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Making personalised short breaks meaningful: a future research agenda to connect academia, policy and practice

Seddon, Diane; Miller, Emma; Prendergast, Louise; Williamson, Don; Cavaye, Joyce

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Making personalised short breaks meaningful: A future research agenda to connect academia, policy and practice

Abstract

Purpose

There is a growing policy impetus to promote carer well-being through the provision of personalised short breaks. However, understanding of what makes for a successful personalised short break is limited. This paper identifies key evidence gaps and considers how these could be addressed.

Design/methodology/approach

A scoping review mapping the evidence base relevant to respite and short breaks for carers for older people, including those living with dementia, was completed. National and international literature published from 2000 onwards was reviewed. The scoping review focused on wellbeing outcomes, identified by previous research, as being important to carers.

Findings

Most studies investigating the outcomes of short breaks for carers supporting older people focus on traditional day and residential respite care. Although there have been developments in more personalised break options for carers, research exploring their impact is scarce. There is limited knowledge about how these personalised breaks might support carers to realise important outcomes, including: carer health and wellbeing; a life alongside caring; positive caregiving relationships; choices in caring; and satisfaction in caring. Three priority lines of inquiry to shape a future research agenda are identified: understanding *what matters* - evidencing personalised short break needs and *intended* outcomes; capturing *what matters* - outcomes from personalised short breaks; and, commissioning, delivering and scaling up personalised short breaks provision to reflect *what matters.*

Originality

This paper contributes to the development of an outcome-focused research agenda on personalised short breaks.

Key words
Carers, personalised short breaks, respite, outcome-focused research

Classification
Research Paper

Introduction

Research acknowledges the complexities of caring relationships, that can confer benefits and significant challenges. It identifies support for carers (family members, friends or neighbours who provide help and assistance to someone) as a global public health issue with a focus on maintaining carer wellbeing (Zwingmann *et al.,* 2020). The impact of the caring role and the stressors carers can experience when supporting people with complex care needs are well documented (Katbama *et al.,* 2016; Farina *et al.,* 2017; Temple and Dow, 2018). The provision of short breaks is identified as a means of sustaining caring relationships. A break from caring can make a positive difference to carers' physical and emotional wellbeing and sense of resilience (Wilz and Fink-Heitz, 2008; Liu *et al.,* 2018; Roberts and Struckmeyer, 2018).

The terminology surrounding short breaks can vary, with alternatives including restorative, replacement or relief care. The most common terms are short breaks and respite care. Although the latter two terms are sometimes used interchangeably, distinctions are sometimes made. There is no universally agreed definition of respite in the research or policy and practice literature (Kirk and Kagan, 2015), however, some authors associate respite with traditional services, usually involving the person with complex care needs being supported in settings outside the home (Longshaw and Perks, 2000). There is an implicit assumption that the term respite indicates a pause from something that is difficult or unpleasant, even though there can be positive aspects to caring (Rochira, 2018). While traditional forms of respite can be beneficial for families and have their place, it is suggested that the concept of a short break is more acceptable to carers (Bliss, 2006).

A further distinction between respite and short break is that the term short break sometimes has broader connotations in the literature than impacts for carers. This is

associated with a shift in focus from supporting carers in their caring role to improving quality of life for *both* the carer and the person they support, potentially including a break from routine *together* (Longshaw and Perks, 2000). The term personalised short break therefore can be associated more with the advent of bespoke, outcome-led approaches to achieving those things that matter most to carers and those they support and with provision that reflects the unique nature and qualities of caring relationships (Scottish Government, 2008).

Existing knowledge of what makes for a successful personalised short break is limited. This paper contributes to shaping a future research agenda on personalised short breaks. Informed by a scoping review that mapped the evidence base supporting respite and short breaks for carers for older people, it identifies evidence gaps and highlights three priority lines of inquiry about evidencing personalised short break needs and their intended outcomes, capturing outcomes from personalised short breaks and commissioning, delivering and scaling up provision.

