

the UK total reliance on formal care provision would cost £34.7bn annually (Alzheimer's Society, 2020)-one fifth of the entire health expenditure in England (2018–19) (Harker, 2019). While reliance on formal care of older people was possible in the 20th century, this is becoming less tenable in the 21st century as advances in medicine and a rapidly ageing demographic across Europe (GCOA, 2017) mean the numbers of those reliant on formal support will become overwhelming.

Family care represents the preferred method of care for the majority of carers/carees (Dowrick & Southern, 2014) and families

generally strive to accommodate this. In the UK Governmental policy (DOH, 2015) also explicitly favours continued reliance on care in the community/family carers to provide the majority of care, prioritising care in the home/independent living for as long as possible.

Family care research has primarily focused on the negative impact on carers' health as assessed by 'burden of care' measures (Bastawrous, 2013) which emphasise carers' 'psychological dysfunction'/negative consequences of caregiving (Kramer, 1997). The 'burden of care' paradigm has also narrowed formal providers' policy focus on 'relieving carers' heavy burden', e.g. via respite care (O'Shea, Timmons, O'Shea, Fox, & Irving, 2019). This paradigm portrays family care in a somewhat negative light, i.e. as fundamentally 'burdensome' and unsustainable. Arguably, such a perspective remains incompatible with governmental policy throughout Europe that promulgates the need to make family care sustainable (Glasby & Thomas, 2018). This has led to calls for new care paradigms that present ways to support carers to *cope* with long-term care (Carr, Wolkowski, & Parkinson, 2019) and fulfil policy ambitions to make domiciliary care/living out a good quality of life within communities a priority for older people (Curry, Castle-Clarke, & Hemmings, 2018). However, a key issue this study investigated concerned how such a paradigm shift can be facilitated.

1.1 | Policy relevant to this research

The location for this study, a N.E. England suburb, was particularly affected by council budgetary cuts which exerted significant impact on adult social care policy/budgets throughout the duration of this study (2016–2018) when Government-imposed 'austerity measures' were in place. Between 2010 and 2019, the local council was forced to save £168m, losing 40% of real spending power (Centre for Cities, 2019).

While the issues/challenges outlined here were salient in N.E. England (Marmot, 2020, p.142), they are far from unique. Areas also affected include the Midlands and Southern coastal towns (Marmot, 2020, p.93) and a further 25 areas ranked with worse levels of deprivation than the study area (TEIOD, 2019). Moreover austerity was not the only driver for policy/practice leading to limited support for carers in England. Arguably, the most important driver was Central Government's limited response to making family care of people with dementia sustainable. Provision of preventative services by many local authorities in the UK was severely hampered (Curry et al., 2018), exacerbated by chronic under-funding of social care and substantial cuts to adult social care budgets from 2010 onwards (Brimblecombe, Fernandez, Knapp, Rehill, & Wittenberg, 2018a). In England 77% of carers received no support that might assist them to cope (CQC, 2018), despite carers facing substantial physical, psychological and financial challenges (Brimblecombe, Fernandez, Knapp, Rehill, & Wittenberg, 2018b)-a situation replicated throughout Europe (ibid).

What is known about this topic

- Dementia prevalence predicted to increase exponentially;
- Majority of dementia care delivered by family carers and estimated to reduce carees' risk of institutionalisation by a factor of 20;
- Family carers of people with dementia face high levels of stress that precipitates cessation of care: an issue seldom fully addressed.

What this paper adds

- Social coping (SC) presented as a critical strategy to the long-term maintenance of family care;
- Causal mechanisms that hinder/promote SC exposed, paving the way for clearer guidelines for how providers/ practitioners can contribute to carers' use of SC.

2 | BACKGROUND

2.1 | Coping

'Coping' is the process by which we try to manage stress (Lazarus & Folkman, 1984) via constant cognitive/behavioural actions. Perceived stressors are evaluated as demands which exceed our current resources (ibid). Crucially, it is not stressors but how people cope with stressors that will determine the consequences for health and well-being (Dijkstra & Homan, 2016). An important feature of the findings is that while the focus of much previous research has been on 'care as burden' (Hughes et al., 2014; Svendsboe et al., 2016) and its assumption carers will inevitably succumb to stress (Cheng, 2017), this paper details how carers can be supported to maintain family care. Coping represents a mediator variable that is modifiable and lends itself to interventions to deal with stress. However, what is less well known is which coping approaches/strategies carers find most effective and how these might be promoted (Sun, 2014; Tang, Jang, Lingler, Tamres, & Erlen, 2015).

