



Respite Care Research: What does the evidence tell us?

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Respite Care: Back to basics

- ◆ What is respite care?
 - ◆ “Any service that gives a break to the person with dementia and/or their care-giver from their usual routine”
- ◆ Who is respite care aimed at – care-givers? care recipients?
- ◆ What models of respite care are there?
 - ◆ Home-based; day care; specialist respite facility; respite beds



Functions of respite care

- ◆ An intervention and preventive service
- ◆ A crisis service
- ◆ To provide relief to the family
- ◆ To offer primary care-giver personal time and space
- ◆ To address the needs of the care recipient
- ◆ Preparation for entry to long-term care



Overview of research literature: topic areas

- ◆ Nature and context of respite care services
- ◆ Experiences of using respite care
- ◆ Utilisation rates; characteristics influencing people's use of respite care
- ◆ Access issues; barriers to uptake
- ◆ Good practice
- ◆ Impact of placement into residential care
- ◆ Links between respite care and academic achievement
- ◆ Impact and outcomes of respite care
- ◆ Cost-effectiveness, and value for money



Overview of research literature: study groups

- ◆ Care-givers
- ◆ Young carers
- ◆ Ethnic minority populations
- ◆ Frail older people
- ◆ People with dementia
- ◆ (Parents of) disabled children
- ◆ People with (severe) mental illness
- ◆ Children/adults with learning difficulties
- ◆ People with TBI (Traumatic Brain Injury)
- ◆ Terminally ill children and adults



Respite care services – a good thing?

- ◆ Evidence is mixed
- ◆ Agreement on carer satisfaction
- ◆ Some practical benefits for care-givers
- ◆ BUT inconsistent and unclear results for:
 - ◆ care-giver outcomes (e.g. levels of depression, stress, burden, health)
 - ◆ care recipient outcomes (e.g. ADLs, physical functioning, behaviour, self-care)
 - ◆ delaying institutionalisation



Respite care evidence base: conclusions from literature reviews

Respite services for carers of people with dementia and carers of frail older people:

- ◆ Though mixed, the evidence reveals that any significant effects ... are quite modest (Gottlieb and Johnson, 2000)
- ◆ Limited evidence of the effectiveness and cost-effectiveness of respite care and short-term breaks (Arksey *et al.*, 2004)
- ◆ No evidence of any benefit of respite care for people with dementia or for their care-givers for any outcome (Lee and Cameron, 2004)
- ◆ Some evidence that respite for care-givers for carers of frail elderly people may have a small positive effect (burden; mental or physical health); no evidence that respite delays entry to residential care or adversely affects frail older people (Mason *et al.*, 2007)
- ◆ Some evidence that respite has a positive effect on care-givers of frail elderly but evidence limited and weak (Shaw *et al.*, 2009)



Respite care evidence base: conclusions from literature reviews

Respite services for care-givers of people with severe mental illness:

- ◆ Contradictory findings on outcomes of respite care services (Jeon et al., 2004)



Evidence base for respite care for children

Evidence that care-givers may benefit from use of respite care, but this can be accompanied by:

- ◆ Feelings of guilt
- ◆ Feelings of loss
- ◆ Concerns about safety
- ◆ Increase in carer stress



Methodological issues

HOWEVER:

- ◆ It would be wrong to assume that lack of evidence of effectiveness means that respite care is ineffective
- ◆ It's more about methodological weaknesses



Limitations of research methods

- ◆ Too few good quality controlled studies
- ◆ Sample sizes are too small
- ◆ Heterogeneity of outcomes
- ◆ Lack of robust outcome measures
- ◆ Short-term intervention
- ◆ Short follow-up period; no longitudinal studies
- ◆ Lack of economic evaluations for range of respite services
- ◆ Descriptive studies rather than outcome evaluations
- ◆ Studies may not identify the particular component of respite care that most benefits care-givers and care recipients
- ◆ Difficult to generalise because of so many variables involved: type of respite service/model; timing and duration of provision; training and skill mix of care providers



Why better research is needed

- ◆ To demonstrate that respite care is effective and improves the intended outcomes for care-givers (and care recipients)
- ◆ To show the effectiveness of specific/different types of respite care in different situations
- ◆ To develop criteria and methodologies to measure outcomes and assess (cost-) effectiveness
- ◆ To understand the wider implications of respite for everyone involved
- ◆ To present a strong objective case for services in today's current economic climate



Generating more robust evidence about the effectiveness of respite care

Questions/Discussion

- ◆ How to generate a strong evidence base?
- ◆ What outcomes to collect, from whom and when?
- ◆ What outcome measures to use?