Background

Policy impetus to promote carer well-being through the provision of short breaks

Many economically developed countries recognise the importance of personalised short breaks in supporting interdependent caring relationships. In the USA, the Lifespan Respite Care Program Reauthorization Act (2019) acknowledges the need to expand the range of community-based break options. In Australia, the Carers Recognition Act (2012) highlights the importance of carers' social wellbeing; initiatives, including the Integrated Carer Support Service Model (Australian Government, 2019) prioritise flexible, responsive breaks provision as a critical preventative resource to support carer wellbeing and maintain family and community connections. In Sweden, self-governed municipalities are mandated by the Social Services Act (2001) to provide flexible support for carers, including personalised breaks from caring.

A duty to promote carer wellbeing is enshrined in UK legislation, which stipulates that support must be personalised to help individuals to maximise their own wellbeing outcomes (Carers and Direct Payments Act (Northern Ireland) 2002; Care Act (England) 2014; Social Services and Wellbeing (Wales) Act 2014; Carers (Scotland) Act 2016). In Wales, codes of practice relating to the assessment of need emphasise

the importance of understanding, capturing and responding to *what matters* (Welsh Government 2015:15). One of three national priorities for carers is to *support a life alongside caring* (National Assembly for Wales, 2019). According to the Carers (Scotland) Act 2016, each local authority must publish a short break services statement setting out information about short break services for carers and people with complex support needs.

Translating the policy impetus into practice

Despite the policy impetus to deliver personalised, outcome-led support, further change is needed to ensure that the wellbeing outcomes mattering most to carers and those they care for are given meaningful consideration (Social Care Institute for Excellence, 2018; Carers UK, 2019a). In the annual *State of Caring s*tudy (Carers UK, 2019b) merely one quarter of carers who completed a carer assessment felt that their break needs were sufficiently explored during the assessment.

The call to *re-think respite* for people living with dementia and their carers (Rochira, 2018:5) highlights that respite is synonymous with traditional day and overnight services to the neglect of personalised break options that may be *as* if not *more* impactful in supporting caring relationships and may be delivered at a lower cost. Other research suggests that personalised community-based breaks may accrue lower costs than traditional services such as day care (Fox, 2011).

The challenges of supporting an ageing population, including those living with dementia, are well documented. With the global cost of dementia estimated at one trillion US dollars (Pickett and Brayne, 2019), the need to prioritise limited service budgets is recognised (Jones *et al.,* 2018), including those for respite care and personalised short breaks. However, considerable resource is expended on services that do not always support individuals to achieve meaningful outcomes (O'Shea *et al.,* 2020). A national inquiry into the impact of the Social Services and Wellbeing (Wales) Act (2014) acknowledges that the traditional respite model is no longer viewed positively by many carers or by individuals with care and support needs (National Assembly for Wales, 2019). Carers report difficulties in accessing breaks, a lack of flexibility and limited opportunities to take a break together (National Assembly for Wales, 2019). In Scotland, carers report difficulties in sourcing information about short

breaks, difficulties with the planning process, a lack of personalised provision and uncertainty about eligibility (authors own, 2012).

In 2019 Carers UK called for increased and ring-fenced funding for quality breaks. Along with the Social Care Institute for Excellence they developed guidance for commissioners and providers, including general principles that emphasise the importance of a flexible range of inclusive breaks co-produced with carers and shaped by their experiences (Carers UK, 2019a).

Method

Arksey and O'Malley's (2005) framework for scoping studies guided the review of the respite care and short break literature. Their approach helps capture a breadth of material and identify under-researched areas (Levac *et al.,* 2010). Used successfully in carer research (Larkin *et al.,* 2019), it involves identifying the research question(s); identifying relevant studies; study selection; charting the data; and collating, summarising and reporting results.

Identifying the research question(s)

The research questions were:

- What does research tell us about the impact of short breaks for carers?
- What are the gaps in the existing research literature?

This paper focuses on the evidence gaps. The following terms underpinned the scoping review:

Carer

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. (Carers Trust, 2019; https://carers.org/what-carer)

Short break

A short break is any form of service or assistance, which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities, with the purpose to support the caring relationship and promote the health and well-being

of the carer, the supported person and other family members affected by the caring situation.