2.2 | Social coping

Social coping (SC) has been loosely captured by the umbrella title: 'seeking social support' (Folkman & Lazarus, 1980; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985) and is based on Lazarus and Folkman's (1984) coping theory. It is included in the Transactional Model of coping and Ways of Coping Checklist-Revised (Vitaliano et al., 1985). Its significance as a coping process was underlined by Thoits (1986) who identified SC as pivotal in providing relief from stressors. Factor analysis and the distillation of some 161 coping responses pinpointed SC (under its broader title 'seeking support') as one of the most critical coping processes at our disposal (Amirkhan, 1990). This was confirmed

by Zautra, Sheets, and Sandler (1996) who identified SC as one of the four essential coping strategies. The four factor solution produced (ibid) has since become a cornerstone of coping theory/research.

The definition of SC employed here: 'seeking emotional and practical support from others'-reflects this study's consistent finding that in the context of family care SC often includes an emotional support component as a critical mediator of stress. This represents an important addition to seeking practical support.

SC has gained some traction as a useful coping strategy for individuals who face especially challenging/stressful events where it can provide a protective factor for mental health (Norris; & Stevens, 2007; Rodrigo, Martín, Máiquez, & Rodríguez, 2007) through positive interactions, affirmation and assistance (Lee, Anderson, Horowitz, & August, 2009). More recently, Chen, Huang, Yeh, Huang, and Chen (2015) revealed how SC can reduce carers' perceived levels of stress, while Gallagher et al. (2011) found SC alleviated carer depression.

Exploratory factor analysis (Dijkstra & Homan, 2016) reveals SC maps well onto an Engagement category of coping, characterised by this coping strategy's deliberate, premeditated employment to mediate stress. This.

emphasises the requirement for individuals to actively engage in SC to initiate it (ibid, p. 9).

Despite potential benefits, this study uncovered hindrances to carers' adoption of SC. While the issue of carers demonstrating reticence to taking up external support is well documented (Brodaty, Thomson, Thompson, & Fine, 2005; Morgan, Semchuk, Stewart, & D'arcy, 2002), what is less clear are underpinning causal factors and how these might be mitigated. Better understanding of factors which hinder/facilitate carers' employment of SC as an adaptive coping strategy is required to reverse SC's position as an under-represented carer coping strategy. Effective coping is essential to the long-term maintenance of family care (Toot, Swinson, Devine, Challis, & Orrell, 2017) and therefore supportive of most European (Glasby & Thomas, 2018) and global (Brodaty & Donkin, 2009) policy that places heavy reliance on family care.

The findings offer guidelines for the construction of a new care paradigm based on sustaining family care that might inform future policy/practice.

2.3 | Project overview

2.3.1 | Aims/objectives

Phase 1 of this multi-phase Realist Evaluation (Pawson & Tilley, 1997) investigated 'what works to support family carers' despite the impact of stress. This initial phase (Rapid Realist Review) (RRR) (Parkinson, Carr, Rushmer, & Abley, 2016) established 'coping' as a principal means by which carers could mediate stressors associated with caregiving (Appendix A).

Phase 2 built on Phase 1 by investigating which coping approaches/strategies carers deemed critical to maintaining care,

including causal mechanisms that facilitated/hindered these. Synthesis during Phase 3 led to the emergence SC as a strong candidate theory for what supports carers.

2.3.2 | Purpose of this paper

The paper focuses on the relationship of carers to formal service provision and how formal providers and practitioners* can facilitate SC to make family care of people with dementia sustainable.

*Hereafter, reference to 'providers' can be assumed to refer to 'formal providers', including 'practitioners.' The exception will be where specific reference is made to 'informal providers,' e.g. those working in the voluntary/charity sector.

3 | METHODS

Employment of a Realist Evaluation (RE) was deemed appropriate for explicating not only 'what' enables family care, but also 'how,' 'for whom' and 'in what circumstances' (Pawson & Tilley, 1997). RE deliberately attempts to capture the 'reality' of how causation is generated by identifying the specific contexts/reasoning (generative mechanisms) that naturally exist (ibid). Emphasis is also placed on extracting evidence from service users (i.e. family carers) to provide empirical evidence to reveal insights into 'the real', i.e. 'whatever naturally or socially exists, including...experiences and events' (Angus, Miller, Pulfer, & McKeever, 2006, p.E65).

3.1 | The RE comprised three cumulative phases

Phase 1: RRR investigated 'what works to support family carers.' Dominant finding was the significance of coping as a primary means by which carers mediate stressors associated with caregiving.

Phase 2: Interviewing represents a valuable means of testing/validating research questions (Pawson, 1996) and was employed to uncover critical coping strategies utilised by carers. In-depth interviewing of family carers ($n = 18$) elicited details of types of coping approaches/strategies employed, reasons employed, facilitative/hindering factors.

