Sleep in Dementia and Caregiving:
The Impact of Respite Care.

by

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ABSTRACT

The Impact of Respite Care on the Sleep of People with Dementia and their Primary Caregivers

In order to investigate the relationship between the sleep of older people with dementia and their caregivers and the impact of respite care on the sleep of these groups: 68 dyads who were approached to participate in this actigraphic sleep study. Agreement to participate in the study was given by 40 caregivers Questionnaire and sleep diary data were retrieved from all 40 caregivers Owing to non-compliance and technology failures: 36 caregivers and 34 care recipients provided data at baseline, 34 caregivers and 32 care recipients successfully completed the respite period of the study and 31 caregivers and 30 care recipients finished the entire study protocol. Analyses revealed that caregivers experienced clinically disturbed sleep and excessive daytime sleepiness. Health-related quality of life scores revealed that caregivers experienced reduced mental health; social functioning; and energy/vitality scores compared to the general population. The principal effects of respite care services indicated that caregivers experienced significantly increased total sleep time ($p = 0.002$) and significantly reduced nocturnal activity levels ($p = 0.001$) during periods of respite care. Caregiver subjectively rated feelings of wellbeing were positively impacted by respite care ($p = 0.011$). Care recipients experienced significant decreases in total sleep time during respite ($p = 0.016$) and increased nocturnal activity levels. There was a high correlation between caregiver and care recipient total sleep time ($p = 0\ 005$). Post discharge, both caregivers and care recipients experienced reduced sleep outcomes compared to baseline levels, indicating difficulties in readapting to the caregiving role in caregivers and to sleeping in the community post-respite in care recipients. These findings suggest that respite care services lead to improvements in caregiver sleep that may extend care in the community. There are implications for improved management of dementia care recipients post-discharge, particularly in terms of supporting caregivers in the community. Examination of disturbance factors in the hospital from the perspective of dementia care recipients are discussed.

ACKNOWLEDGEMENTS

Special thanks are extended to my supervisor Professor Kevin Morgan, without whose regular and pertinent advice this project would not have been possible. Grateful thanks are also extended to Dr. Sarabjit Mastana, Dr. Nick Norgan and Mr. Nick Smith for their support and encouragement over that last few years.

This study would also not have been possible without the exceptional effort given to the project by those who agreed to participate in this study. The caregivers and their dependent care recipients who took part in this six-week study protocol, considering the difficult situations most of these dyads were living in, their participation and mostly successful completion of such a long study is truly remarkable, I cannot thank them enough.

I would also like to extend my thanks to a number of healthcare professionals who assisted in the acquisition of participants for the study and for monitoring their progress through respite care. To Professor James Lindesay, Dr. Mick Dennis, Dr. Richard Parerah, Dr. Simon Thacker, Sister Pat Harris, Sister Eileen McBride, Mr. Mike Tuohy, Mr. Kevin Appodoo and Mr. Roger Milligan.

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CHAPTER ONE

SLEEP IN AGEING AND DEMENTIA

1.1 INTRODUCTION

This thesis is concerned with the sleep of both older adults with dementia and their caregivers. The following chapters will review the literature pertinent to this line of enquiry focusing in particular on the structure and quality of sleep in relation to normal ageing and then with respect to pathological ageing The impact of caregiving on the sleep of caregivers will then be examined in Chapter 2. The possible origins of sleep disturbances in older age, caregiving and in dementia will then be reported in Chapter 3, before discussing a methodology for examining sleep in dementia and caregiving in Chapter 4. The results from these analyses will be presented in Chapters 5, 6 and 7, and discussed and concluded in Chapter 8.

1.2 AGE-RELATED CHANGES IN SLEEP

Both the structure and subjective experience of sleep change as chronological age increases (Roffwarg *et al* 1966; Miles and Dement 1980; Bliwise 1993; Cauter *et al* 2000) Compared to younger people, older adults generally take longer to initiate their sleep and experience less total sleep time during the night. Later adulthood also brings with it the increased likelihood of nocturnal arousal (Prinz 1977). As measured using polysomnography (PSG), total sleep time (TST) has been estimated to diminish by approximately one hour between the ages of 25.5 and 80.5 years (Monk *et al* 1992). Caulter *et al* (2000) examined the TST of 149 healthy men (age range 16 – 83 years) and described a reduction of approximately 27 minutes TST per decade of life in their middle to older age groups ($p < 0.001$). The reduced TST reported by Caulter *et al* (2000) was only significantly demonstrable after mid-life (44 years and above). For their younger participants (<44 years old) age related

declines in TST were reported, however the reduction in TST in their younger group failed to reach significance (p =0 28).

