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?