(Shared Care Scotland, Position Statement, 2017)

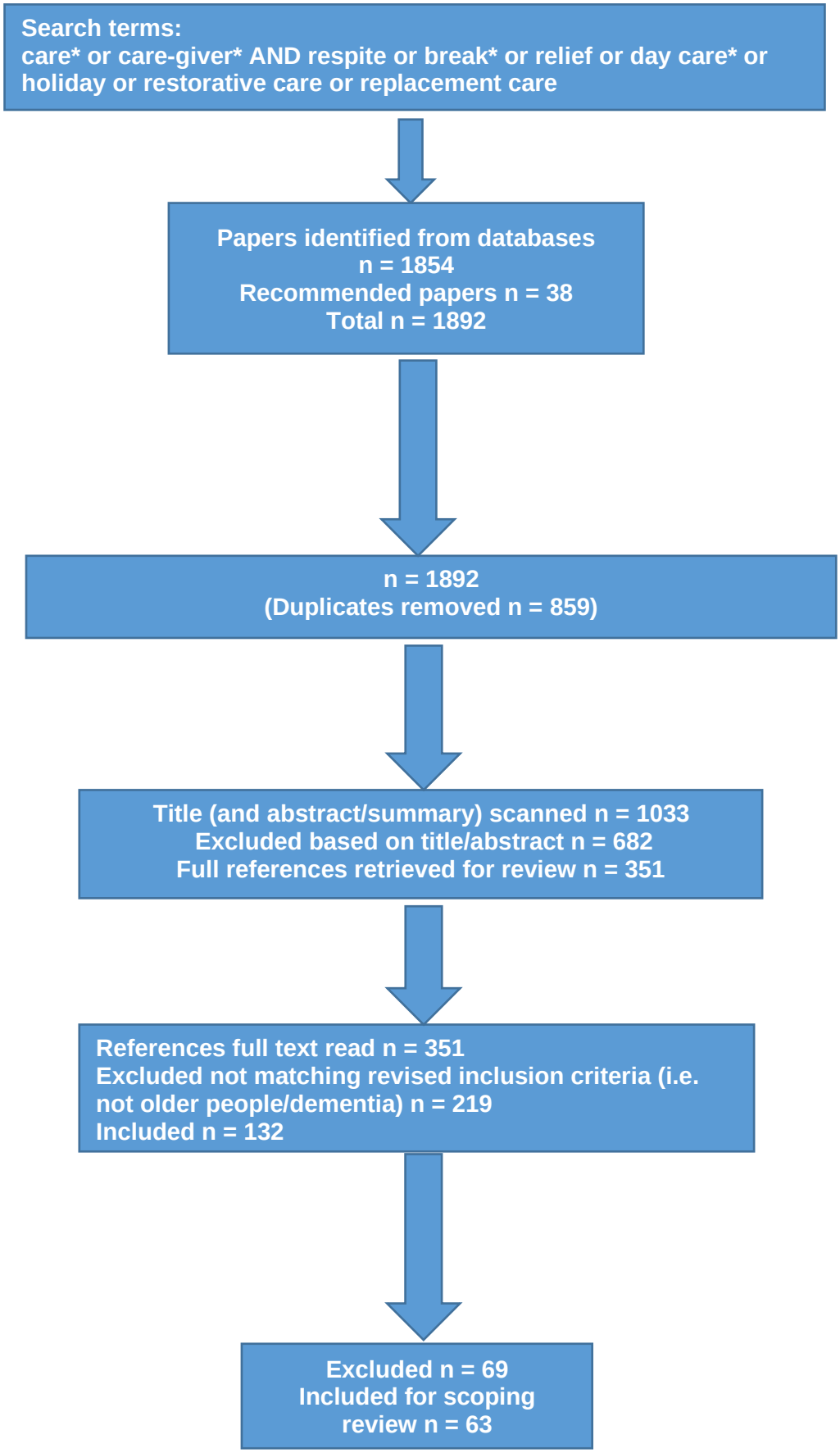
Identifying relevant studies

The literature on caring is fragmented; it is published in peer reviewed journals and in the grey literature (Social Care Institute for Excellence, 2018). The Carers and Disabled Children Act (2000) challenged organisations to develop more creative ways to meet carer needs, hence, we identified English language publications from 2000 onwards, including:

1. Peer reviewed articles (qualitative, quantitative or mixed methods studies and systematic reviews)
2. Grey literature
3. Policy and practice reports

Figure 1 summarises the literature search.