Phase 3: Synthesis followed a logical course based on Manzano's (2016, pp.14–17) guidelines, with attention paid to rigorous analysis to create an explanatory account of the data by elucidating 'what enables family care', 'how' and 'in what circumstances.' This led to the formulation of retroductive inferences based on the original conceptual framework developed in Phase 1 (Parkinson et al., 2016) and further informed by empirical evidence (Phase 2). This allowed inference-making/insights to emerge and pinpointing of those factors deemed by carers to be most supportive (Phase 3). SC emerged out of a range of candidate theories-its prominence based on: strength of empirical evidence

and literature; cogency/explanatory power of the argument supporting SC as a critical strategy and prime mediator of care-based stress; the translational potential of SC.

TABLE 1 Purposive sampling criteria

- Carers were selected who were aged 50 to 79 years of age. This excluded carers aged 80 or over who were statistically more likely to have the additional challenge of dealing with their own co-morbidities. Imposing this criterion helped to keep to a minimum this additional layer of complexity to the family care of people living with Alzheimer's disease, allowing a greater focus on the care-based factors which affect carers and how these might be addressed.
- This age limit allowed comparability between participants, but without making the age restriction so rigid it prevented recruitment of sufficient numbers of participants. It also ensured some heterogeneity in the sample.
- Family carers of people living with AD were selected to provide greater specificity regarding the context of care. However, since AD represents the most common form of dementia in the U.K. accounting for some 62% of all cases (Age UK, 2015), selecting carers from within this population group assisted the generalisability of the findings.
- Participants were sought via their contact details which were held by the Alzheimer's Society branch based in the South Tyneside area of the North East of England. Recruiting family carers of people living with AD from a similar geographical area helped to ensure that the range of services available might be comparable.
- Carers were required to have been caring for a minimum of 12 months at the time of interview to ensure that they had gained sufficient experience of caregiving to be in a position to provide rich and detailed feedback during interviewing.

3.2 | Participants

Participants provided informed consent to their participation in the research. Recruitment of carers took place via voluntary sector organisations situated within a suburb in the North East of England. Gatekeeping ensured participants included a mixed group with some regular voluntary sector attendees, but an equal number who seldom made contact. Balance was important since carers' utilisation of this sector can confer emotional/social advantages over non-attendees (Smith, Drennan, Mackenzie, & Greenwood, 2018). Recruitment was narrowed by location to ensure relative parity regarding carers' access to local support services and to permit clearer comparisons between participants. Purposive sampling criteria were used (Table 1).

These criteria targeted a specific population, yet remained flexible-permitting a diverse range of carers to be recruited covering caregiving over the full dementia trajectory (excepting palliative stage) (Tables 2 & 3 below). Achieving sample heterogeneity was important to permit generalisability of the findings to the broader carer population. The gatekeeper guided participant selection with emphasis on diversity-achieved via a wide range of carer/caree characteristics (Table 2).

3.3 | Data collection termination

RE relies on building, testing and refining theories (Pawson, 2013). Manzano (2016, p.8) recommends this be.

Participant	Age of carer	Gender of carer	Relationship to person with dementia	Duration of family care	Age of person with dementia
1	73	F	Spouse	3 years	78
2	70	F	Spouse	5 years	89
3	75	F	Spouse	3 years	78
4	54	F	Daughter	3 years	80
5	60	M	Son	5 years	85
6	73	M	Spouse	10 years	70
7	78	F	Spouse	5 years	78
8	62	M	Son	1 year	92
9	56	F	Daughter	3 years	75
10	62	F	Spouse	1 year	78
11	53	M	Son	1 year	80
12	78	F	Spouse	9 years	83
13	73	F	Spouse	8 years	76
14	75	F	Spouse	3 years	76
15	70	F	Spouse	4 years	71
16	63	F	Daughter	5 years	91
17	68	F	Spouse	3 years	74
18	50	F	Daughter	1 year	90

TABLE 2 Wide-ranging sample characteristics to introduce some heterogeneity to the sample

rigorously achieved by collecting large amounts of data to ensure sufficient data to explain how causation is generated. In RE data collection termination decisions tend to be reached once sufficient data is gathered to meet these criteria and no new information/insights emerge. Here this was juncture was reached by the eighteenth interview. These criteria replace reliance on 'data saturation' per se and acknowledge the iterative nature of RE (ibid) and its premise that findings will be further confirmed/refined/refuted by subsequent research/researchers.

3.4 | Ethical approval

Ethical approval (HLS-PHW151616) for this study was granted by the Faculty of Health and Life Sciences Research Ethics Committee at Northumbria University.

3.5 | Findings

The dominant finding was the need consistently expressed by experienced carers to adopt SC as an essential coping strategy. These carers had learned the hard way to embrace SC as a means to recruit external support and/or reported that such a strategy came highly recommended by experienced voluntary sector staff.