1.2.1 Ageing and sleep efficiency

Sleep efficiency is defined as the amount of time spent in bed asleep divided by time spent in bed either awake or asleep. This ratio is then multiplied by 100 to convert the result into a percentage Sleep efficiencies have been shown to diminish to an average of 80% (p <0.01) in older adults (over 65 years of age), some 10% less than those seen in healthy younger individuals (Monk *et al* 1992, Landholt *et al* 1996; Landholt and Borbely 2001).

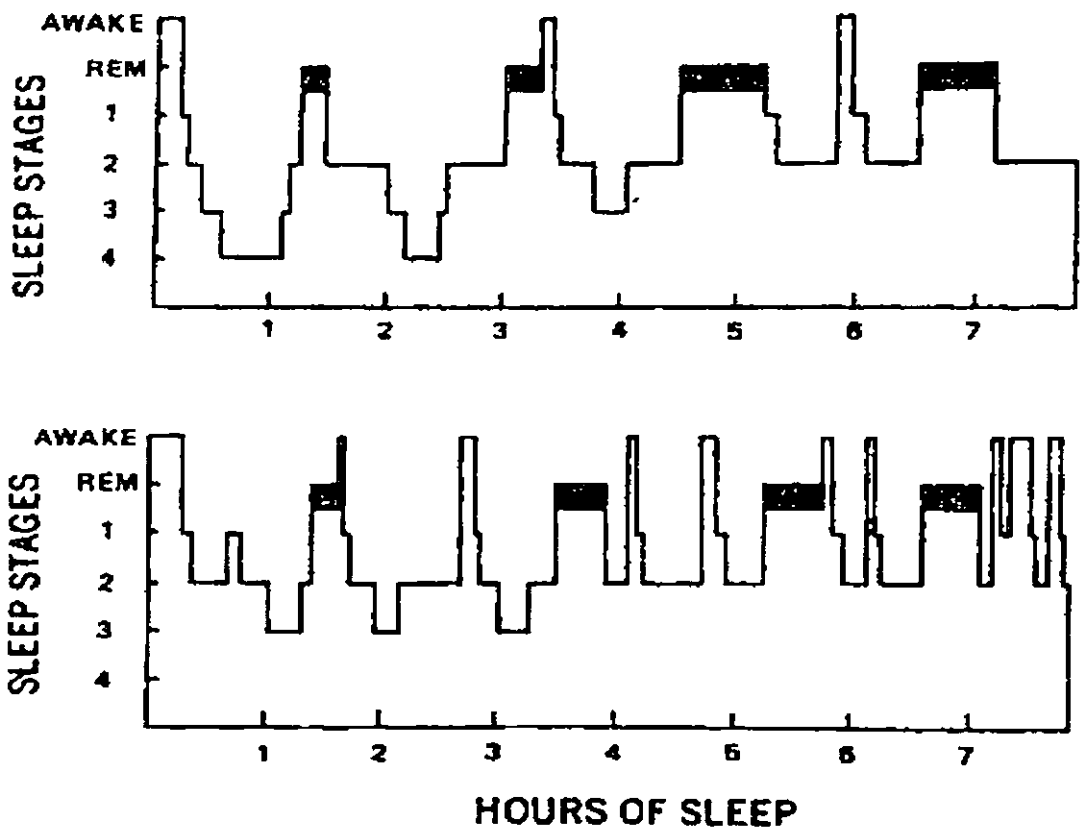
1.2.2 Sleep stages

The organisation of sleep changes throughout the human lifespan. These ontogenetic changes have been reported electroencephalographically by the separation of sleep into distinct frequency ranges or sleep stages (Rechtschaffen and Kales 1968). These frequency ranges have been categorised into five sleep stages as shown in Figure 1.1. Stage 0 is representative of wakefulness and comprises what is referred to as alpha and beta activity Stage 1 sleep is light, drowsy sleep represented by the appearance of theta and a loss of alpha activity, this is a transitory state between stage 0 and true sleep (stage 2 sleep or deeper). Stage 2 sleep mainly consists of so-called theta activity and some delta activity. Stages 3 and 4, or slow wave sleep (SWS) are characterised by a continuing loss of theta activity and an increasing amount of delta activity (Rechtschaffen and Kales 1968). The changing make-up of sleep, in terms of proportions of TST spent in the different sleep stages, and the changes in this sleep structure with age are reviewed in the following section.