Figure 1 Literature Search



The *initial* search included a range of carer groups. Following first screening, where a large volume of literature was identified, the review then focused on carers supporting older adults, including those living with dementia. This is consistent with the iterative nature of scoping reviews to balance the breadth and comprehensiveness of studies (Levac *et al.,* 2010). Scoping work synthesizing knowledge about carers identifies old age and dementia as *the* most frequent reasons for caregiving (Larkin *et al.,* 2019). Older carers play a critical role in supporting individuals with care needs, including caring for their spouse (Greenwood *et al*., 2019).

Study selection

Citations were imported into the bibliographic management software Mendeley. Literature was included evidencing the contribution of short breaks or *respite* to achieving the following carer-generated outcomes:

- Health and wellbeing
- A life alongside caring
- Positive relationships with the supported person
- Choices in caring
- Satisfaction in caring

These outcomes were chosen, as previous research looking at personal outcomes confirmed that they were key to understanding what matters most to carers (Miller and Barrie, 2018). Sixty-three studies from the UK, North America, Scandinavia, Australia and New Zealand, Spain and Germany were included in the scoping review.

Charting the data

Data were charted in an Excel file, recording the author, year of publication, title, carer population, research method and key findings. A qualy metric was not used to appraise the quality of included studies as this is not a requirement for scoping review work (Levac *et al.,* 2010).

Collating, summarising and reporting results

Data were transferred to a summary table, recording:

- Author(s), year of publication, country

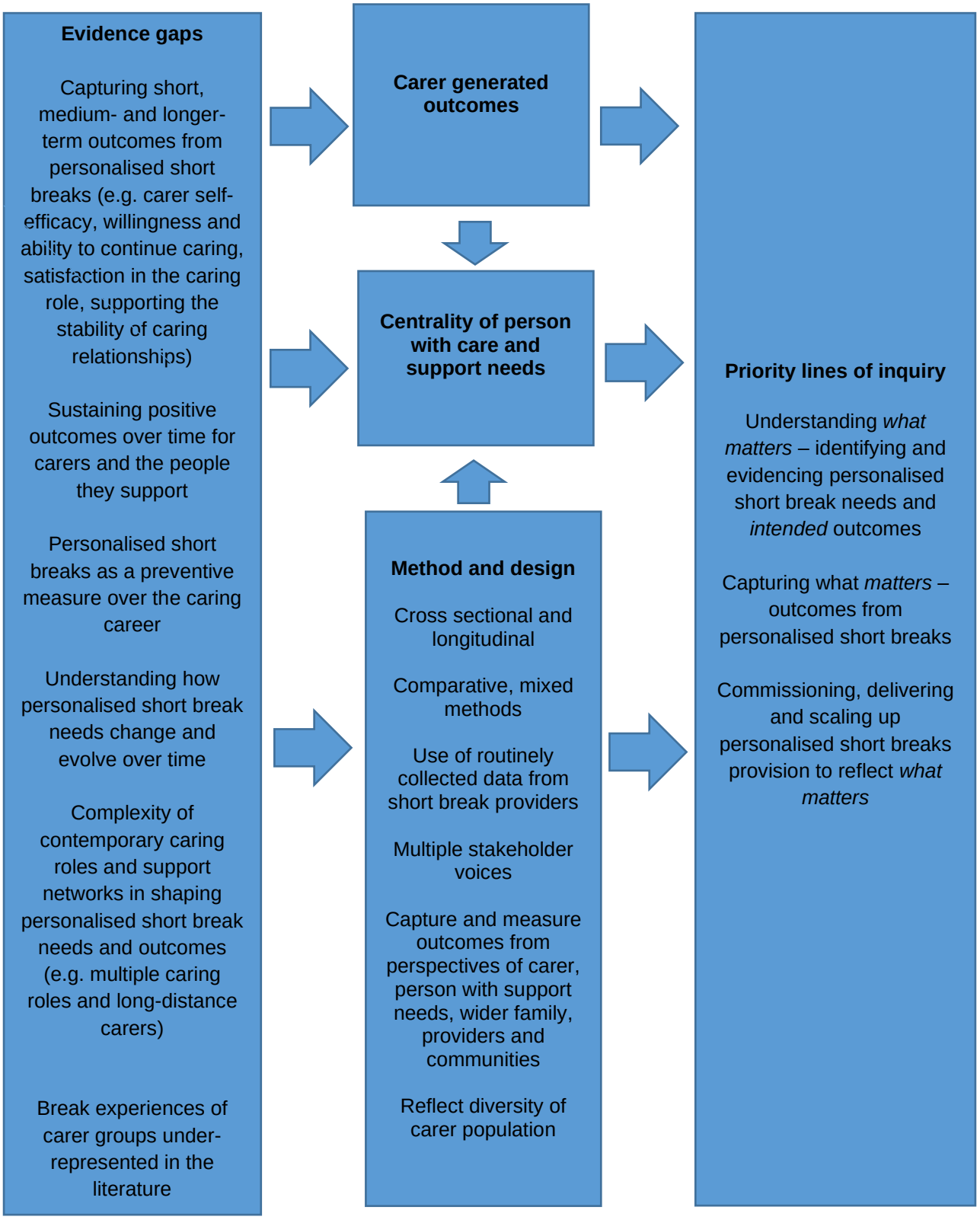
- Break type
- Study aims
- Methods
- Outcome measures (where specified)
- Findings
- Recommendations
- Research gaps