TABLE 3 Descriptive statistics illustrating the wide-ranging sample characteristics

Mean Age of family carer: 66.28 years
S.D.: 9.00 years
14 Female carers
4 Male carers
11 spouses
4 Daughters
3 Sons
Mean duration of care: 4.06 years
S.D.: 2.69 years
Mean age of PWA: 80.22 years
S.D.: 6.73 years

Those not directly immersed in family care on an every-day basis may be unaware of how systemic problems associated with delivery of carer support and the unique context of family care currently limit the potential of SC. This study unpicks some of the complexity surrounding these issues to reveal how six factors may be instrumental in determining the utilisation/effectiveness of SC. Each factor is presented in turn in the following section.

3.5.1 | Recognising current range of service options may be too rigidly fixed

SC was hindered where service options were strictly limited and bound by a predominantly medicalised approach-a finding supported by Bruens (2014, p.89). This approach relied heavily on encouraging

carer breaks, often entailing transfer of carees to quasi-institutional settings providing day care, respite care etc-a finding also noted by Dementia UK (2017) and Age UK (2020). This presented carers with limited support options, ignoring a frequent finding of this study and elsewhere (e.g. Batch & Mittelman, 2012) that carers/carees may often be reticent to utilise services in settings perceived as staging posts that presage full institutionalisation of carees:

> "(On respite Care): I've always said it's like going into a home...hopefully, it doesn't come." (P11)

> "(On respite care): You would have to lock him up, well I couldn't do that. I don't think anybody would...it's just not on." (P17)

Some of the fear/mistrust generated by quasi-institutional settings may be based on anachronistic perceptions, however the reality is this fear continues to be very real for carers/carees:

> "My Nana...went into a care home...she then went into the lock ward...I think my dad was thinking he was going to end up like her...he was panicking because he used to say, "if I end up like her- don't put me away!"(P18)

Arguably, there is a need to re-examine providers' reliance on services based around such settings and to consider a wider range of options. Where service options were too rigidly fixed this discouraged carers from utilising SC:

> "I also tried for continuing health care (in the caree's own home)-my daughter had said someone in her team had recommended that...but that was a nonstarter and they kicked it out." (P8)

A crucial point is that carers are more likely to adopt SC as an adaptive coping strategy where there is a match between services and the needs/values of individuals. Conversely, rigidly fixed services reinforces carers' perceptions of SC as having limited utility. Facilitating SC requires the power imbalance between professionals/family carers to be redressed with carers afforded a closer participatory role in deciding which services are best:

> "You still feel powerless because people don't necessarily listen because they are working off a set piece...what you say, and I've found this countless times, is nodded at but not listened to...But the reality is family members can see it close hand-the effects-to be honest, far better than the professionals." (P8)

These findings underscore the need for wider carer consultation to evaluate the appropriateness of services. SC cannot be envisaged to

be adaptive unless it consistently succeeds in delivering services carers truly need.

3.5.2 | Carers compelled to develop a strong sense of autonomy from the outset

Following people's initial diagnosis carers reported how they felt left to their own devices to manage care:

> "You are chucked in at the deep end when they are first diagnosed. You think: "where do I go from here? Where do we go now?" So you are finding out for yourself what to do and how. It's a learning curve and you are left to your own devices to get on with it." (P18)

A pattern was set from the outset in which carers perceived the only option was to develop independence regarding caregiving in the absence of offers of external support. This pattern became normalised. Carers even took pride in managing autonomously:

> "Up until this point I've never really felt the need to do that (invite external support) and I've also I suppose been quite independent and wanted to sort things out myself." (P10).

However, dementia represents a highly variable/unpredictable disease. As symptomatology deteriorates, the challenges carers encounter tend to increase in frequency and severity, but in a progressive, incremental manner carers may not be fully alert to:

> "You had to continually adapt…you get drawn into it further and further…it…evolves without you realising, you just had to react all the time." (P8)

Once the full import of becoming habituated to autonomy is realised it may be too late:

> "And then a year went by and I couldn't do it anymore." (P5)

Eschewing SC that might elicit support to mediate stress can bring carers to breaking point, ending family care. Carers need to be wary of going it alone and the repercussions of unmediated/unsupported chronic stress. Promotion of SC relies on providers' effective response, i.e. SC needs to be seen by carers to confer adaptive benefits. This requires closer collaboration and trust-building between carers/providers to prevent any dissociation becoming permanent:

> "You have to accept…that people may knock on the door and get used to having other people in your

home-and they're not your family, but you have to be used to it." (P11)

Providers can perform a key role in promoting SC by establishing close links and access to meaningful support early on and for the duration of family care:

> "I've had to learn the hard way and I think a lot of carers-they try to manage on their own…Now that I've come to terms with that. I need support, I know that." (P12)

3.5.3 | SC often limited to practical support

Carers frequently cited being offered practical support by providers. While valuable, this omitted carers' often stated but unmet need for personalised/individualised emotional support:

> "The most important thing I appreciate…one to one with somebody who will listen, someone who is caring." (P12)

> "Often…this doesn't apply to anyone else in the room-I want to talk to them one to one." (P10)