1.2.3 Age-related changes in sleep depth

The examination of sleep stages is facilitated by the *hypnogram* which displays the various sleep stages across the night. Figure 1.1 shows simplified versions of two hypnograms. The first (top) displays a hypnogram which is typical for younger people and second (bottom) shows another hypnogram which is more characteristic of the sleep of older adults.

Figure 1.1 A simplified hypnogram displaying a typical nights sleep of a younger person (top) and an older person (bottom).



Reproduced with permission from Morgan (1987)

Figure 1.1 shows that a diminution of stages 3 and 4 in the hypnogram of a typical older person's sleep is accompanied by reciprocal increases in stages 1 and 2 sleep compared to a younger person's typical sleep (Feinberg *et al* 1967) Older adults can also be seen to experience a greater number and an increased duration of nocturnal arousals compared to the sleep experienced by younger individuals. This is perhaps most clearly described by research conducted into auditory awakening thresholds across age groups.

The auditory awakening (or arousal) threshold (AAT) is defined as the minimum amount of sound pressure, measured in decibels, required to arouse an individual from their sleep. It has been clearly shown that older adults are more easily awakened by noise in stages 2, 4 and REM sleep than are younger persons, despite the age-related reduction in the hearing sensitivity of older people, and that the deeper sleep stages require more white noise intensity to invoke arousal (Zepelin *et al* 1984) Zepelin *et al* (1984) data are summarised in Figure 1.2, these data are presented for AATs from stage 2 sleep across the lifespan.

Figure 1.2 Minimum auditory awakening thresholds (AATs) from stage 2 sleep for men and women at three age levels

This examination of auditory awakening thresholds clearly shows the decreasing depth of sleep seen with advancing age. Structurally, sleep also undergoes age-

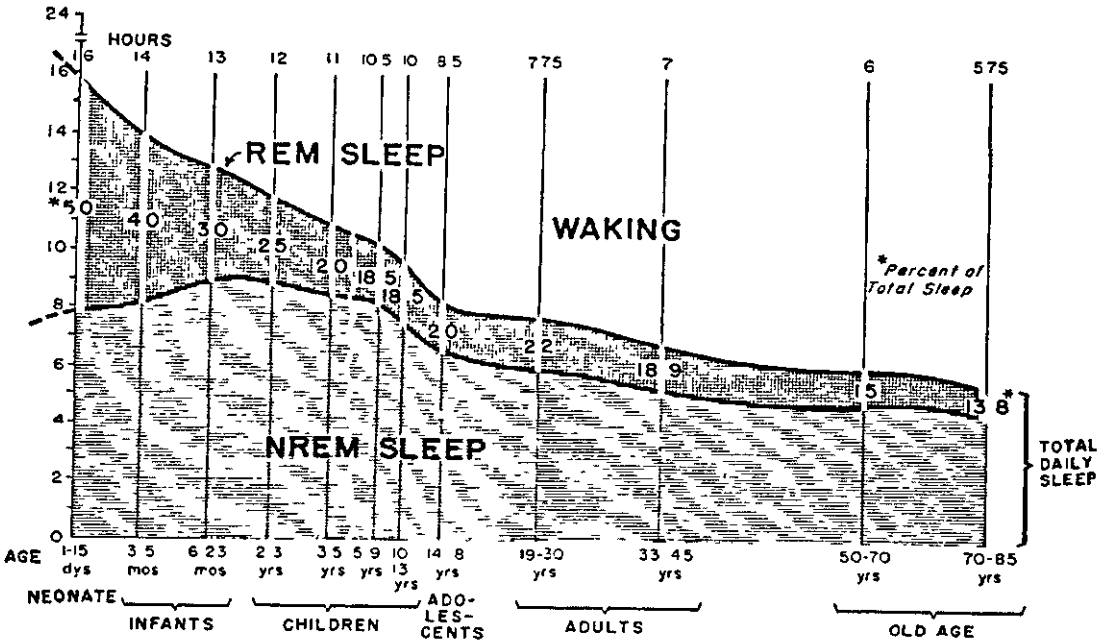
related changes in terms of alterations in time spent in the different sleep stages (Rechtschaffen and Kales 1968)