A thematic analysis aligned to the phases described by Braun and Clarke (2006) was completed, involving: familiarisation by immersion in the literature; coding the material and refining the codes; identifying themes and coding data relevant to each theme; reviewing themes to ensure a convincing story; defining and naming the themes, to capture the essence of each and produce an initial thematic map; and writing.

Findings

The key evidence gaps, and priority lines of inquiry are presented in Figure 2 to inform a future personalised short breaks research agenda.

Figure 2 Shaping a Future Research Agenda: Evidence Gaps and Priority Lines of Inquiry



A range of break options are described in the literature, including traditional day-care (Liu *et al.,* 2018), residential respite care (Burglund and Johansson 2013) and in-home respite (Washington and Tachman, 2017), as well as personalised breaks delivered via host family support arrangements (Bell and Litherland, 2013), supported holidays (Wilz and Fink-Heitz, 2008) and leisure and arts facilities (Pienaar and Reynolds, 2015). Most studies investigating the outcomes of short breaks for carers supporting older people focus on day and residential respite care services rather than the personalised break options that have developed in the UK and other countries. This is a key gap in the existing research literature.

Where personalised break options are reported they are mainly in descriptive accounts of provision, framed as innovative practice, or they are highlighted in service evaluation work published in the grey literature (Dementia Adventure, 2017). Peer reviewed research exploring what makes these personalised breaks meaningful, and their impact, is scarce. There is a lack of research evidence from carers, the individuals they support, staff involved in delivering personalised short break interventions, practitioners involved in assessment and support planning processes and commissioners. The limited evidence base does not reflect the heterogeneity of the carer population; carers under-represented in the short break literature include those from black and minority ethnic groups, carers from the lesbian, gay, bisexual, transgender, queer (or questioning) and intersex community and carers living in remote rural areas. As noted in Figure 2 above, future research capturing carers' personalised short break experiences should reflect the diversity of the carer population.