For SC to be encouraged it needs to be capable of meeting carers' wider spectrum of needs. Providers' promotion of the value of emotional support and facilitation of access to it needs to be considered:

> "A lot of people are proud and say they don't need this, but yes they do, they need someone to talk to." (P17)

3.5.4 | Lack of provider consensus regarding what carers need

The uniqueness/complexity of dementia and family care associated with it, which can be highly individualised, calls for tailored support (Anderson, Nikzad-Terhune, & Gaugler, 2009). However, developing such support amid such complexity can seem insurmountable, leading to a 'one-size-fits-all' approach to service provision (Gaugler, Reese, & Tanler, 2016). A start-point for provision of bespoke support is to set a mandate for consulting carers to establish individual needs and closely negotiated/flexible responses by providers, including wider options. Options which are too generic (see Finding 1) and/or contingent on location hinder SC:

> "I have absolutely no help with the dementia…There seems to be nothing, no support. For the carers-there is nothing…I've looked everywhere for help and there

is none. And if I can't find it knowing the system, I don't believe anyone can...There may be some in other towns...but it's not here." (P17)

Lack of consensus contributes to and is exacerbated by systemic problems co-ordinating support:

"The people are lovely, people are skilled and trained and want to do well-the systems are all rubbish... Everybody works in silos." (P5)

The uniqueness/complexity of dementia requires tailored support delivered according to a clear, well-informed, co-ordinated plan:

"You need more knowledge than an average person has." (P6)

Even the most assiduous carer is liable to struggle alone with the uniqueness/complexity of dementia care:

"I have a box file...which is my ongoing things that I need every day and there must be 50 sleeves in it, with a different person, different names, different things." (P5)

Lack of consensus generated by the uniqueness/complexity of dementia and dementia care create fundamental problems for carers and providers alike. Overcoming this and the hindrance it presents to SC requires collaborative inter-professional and inter-carer partnerships from the outset and duration of care.

3.5.5 | Flawed assumption SC will be provided for by relational support

Formal providers' assumption carers can automatically anticipate family/friends' support (relational support) as a substitute for formal support was fundamentally flawed. 50%+ participants reported insufficient/no relational support:

"That's why dementia/Alzheimer's are at the bottom of the heap because you depend on families to look after them. Nobody thinks they may not have a family." (P17)

Deteriorating dementia symptoms that generate increasing need for support were met by actual declines in relational support: a paradox prompted by family/friends' withdrawal as dementia symptoms became more profound. The irreparable relational schisms dementia can provoke needs to be acknowledged and addressed by providers:

On receiving family support: "*Next to nothing-I have a lovely family but there's obviously a reason behind that. X (the caree) has a brother and a sister...they are mortified, not facing the reality of what's happened. I don't think they can cope with it. In fact...I wouldn't be surprised if they never came to visit her again.*" (P6).

This can leave carers/carees more isolated than ever when deteriorating symptomatology may already seriously limit socialisation, exacerbating loneliness:

"The problem is the isolation of the carers. So if the carers can get out...Now because they are isolated it is impossible to even start that. It's a vicious circle." (P17)

High levels of isolation/loneliness are commonly experienced by carers/carees (Kovaleva, Spangler, Clevenger, & Hepburn, 2018) and strongly associated with early cessation of family care (Gaugler, Yu, Krichbaum, & Wyman, 2009). There is a need to move beyond flawed assumptions about SC being provided for by relational support and towards providers' wider exploration of interventions to address carer/caree isolation.

3.5.6 | Overcoming carers' tendency to adopt a short-term perspective

Carers universally adopted a short-term perspective regarding day-to-day management of care:

"I've had to stop looking at the picture long term...to live in the moment, which is hard for me...So, I have to take it a day at a time. The old cliché: a day at a time. It's actually an hour at a time-sometimes it's a minute at a time...and respond to everything that comes up... rather than become overwhelmed." (P4)

While this approach allowed carers to focus on the task in hand, rather than be overwhelmed by the challenge of dementia care, it also presented a significant hindrance to forward planning. Strategic planning often becomes essential, particularly where a finite number of services exist and access depends on carers' ability to arrange support well in advance. Carers' employment of SC was limited where external support was contingent on long-term planning/a long-term perspective:

"You just take things from day-to-day. It works better than trying to plan too far ahead." (P14)

Promotion of SC relies on providers' ability to offer support flexibly/at shorter notice, overcoming carers' tendency to adopt a short-term perspective.

4 | DISCUSSION

A notable finding was the potential importance of SC to carers' maintenance of dementia care. SC was proactively advocated to less experienced carers by their peers and by knowledgeable

voluntary sector staff. Those with experience perceived SC to be a vital means of eliciting valuable support, including emotional and practical support, to mediate care-based stress and prolong family care. Nevertheless, not all carers, either in this study or more generally, utilise voluntary sector support. Formal services/practitioners can therefore play an important role in signposting carers to this sector. Formal services/practitioners can also be more influential in delivering additional support that encourages SC. However, this study reveals this relies on overcoming six principal hindrances.

