

Trial of an Information Package to Improve the Sleep of Carers of People with Dementia



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Overview

- Acknowledgement:
QNC Early Career Researcher Grant
- Background and rationale
- Aims of the trial
- Description of the package
- Results
- Conclusions
- Future testing and potential uses of the package



Background

- Sleep loss & poor quality sleep common in carers: 53-86% (McCurry & Teri, 1995; Pruchno & Potashnik, 1989; Wilcox & King, 1999)
- Reductions in carer sleep quantity & quality are amongst the most common reasons for early institutionalisation of PWD (Lee, Morgan & Lindsay, 2007; Pollack et al, 1990)
- Clinically significant sleep disturbance in almost ½ of PWD (Devanand, 1992; Eeles, 2006)
- Other effects on carers of sleep loss – daytime fatigue, depression, anxiety, stress, reduced activity, obesity



Studies Showing Beneficial Effects of Cognitive, Behavioural & Lifestyle Approaches



- CBT of benefit for older adults with insomnia (Cochrane review: Montgomery & Dennis, 2002)
- Sleep hygiene strategies, cognitive restructuring, comprehensive lifestyle advice & behavioural approaches - improved sleep patterns of PWD & their carers (Eeles, 2006; McCurry et al, 2005)
- Interventions to address carer routines, daytime activity levels & background light exposure – improved markers of sleep & agitation in PWD (RCT: Alessi et al, 1999)

Studies Showing Beneficial Effects of Cognitive, Behavioural & Lifestyle Approaches

- Comprehensive patient & carer lifestyle & sleep hygiene advice – more appropriate timing of sleep & reduced caregiver stress (RCT: Gallagher – Thompson, Brooks & Bliwise, 1992)



Aims of the Trial

- Investigate the baseline sleeping/lifestyle habits, of a small sample of PWD & their carers
- Investigate baseline daytime functioning & cognitions related to sleep in carers
- Determine whether an evidence-based information/education package could improve sleep & related factors in carers



Hypothesised Effects of Sleep Package on Carers

- Increased total sleep time
- Reduced sleep onset latency
- Improved sleep quality
- Improved daytime feelings & functioning – reduced sleepiness
- Fewer dysfunctional beliefs & attitudes about sleep



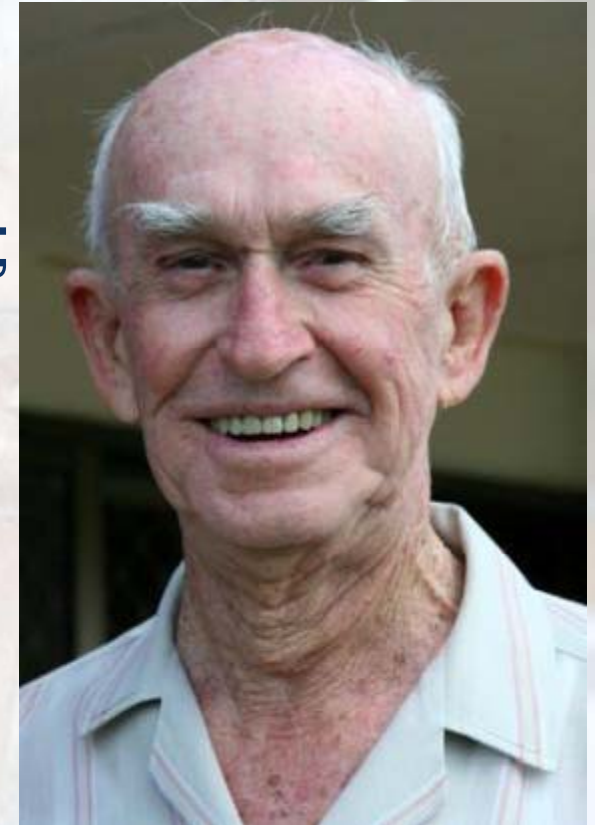
Sample Description

- 26 live-in community-dwelling carers of PWD across Qld & NSW: All primary caregivers for > 6 months
- 77% female; 33% male; Aged 52-89
- 61% spouses; 27% adult children; 12% other
- All reported change in normal sleep patterns since started caregiving
- None taking regular sleep medication; or had sleep disorder other than insomnia



Measurements & Scales

- Demographic: Age, gender, relationship with PWD
- Lifestyle (Carer & PWD): Nap, sunlight & activity duration; caffeine; sleep hours; sleep disturbance (frequency & duration)
- Sleep quantity & quality measures
- Sleep-related cognitions & behaviours measures
- Daytime consequences measures



Sleep Quantity & Quality Measures

- Total average hours sleep per night
- Sleep onset latency
- Pittsburgh Sleep Quality Index (PSQI; Buysse et al., 1989)



Sleep-related Cognitions & Behaviours Measures

- **Penn State Worry Questionnaire** (PSWQ; Meyer, Miller , Metzger & Borkovec, 1990)
- **Dysfunctional Beliefs & Attitudes About Sleep Scale** (DBAS-10; Espie, Inglis, Harvey & Tessier, 2000)
- Total nap time
- Total daylight time
- Total activity time



Daytime Consequences Measures

- Epworth Sleepiness Scale (ESS; Johns, 1991)
- Daytime Feelings & Functioning Scale (DFFS; Gradisar et al., in press)



Study Design

- Recruitment via Seniors groups, Alzheimer's Assoc. newsletter, media coverage, leaflets at respite centres – telephone screening
- Control period (4 weeks)
- 2 phone calls in control period
- Intervention period (4 weeks)
- 2 phone calls in intervention period to answer questions about the package & encourage use
- Tested at baseline, prior to intervention & post-intervention + phone call for verbal feedback



Sleep Package Contents

Introduction 3

The Value of a Good Night's Sleep.....5

Thinking About Sleep:

How Much Sleep Do I Need? 6

How Often Do Most People Wake Up at Night..... 8

What Other Conditions Can Cause Sleep Loss? 9

The Sleep of a Person With Dementia:

The Circadian Cycle..... 10

Sundowning..... 11

Staying Awake and Getting Tired:

Get Out and About..... 12

To Nap or Not to Nap..... 14

Lighten Up Your Day..... 15

Worrying and Wakefulness..... 16

What You Eat Affects Your Sleep..... 18

What Are You Doing This Evening?..... 21

In Bed Behaviours..... 24

Added Benefits of Improved Sleep..... 29

Why Taking Sleep Medications Can Be Counterproductive..... 31

Alternative and Complementary Therapies..... 33

Other Queries..... 36

Good Luck!..... 37

How Can I Learn More?..... 39

Interesting Research..... 41



Baseline Measurements

- Sleep $M = 5$ hrs 26 mins ($SD = 1.29$ hrs)
(Norm: 6 hrs 48 mins: MBF survey Australian adults, 2007)
- 88% Sleep disturbance relating to PWD activity
(69% toileting; 31% wandering; 27% hallucinations; 27% talking/yelling)
- 58% Other disturbances: Worry 31%; noise 15%; own toileting 12%; pain/discomfort 8%
- Sleep onset latency $M = 41.37$ mins ($SD = 32.72$)
(31 mins is threshold for insomnia – Lineberger, Carney, Edinger & Means, 2006)
- Insomnia Severity Index $M = 15.62$ ($SD = 5.31$)
(Clinical insomnia – moderate severity – Bastien et al, 2001 guidelines)
- Pittsburgh Sleep Quality Index $M = 10.69$ ($SD = 3.51$) ($> 7 =$ “poor sleeper” – Buysse et al, 1989)

Baseline Measurements

- Normal daytime sleepiness scores (ESS)
M = 6.86 (SD = 4.17) (Normal range < 10; Johns, 1991)
- Daytime Feelings & Functioning (DFFS)
M = 14.0 (SD = 7.05) ('Poor sleepers' M = 15.52, 'good sleepers' M = 8.56 in normative sample according to PSQI; Gallasch, 2005)
- Dysfunctional Beliefs & Attitudes About Sleep (DBAS) M = 4.68 (SD = 1.77) ('Primary insomniacs M = 4.72, 'good sleepers' M = 3.56; Carney et al., 2007)
- Penn State Worry Questionnaire (PSWQ)
M = 50.73 (SD = 13.94)
(Normative sample of >45 year olds M = 38.9, SD = 9)

Control Period

Variable	Baseline		4 weeks later		t (sig)
	M	SD	M	SD	
Hrs slept	5.44	1.29	5.35	1.35	
SOL	41.37	32.72	34.02	28.16	2.86 (p<.01)
PSQI	10.69	3.51	10.15	3.50	
PSWQ	50.73	13.94	51.42	15.02	
DBAS	4.68	1.77	4.80	1.48	
ESS	6.86	4.17	6.77	4.70	
DFFS	14.00	7.05	13.85	8.46	

Note. SOL = Sleep Onset Latency (in minutes); PSQI = Pittsburgh Sleep Quality Index; ESS = Epworth Sleepiness Scale; DFFS = Daytime Feelings and Functioning Scale; DBAS = Dysfunctional Beliefs and Attitudes about Sleep scale; PSWQ = Penn State Worry Questionnaire.

Intervention Period

Variable	Pre-Intervention		4 weeks later		F	η_p^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Hrs slept	5.35	1.35	6.06	1.20	13.39*	0.35
SOL	34.02	28.16	24.38	19.66	9.95*	0.29
PSQI	10.15	3.50	7.88	3.57	14.74*	0.37
PSWQ	51.42	15.02	46.69	15.07	10.05*	0.29
DBAS	4.80	1.48	3.75	1.84	14.24*	0.36
ESS	6.77	4.70	5.67	4.24	3.47	0.12
DFFS	13.85	8.46	10.40	6.59	12.83*	0.34

* $p < .01$, two-tailed (Bonferroni adjusted)

Note. SOL = Sleep Onset Latency (in minutes); PSQI = Pittsburgh Sleep Quality Index; ESS = Epworth Sleepiness Scale; DFFS = Daytime Feelings and Functioning Scale; DBAS = Dysfunctional Beliefs and Attitudes about Sleep scale; PSWQ = Penn State Worry Questionnaire.

Behavioural Effects

- **No** significant change in average length of daily napping time for carer or PWD
- **No** significant change in average time spent outside or in bright sunlight for carer or PWD
- **No** significant change in light or moderate exercise for carer or PWD
- **No** significant change in caffeine intake for carer or PWD
- I.e., no change in any actual behaviours, despite sleeping better & feeling & functioning better

Feedback about the Package

- Laminated “Fast Fact Sheet” was found useful for quick referral
- Some participants reported they felt encouraged just to know that the research community was aware of their sleep problem
- Normative info was helpful to many – just to know that the amount of sleep they were getting was normal if they felt refreshed
- Phone calls valued (reported by 27%)
- Sleep issues in some PWDs were not improved by strategies in the package

Conclusions



- Package had considerable impact on amount & quality of sleep
- Reduced unhelpful thinking & worrying
- Also improved daytime feelings and functioning
- Consistent with previous research on sleep hygiene, psycho-education & CBT approaches with this population
- Important to address worry (not just PWD behaviours keeping carers awake)

Future Testing & Use of Package

- Trial has confirmed the importance of interventions addressing sleep loss in carers
- Larger scale testing needed – large grant would be needed as this type of research is very labour intensive
- Potential for adaptation as an intervention delivered via dementia carer support groups



Questions???
Comments???



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