Health outcomes

Although there is some research to suggest that personalised breaks can support positive health outcomes (Washington and Tachman, 2017), including improvements to carer physical health (Wilz and Fink-Heitz, 2008) and mental health (Bell and Litherland, 2013), the evidence base is too limited to draw firm conclusions about the contribution of these personalised breaks to realising positive health outcomes and, if realised, whether they are sustained over time. Aside from Wilz and Fink-Heitz's (2008) work on supported holidays for spousal carers and their partners living with

dementia, we found no published peer reviewed research, longitudinal in design, following-up carers at specified time points after their personalised short break(s) to explore the medium- and longer-term outcomes and identify what matters in shaping positive health outcomes *over time*. Evidence gaps include:

- The key features of a personalised short beak that make it impactful and support the realisation of positive health and wellbeing outcomes
- The timing of personalised short breaks as a preventive health measure over the caring career
- How personalised short break needs may change over time, for example, changes in the optimal break length and type to realise positive carer health outcomes
- Comparative work addressing the short-medium- and longer-term health outcomes from traditional versus personalised short breaks

A review of the international evidence on support for carers suggests that a combination of interventions may be most effective in helping carers (Brimblecombe *et al.,* 2018). However, little is known about how personalised break options can combine with other interventions to achieve health and wellbeing outcomes, including combining personalised short breaks with training or learning relaxation or sleep management techniques. Whilst Wilz and Fink-Heitz (2008) included psychoeducational group sessions in their supported holiday, research evidence is scarce.

A life alongside caring

Studies document how short breaks support *a life alongside caring,* including traditional breaks afforded by day care (Schacke and Zank, 2006) and personalised breaks (Bell and Litherland, 2013). However, research fails to capture the complexity of caring relationships, responsibilities and arrangements. For individuals who have multiple caring roles, time away from one caring role may be occupied by other caring commitments; this is not reflected in the literature. Whilst there is research looking at the break experiences of parent carers supporting a child with a disability who have other childcare commitments (McConkey, 2011), there is limited evidence about the experiences of carers for older adults who occupy multiple caring roles. This is an important knowledge gap, as the number of individuals caring for more than one person is increasing, as is the number of carers with multiple caring roles. Of the current carers responding to the *State of Caring Survey* (Carers UK, 2019b), 20% were caring for two people, 5% were caring for three people and 2% were caring for four or more. This includes those referred to as sandwich carers because of their dual roles caring for ageing parents and young children. There is limited knowledge about the personalised short break needs of these carers, *what matters* to them and the outcomes from their break experiences.

A life alongside caring is conceptualised narrowly as an opportunity for carers to pursue hobbies and maintain friendships and social networks. There is a dearth of research exploring the role of personalised short breaks in supporting other aspects of life - enabling carers to enter, retain or re-engage in paid employment, work in a voluntary capacity or complete educational or training programmes. Allied to this, the potential to yield financial wellbeing outcomes is not considered, for individual carers or at a societal level as reflected in employee retention rates and productivity levels. As noted in Figure 2, a future research agenda should be underpinned by a commitment to understanding personalised short breaks from multiple stakeholder perspectives and this should be reflected in future research designs.

Supporting positive caring relationships

Traditional respite services such as day care can help to support positive caring relationships (Roberts and Struckmeyer, 2018). Whilst there is grey literature suggesting that personalised break options *may* support improvements in dementia caring relationships (Bell and Litherland, 2013), there is limited understanding of how these personalised short breaks support caring relationships, including relationship stability over time, in the peer reviewed literature. This is a significant evidence gap that should feature prominently in a future research agenda (see Figure 2 above) and it should be reflected in study designs, for example, through the recruitment of caregiving dyads to explore the impact of personalised short breaks from the perspectives of carers and the individuals they support.

Caring relationships are complex, dynamic and often reciprocal in nature (Larkin *et al.,* 2019). However, short break research fails to capture the complexities of caring relationships, support arrangements and caring networks. Mostly, it is predicated on the assumption that an individual occupies the caring role who is related by blood, marriage or adoption to the person they support. This does not reflect contemporary caring arrangements and support networks. Friends and neighbours can play a key role in caring for people. Individuals living at a distance provide much needed support to enable people to stay in their own homes. Distance carers combine multiple caring responsibilities for different generations of their family whilst in paid employment (Carers UK, 2019c). Research does not address the personalised short break needs of these carers.