Hindrances included providers' relatively fixed response to carers' needs, manifest in a predominantly generic, medicalised approach based around quasi-institutional settings. In England, this is reflected in the general advice given to carers which steers them towards day centres/respite care (NHS, 2018). The majority of carers/carees in this study expressed concern that transition to quasi-institutional settings was perceived to represent a staging post for full institutionalisation-a finding endorsed by previous studies (Batch & Mittelman, 2012).

Carers'/carees' preferred option was 'ageing in place,' relying on community/domiciliary care-a finding also replicated by previous studies (Kampanellou et al., 2019). 'Ageing in place' represents a policy objective that is high on the agenda, including in the UK (NHS Long-Term Plan, 2019). However, a setback is how to move away from previous reliance in many parts of Europe, including the UK, on long-term care (LTC) models that promote institutional care (Challis, Darton, & Stewart, 1998). A rapidly ageing demographic across Europe necessitates a wholesale shift away from such LTC models and towards effective 'ageing in place' (GCOA, 2017). This study found 'ageing in place' was not fully supported. Consistent with previous reports, effective domiciliary support may be contingent on location (Age UK, 2017). This has led to calls for 'strategic/systemic reforms' to make 'ageing in place' viable, especially for family carers (GCOA, 2017, p.29). Based on the findings, these reforms should include wider options: emotional support; opportunities to socialise despite dwindling/non-existent relational support; access to quality domiciliary care. Promoting this requires governmental investment in continuing care to enable longer duration of paid care, establishment of good relationships between paid carers/users; fairer remuneration for paid carers; closer regulation to ensure care quality (Atkinson; & Crozier, 2016). These issues need to be prioritised to encourage carers to associate SC with receipt of quality support.

Reticence to engage in SC was generated from the outset where carers initially felt compelled to develop a strong sense of autonomy in the absence of formal support. Over time, carers became habituated to operating autonomously. This became the norm, widening the gulf between carers/formal providers. Ultimately, this proved counter-productive, stymieing carers' employment of SC. Moreover, carers appeared unaware of the impact of going-it-alone/eschewing SC until it was too late to avoid cessation of family care. Sustaining family care requires a balance between carer autonomy/formal provision of support from the outset and

duration of care via a closer, collaborative approach. This study endorses Stephan's, Möhler, Renom-Guiteras, and Meyer (2015) call for research to examine the intricacies involved in forging such collaborations.

The findings revealed how lack of clear consensus among formal providers regarding 'what works to support carers' led to services being presented as 'one-size-fits-all' packages. Arguably, this ignores the complexity/uniqueness of dementia and bespoke needs of individual carers. For example, this study found that formal support regularly focused on practical support, overlooking carers' often cited need for emotional support. Ideally, bespoke support should also include a wider range of choices, including different settings (home, dementia cafés, voluntary organisation), acknowledging individuals' preferences. Where consensus has emerged regarding 'what works' this needs to be capitalised upon. Services demonstrating effectiveness tend to be individualised/community-based, including: Admiral Nurses (Bunn, Goodman, Pinkney, & Drennan, 2016), psychoeducational training (Dickinson et al., 2017), dementia cafés (Greenwood, Smith, Akhtar, & Richardson, 2017) and reminiscence groups (Charlesworth et al., 2016). Services can also be designed that are cost-effective, e.g. emotional support via tele-medicine (Waller, Dilworth, Mansfield, & Sanson-Fisher, 2017) and online video-counselling (Chatwin; & McEvoy, 2019). Services which prove effective could be invested in as part of a LTC strategy to embed carer support within communities. A variety of macro-level models exist throughout Europe that might usefully inform how governments could fund such initiatives (GCOA, 2017) (Appendix B). Meanwhile, at a local level, co-ordination between LTC (e.g. as organised by local authorities) and healthcare systems offers an effective means of improving services' efficiency/reducing care costs (GCOA, 2017).

Currently, the paradox remains that while family carers are recognised as forming 'a critical and valuable part of any high-quality local health and social care system' (CQC, 2018, p.28), even the UK-the world's 5th largest economy (IMF, 2019)-allows the majority of carers to absorb the bulk of the pressure for care provision with no support (CQC, 2018, p.21). This stymies carers' employment of SC and the future outlook continues to generate concerns with minimal steps towards cross-party talks to find consensus on the future of social care and no clear proposals for reform (Holmes, 2020). At a macro level, consensus is needed concerning where social care, LTC and family care fit within governmental policy hierarchies and a proposed commitment to family care/'ageing in place.' At an individual level, consensus is needed regarding the types of services most beneficial to carers, how these can be tailored to meet individuals' needs and how this will be funded so that it is not contingent on carers' location.

