

Respite Care/Short Breaks What the research tells us

Emma Miller

University of Strathclyde



Purpose of the research group

UK short breaks research and practice development group

- To date the group has directly involved Wales and Scotland, though Interest in the UK is broad and connections are wider

Terms of reference drafted April 2017

- The purpose of the Research and Practice Advisory Group (RPAG) is to support a culture of research and build research capacity across the short breaks sector.
- The aim of this work is to improve understanding of the role of short breaks and respite care and to help structure future research in ways that will help support continuous improvement in policy and practice

Wider KE and collaboration between research, policy and practice central

More about the research group

Initial concept from **Nick Andrews**, University of Swansea, interest in developing more flexible, personalised short breaks provision

Shared Care Scotland

- Aims to improve the quality and provision of short breaks in Scotland. offer services including events, publications, research reports, online directory, managed by **Don Williamson**

Research on carers outcomes in Scotland and Wales

- Research on carers outcomes in both Wales and Scotland over many years – **Diane Seddon** in Wales and **Emma Miller** in Scotland

Diverse carer research work at the OU

- **Joyce Cavaye** – carer journeys, hidden carers, life after caring
- **Roseanna Ware** - carers and disabled children

Spoiler alert...

This research tells us as much about the gaps as it does about the evidence

overwhelmed-at-work



Scoping review

- Funded by Shared Care Scotland
- Purpose: better understand the research evidence about short breaks for carers (sometimes called respite care) and what this research tells us about the impact of short breaks for carers
- Published literature from 2000 onwards
- Review itself conducted by Diane Seddon and Louise Prendergast
- SBG acted as a reference group and review panel throughout

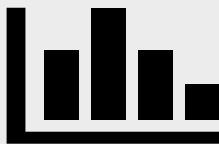
Defining short breaks: our starting point

Shared Care Scotland's short breaks definition underpins the Review. A short break is defined as 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. Breaks from caring could therefore be:

- For short or extended periods
- Take place during the day or overnight
- Involve the person with support needs having a break away from home allowing the carer time for themselves
- Allow the carer a break away with replacement care in place
- Take the form of the carer and the person they care for having their break together, with assistance if necessary, providing a break from the demands of their daily caring routines

(Shared Care Scotland Position Statement, 2017)

Definition: What are short breaks?



- Scoping review identified a broad range of terms, including respite care and restorative care
- Various types of short breaks identified:
 - Includes more traditional, day-care, residential care and in-home respite
 - Alternative breaks, including supported holidays and access to leisure and arts facilities
- Most research focuses on traditional day and residential respite care services
- Role of alternative short breaks in enabling individuals to achieve positive wellbeing outcomes is a key research gap

Short break outcomes

Carer health and well-being

The most prevalent outcome in the research

- Improvements in carer emotional well-being (sense of freedom, peace of mind and relief)
- Enhanced sense of resilience
- Opportunity to attend to self-care needs
- *Retrospective necessity*
- Research confirms that positive health and wellbeing outcomes for carers and the individuals they support are linked to the provision of *personalised* short breaks

Short break outcomes – flipside

Carer health and well-being

- Some research reports short breaks deliver *only* positive physical *but not* positive emotional outcomes (King and Parsons 2005), whilst others conclude that *any* positive benefits accruing from a break soon dissipate (McNally 2013).
- Research confirms that some carers taking short breaks report feelings of guilt, anxiety, emptiness and loneliness, particularly when the break takes the form of residential respite care, as well as sadness at being separated

....guilt. I didn't sleep that night hardly any at all and in the morning I got up andcancelled. (Strang 2001, 78-79).

- Negative effects mitigated when carers supported to accept their need for a short break as legitimate and appreciate its preventative effects



Retrospective necessity

- A sense of *retrospective necessity* is evident in carer accounts. Carers highlight the impact on their wellbeing and ability to cope. Throughout the literature, carers speculate on how they previously coped without a break and the benefit that might have been obtained had the short break provision been available earlier.
- *I initially found myself thinking, I'm the only person... the only one who can't do this, who can't get it right. But then, I began to realise that actually I was normal...they [the day center staff] helped me realise that it was normal to need a break...and after I accepted their offer...I could finally see that it works. (Phillipson and Jones 2012, 11-12).*

Short break outcomes

A life of their own

Supporting a life alongside caring is a key policy priority across the UK regions

- Opportunities to take time away from the 'caring world' to pursue personal interests
- Thinking and relating to others in ways not linked to the caring role enables *temporary disconnect* from caring to focus on other roles (e.g. a grandmother, a wife) and *re-connect* with other family members/friends
- Short breaks afford opportunities to undertake routine domestic chores and mundane tasks, including shopping, but these activities may not be as beneficial as doing things that could not otherwise be done
- Use of short break time has a significant effect on carer outcomes - satisfactory use of time pursuing interests or being with family and friends is associated with positive outcomes and improved wellbeing



Short break outcomes

Positive caring relationships

- Short breaks:
 - play a key role in supporting positive caring relationships and enabling carers to continue caring
 - enable carers to positively frame their relationship with the supported person, their caring role and their achievements
- Nature and quality of the pre-existing relationship is important

Short break outcomes

Choices in caring

- Limited research looking at the ways short breaks might impact on carer choices, including limits to the caring
- Some studies suggest that short breaks play a key role in supporting continued caring and delaying admission to nursing or residential care but there is very limited research evidence
- Important area for future research development



Short break outcomes

Satisfaction in caring

- Limited evidence looking at the impact of short breaks on carer satisfaction with the caring role
- Short breaks contribute to carer satisfaction if they offer some type of educational experience and an opportunity to learn from other carers
- Important area for future research development as levels of carer satisfaction are closely associated with a willingness to continue in the caring role

Important features of short breaks

- **Quality of the break** - experience for the supported person, in particular, the opportunity for safe and meaningful engagement, is critically important in determining outcomes. Short breaks have greater physical, psychological and psychosocial benefit when they are appraised, by the carer, as a positive experience for the supported person. Indeed, research suggests this lessens carers' sense of guilt
- **Duration** - research confirms this is linked to carer reported outcomes, with longer breaks (of more than 24 hours) having a greater positive effect for carers than shorter ones. Research by Dundee Carers Centre (2014) suggests that a period of less than half a day is not considered a short break. Pienaar and Reynold's (2015) work supports this.

Scoping review – priorities for future research

Clustered around three key themes:

- Understanding *what matters* - capture and evidence short break needs (personalisation, planning, restoration of identity, feelings of guilt etc)
- Capturing *what matters* - outcomes from short breaks (measuring outcomes, while retaining meaning, including **process outcomes**)
- Commissioning, delivering and scaling up alternative short breaks provision to reflect *what matters* to carers (commissioners as facilitators, picture building, incl heterogeneity)





Acknowledgments,
connections

- Thanks to Eurocarers for the connections – Care Alliance Ireland, Learn4Carers
- Break Exchange in Wisconsin – all welcome
- kim.whitmore@wisc.edu
- Can we please keep in touch
- e.miller@strath.ac.uk
- [@personaloutcom1](#)

Miller and Barrie (2019) Narrative Recording article in BJSW