Carer choices

Whilst some research suggests that personalised break options can support continued caring and delay admission to a care home (Dundee Carers Centre, 2014), the evidence base is limited. Knowledge gaps include understanding the ways these personalised breaks influence carer:

- *Willingness* to continue caring
- *Ability* to continue caring
- Confidence in the caring role
- Sense of self-efficacy

Carer sense of satisfaction

Carer sense of satisfaction is associated with resilience and sustained involvement in the caring role (McCann *et al.,* 2015). However, studies (looking at either traditional or personalised break options) have not addressed the impact of short breaks on carer sense of satisfaction.

Shaping a Future Research Agenda: Discussion

There is a dearth of research addressing the outcomes from personalised short breaks. Research is needed to explore how these personalised breaks might support the realisation of government priorities for carers and those they care for, especially the achievement of personalised wellbeing outcomes. A future research agenda informed by three priority lines of inquiry is proposed:

- Understanding *what matters* - identifying and evidencing personalised short break needs and *intended* outcomes
- Capturing *what matters* - outcomes from personalised short breaks
- Commissioning, delivering and scaling up personalised short breaks provision to reflect *what matters*

Understanding what matters – identifying and evidencing personalised short break needs and intended outcomes

Understanding *what matters* to carers and those they support is key to impactful research and to future practice development, for example:

- How can individuals be supported to:
    - Identify their personalised short break needs
    - Identify and explore bespoke break options that could potentially be put in place to meet personalised short break needs
    - Understand the break outcomes that matter most and are meaningful to them
    - Recognise and accept their personalised short break needs as legitimate

- What are the:
    - Key aspects of the caring experience shaping personalised short break needs and preferences
    - Defining features of impactful personalised short breaks

Health and social care practitioners are important stakeholders; they help individuals to identify their break needs and are essential to co-creating a future service vision.

Researching assessment and support planning processes and exploring, from carer and practitioner perspectives, their effectiveness in identifying, capturing and evidencing personalised short break needs is essential, including opportunities for carer self-identification of their break needs and how this can be facilitated. This work may sit within a wider programme of research around assessments and support planning as co-produced conversations to generate shared understanding, to facilitate alternative thinking about what works for individuals and to promote positive wellbeing outcomes. Evidence about outcome-focused carer assessments and support planning in the UK (Seddon and Robinson, 2015; Miller and Barrie, 2016; 2020) provides a starting point to frame future research. Similarly, there are established frameworks for researching the *intended* outcomes for people with complex needs (Miller and Barrie, 2016). Ideally, planning with carers should start with what matters to them, what outcomes they would like to achieve or maintain, and involve collaborative conversations to identify creative means of progressing those outcomes. A range of tools and resources are available to support such approaches, including the Carers Outcome Agreement Tool (Hanson *et al.,* 2006) and more general guidance (Miller and Barrie, 2016).

Capturing what matters – outcomes from short breaks

Capturing and evaluating outcomes presents challenges. A key lesson from embedding outcomes in practice in Scotland and Wales is to move the focus from *attribution* to contribution in considering how different factors might influence an outcome for a carer (Miller and Barrie, 2016). Recent work on personal outcomes adds to this, including the Meaningful and Measurable Action Inquiry Project. This project

explores how best to capture and use personal outcomes data, considers the quality of interactions needed to generate robust outcomes data, captures emergent good practice in recording outcomes and highlights the difference made by focusing on outcomes in practice.

Capturing health and wellbeing outcomes resulting from a personalised short break is important, as carers often identify a concern to maintain their own health to be able to continue caring (Oliveira *et al.,* 2019). However, research must consider a range of wellbeing outcomes, not only for carers, but for the individuals they support and their families, including opportunities to re-connect with other family roles. As noted, wellbeing outcomes, including *a life alongside caring*, are prioritised in UK social care policy but are narrowly defined. There is great potential for research to consider how outcomes important to carers, including the contribution of personalised short breaks to supporting carers in paid employment, education and training and to realising financial well-being outcomes, align with wider societal and policy perspectives.