Future reforms need to reach consensus regarding how all sectors (health care providers, social services, voluntary/charity) can work closely and collaboratively to deliver community-based support. Future funding needs to consider not only increased investment in health/social care services, including the allied health services (counsellors, mental health support etc.), but also the voluntary/charity sector-recognising its valuable role in enhancing coping to help sustain family care.

Hindrance to carers' adoption of SC stemmed from formal providers' flawed assumption that SC will be provided for by relational support-a point also raised by Wolkowski et al.(2017). This study found carers/carees often fell into a vicious circle as the care journey advanced, with diminishing relational support exacerbating isolation, while increasing caregiving responsibilities eroded time available for carers to access communities. To date, 365 areas in England have committed to being Dementia Friendly Communities (Powell & Baker, 2019). While welcome, this does not solve the problem of isolation on its own. Carers are highly vulnerable to social exclusion (Greenwood, Mezey, & Smith, 2018) which affects 83% of UK carers (Carers UK, 2015). A dearth of research exists that addresses this issue (Keating, Eales, Funk, Fast, & Min, 2018). The UK Care Act (2014) recommends local authorities promote carers' wellbeing through social activities, however precise details of how this will be achieved are lacking (Greenwood et al., 2018).

A further finding was that as the care journey advanced, carees' deteriorating dementia symptomatology combined with carers' exposure to care-based stress (spanning several years) often compelled carers to adopt a short-term perspective. Although this can provide a means of compartmentalising family care into more manageable chunks of time, it presents a significant barrier to SC and the recruitment of external support that often relies on longer-term planning. Therefore, promotion of SC relies on developing a supportive infrastructure capable of co-ordinating support efficiently and at short notice.

Remoteness/disengagement from support systems and services has led to carers being called the 'silent army' (Brown, 2018) and 'the invisibles' (Carmeli, 2014). This study recommends a new care paradigm that embraces a holistic approach to the promotion of SC with a focus on facilitating carers' receipt not only of practical support, but crucially also emotional support to make family care sustainable. Carer coping that facilitates 'ageing in place' relies not only on individuals' adaptive strategies, but also close collaboration with a wider network of support services (health care providers, social services, voluntary/charity sector). SC represents a critical strategy in the mediation of stress, but it also performs a critical function as a 'bridging mechanism' that facilitates closer integration/networking with wider sectors. However, SC is only as effective as the quality of support it elicits and this is very much contingent on the reciprocity of providers operating collaboratively with carers.

Above all, SC relies on achieving a balance that facilitates its potential to enhance the sustainability of family care. This balance is contingent on addressing six principal hindrances (Figure 1).
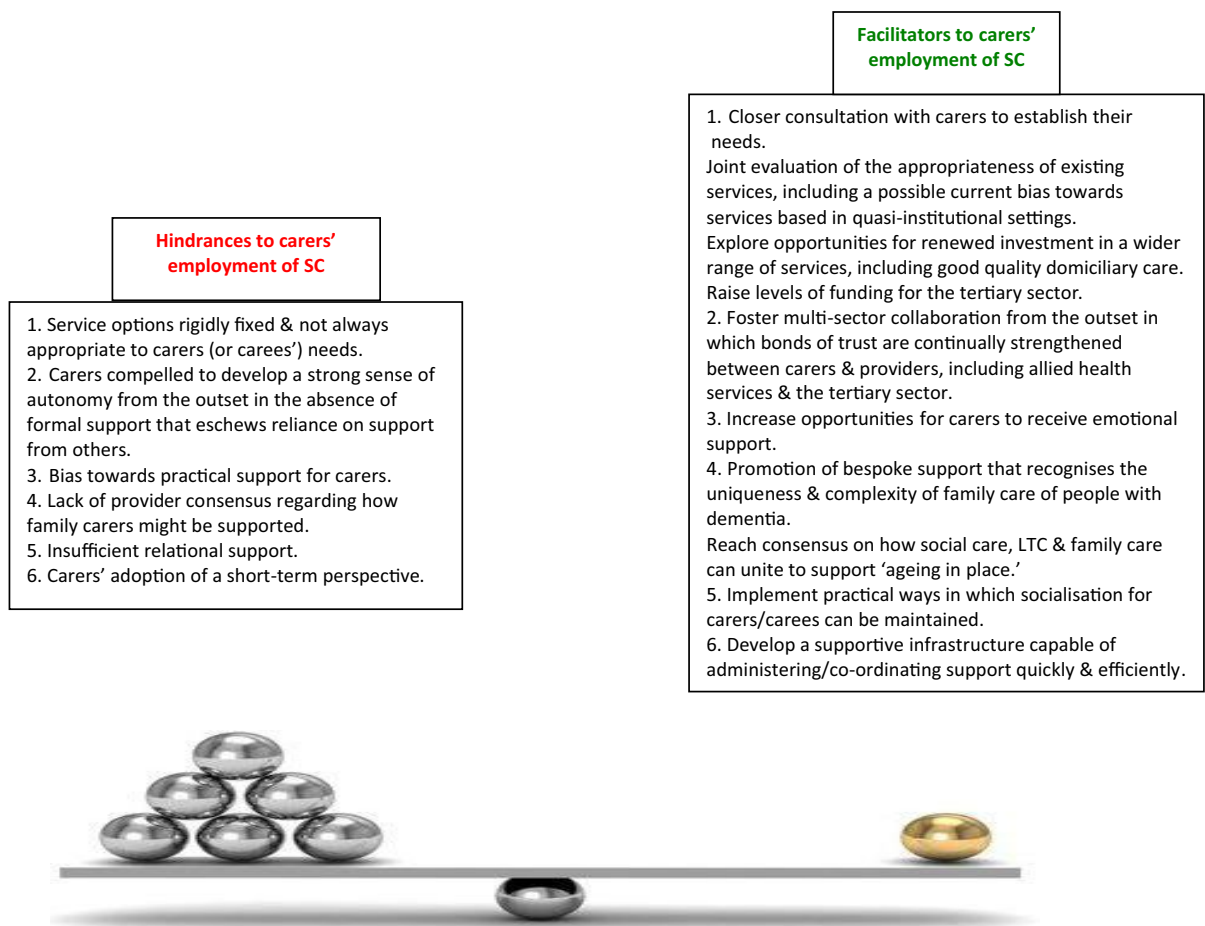
Facilitators to carers' employment of SC

1. Closer consultation with carers to establish their needs.
Joint evaluation of the appropriateness of existing services, including a possible current bias towards services based in quasi-institutional settings.
Explore opportunities for renewed investment in a wider range of services, including good quality domiciliary care.
Raise levels of funding for the tertiary sector.
2. Foster multi-sector collaboration from the outset in which bonds of trust are continually strengthened between carers & providers, including allied health services & the tertiary sector.
3. Increase opportunities for carers to receive emotional support.
4. Promotion of bespoke support that recognises the uniqueness & complexity of family care of people with dementia.
Reach consensus on how social care, LTC & family care can unite to support 'ageing in place.'
5. Implement practical ways in which socialisation for carers/carees can be maintained.
6. Develop a supportive infrastructure capable of administering/co-ordinating support quickly & efficiently.

Hindrances to carers' employment of SC

1. Service options rigidly fixed & not always appropriate to carers (or carees') needs.
2. Carers compelled to develop a strong sense of autonomy from the outset in the absence of formal support that eschews reliance on support from others.
3. Bias towards practical support for carers.
4. Lack of provider consensus regarding how family carers might be supported.
5. Insufficient relational support.
6. Carers' adoption of a short-term perspective.

FIGURE 1 Social coping model: achieving a better balance by addressing the six principal sources hindrances to SC and maximising its potential to enhance the sustainability of family care of people with dementia in the long term

It is likely the findings possess translational potential to other, perhaps similar carer groups-particularly those who care for people with other chronic/irreversible conditions.

4.1 | Future Research

Future studies might examine whether females are more disposed towards emotional support than males and whether males need encouragement to recruit emotional support. Differences could also be explored between urban/rural populations regarding availability/ accessibility of support and how this may differentially impact on carers' propensity to engage in SC. Carers from BAME cultures may have different attitudes/perceptions to SC and generally reduced access to services compared with Caucasian participants in this study. Factors which facilitate/hinder SC for BAME groups may differ from those outlined here.

4.2 | Strengths of this study

- Realist Evaluation can provide the level of specificity needed to address complex social issues and tailor solutions to meet the needs of specific populations.
- SC is revealed as a critical coping strategy/factor in determining carers' ability to maintain family care of people with dementia.
- SC supports 'ageing in place.'
- Causal mechanisms that hinder SC are exposed to pave the way for clearer guidelines for how providers can facilitate its employment by carers.
- Family carers' perspective.
- Wider translational potential.

4.3 | Limitations of this study

- Reliance on a cross section of participants.
- The need for further longitudinal studies to examine SC alongside other adaptive coping strategies.
- The need for studies beyond N.E. England to offer regional comparisons.
- Consistent with the principle of iterative inquiry (Pawson, 2013) there is a need to build on this research and take the findings forward.

5 | ETHICAL CONSIDERATIONS

Full ethics approval for this study was granted by The Faculty of Health and Life Sciences Research Ethics Committee at Northumbria University.

CONFLICT OF INTEREST

There are no conflicts of interest presented by this paper by any of the authors.

AUTHOR CONTRIBUTIONS

MP reviewed the full texts, assessed the risk of bias, extracted the data and wrote the paper. SC critically reviewed the content of the paper and contributed to revising the paper. CA critically reviewed the original manuscript and contributed to its initial submission. All authors have approved the submitted version of the manuscript.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.