When capturing outcomes and the factors shaping these, researchers should consider:

- Different breaks types and how they influence wellbeing, including personalised breaks taken together and taken apart, personalised breaks taken in or away from the home, and personalised breaks offering opportunities for peer support. In light of COVID-19, capturing personalised breaks delivered via on-line resources and breaks in the outdoors take on new significance.
- Optimal personalised short break length and type and how this may change over time
- Carers' use of personalised break time and how this influences outcomes
- How positive outcomes can be sustained *over time*

Commissioning, delivering and scaling up personalised short breaks provision to reflect what matters

Meaningful breaks rely on quality commissioning (Rochira, 2018). Key to future research connecting academia, policy and practice are studies addressing ways to effectively commission and deliver personalised, meaningful breaks at scale. Reflecting the complex, inter-sectoral nature of provision, research should consider the:

- Evolving role of commissioners as facilitators of change, bringing together providers, people with complex care needs and carers to shape future provision
- Range of providers, including, social enterprise services, arts facilities and hospitality
- Different means that offer flexibility and choice, including, social prescribing, social enterprises, community-based groups, direct payments and self-directed support

These issues are key to addressing the challenges of delivering personalised, meaningful breaks to a diverse population in context of rising demand and declining budgets. As noted, there is also an urgent need to generate evidence about more flexible, re-imagined personalised breaks considering COVID-19. A current evaluation of outdoor projects in Scotland highlights benefits for both people living with dementia and their carers (Outside the Box, 2020). When such projects are thoughtfully managed, there are novel opportunities for carers and people living with dementia to socialise outside in limited numbers. Some projects allowed for the person living with dementia to attend on their own; for the person living with dementia and their carer to take a break by attending together, and with the latter option to enable each to have time apart, by mixing with others, or taking part in different activities. While limited in terms of the possibility of a full break away from a caring situation, online resources to provide information and advice for carers, promote carer wellbeing and access to peer support are burgeoning (Aledeh and Adam, 2020).

Research design

It is beyond the scope of this paper to comment in detail on research design; the key points are summarised in Figure 2. There are opportunities for quantitative, qualitative

and mixed-methods studies using cross-sectional and longitudinal designs to capture personalised short break outcomes. Kirk and Kagan (2015) highlight the importance of the proximal (immediate) and distal (over time) outcomes from short breaks. Given the paucity of longitudinal caregiving research (Larkin *et al.,* 2019), longitudinal studies would be welcome, tracking how personalised short break outcomes can change and the contributing factors.

Research designs should reflect the:

- Heterogeneity of the carer population
- Views of people with complex care needs (through the inclusion of caring dyads)
- Complex nature of caring, by including carers with multiple caring responsibilities, wider family perspectives, friends and neighbours who care and distance carers

There are opportunities for researchers to work collaboratively with breaks providers to analyse their routinely collected data. For example, studies adopting a Social Return on Investment (SROI) approach, where routinely collected service data is considered alongside data from standardised and bespoke measures to capture outcomes, determine the added value of personalised breaks and how this is achieved. There are opportunities to analyse anonymised data collected by short break providers pre and post the provision of a personalised break. This might include demographic information to highlight who is/is not accessing personalised short breaks as well as a suite of validated scales that measure outcomes relating to health, quality of life and resilience.

Reporting research findings to inform practice development presents challenges (Andrews *et al.,* 2015). Alongside academic peer-reviewed papers, researchers should devise more impactful dissemination to commissioners and providers (including podcasts and photovoice methods relaying first-hand experiences of personalised short breaks) and targeted messages. Collaboration is key to achieving impact; there are opportunities for researchers to link with networks

nationally (Short Breaks Research and Practice Development Group in the UK) and internationally (International Short Breaks Association).

Limitations

The scoping review focused on carers for older adults. The carer population is heterogeneous in nature. A future research agenda should be underpinned by a commitment to researching personalised short breaks provision for a range of carer groups and from the perspectives of individuals with various care needs, practitioners, commissioners and providers. For pragmatic reasons, only papers published in the English language were reviewed.

Conclusion

The scoping review identified knowledge gaps about the impact of personalised breaks to support the achievement of well-being outcomes and proposed priority lines of inquiry to underpin a future research agenda taking forward research, policy and practice development on personalised breaks benefitting carers and people with complex care needs.

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