1.2.4 Age-related changes in sleep structure

In healthy human volunteers sleep progresses from wakefulness (stage 0) through the progressive sleep stages and into stage 4 sleep. From here there is a reversal of this progression until either wakefulness or a bout of rapid eye movement (REM) sleep is initiated before sleep again moves through the progressive sleep stages defined by Rechtschaffen and Kales in 1968. The cyclical progression through these different sleep stages follows, in the young adult, a 90-minute cycle, approximately. This was first reported in terms of human sleep by Dement and Kleitman (1957), who noted this 90-minute period of rhythmicity between successive bouts of REM sleep.

Roffwarg *et al* conducted a review of the sleep literature across age-groups in 1966 Their review of 16 sleep studies examined the changes in the structure of sleep across the human lifespan A graphical reproduction of their findings is presented in Figure 1.3.

Figure 1.3 Ontogenetic declines in REM and non-REM sleep throughout life



Reproduced from Roffwarg *et al* 1966

From inspection of Figure 1.3 three notable features of the change in human sleep across the lifespan are evident. Firstly, there is a marked diminution in total sleep time throughout life, from approximately 16 hours per-day in the newborn to a mean value of just under 6 hours in the oldest adults. Secondly, the proportion of REM sleep diminishes from approximately 50% (8 hours) of total sleep time in the neonate to only around 13 8% (1 hour) in the oldest adults. Finally, the proportion of non-REM (NREM) sleep also reduces with advancing age, although not to the same extent as reductions in REM sleep (Roffwarg *et al* 1966).

In younger adults (aged between 20 and 30) approximately 5% of sleep comprises stage 1 sleep, 45% of sleep is made up of stage 2 sleep, 7% by stage 3 sleep and around 13% by stage 4 (the deepest) sleep. Stages 3 and 4 are also referred to as slow wave sleep (SWS) or delta wave sleep. Remaining time asleep is occupied by these regular bouts of REM sleep or wakefulness (stage 0).

In healthy older people (over the age of 60) the proportion of stage 1 sleep has also been shown to increase from 5% in the healthy young population to around 8 – 15% in older people, with variation in these figures due to the age and sex of the individual under assessment (Miles and Dement 1980, Monk *et al* 1992). Electroencephalography (EEG) has also revealed that older people experience less delta (slow) wave (0 – 3 Hz) sleep and less REM sleep than younger adults (Feinberg *et al* 1967, Kales *et al* 1967; Prinz 1977). Caulter *et al* (2000) reported a large reduction in the amount of slow wave sleep (SWS) in their older participants: from 18.9% of TST in their younger volunteers to 3 4% of TST in middle-aged (36 – 50 years) adults. They reported significant fragmentation of sleep and increases in sleep stages 1 and 2 which replaced the lost SWS in their older participants They also reported significantly reduced levels (by around 50%) of REM sleep in their older adult participants (Caulter *et al* 2000).

Table 1.1 describes findings from six EEG studies conducted over the last 28 years. These studies were selected for review on the basis of their description of the sleep structures of their participants across the lifespan. Gaudreau *et al* (2001) reported the sleeping EEG structure of four age-groups. from 6 to 10 year-old children, 14 to 16 year-old adolescents, 19 to 29 year-old young adults and 36 to 60 year-old adults Speigel *et al* (1999) examined the sleeping EEGs of a middle-aged group of adults (59 – 67 years-old), and a group of older adults (67 – 87 years-old). Similarly Hoch *et al* (1994) measured the sleeping EEGs of two groups of older adults (61 – 75 years old and 75 to 89 years old), as did Reynolds *et al* (1985) whose participants were divided into a group aged between 60 and 69 years old and 70 to 80 years old Dijk *et al* (2001) reported the sleeping EEGs of their participants who were aged between 21 and 30 in their younger group and between 64 and 74 in their group of older adults. Prinz's (1977) data are also presented as this was one of the first sleep EEG studies to be performed on the over 65 age-group. Her data are presented out of historical interest and deviations in the data reported by more recent research in this field may, at least in part, be due to advancements and refinements in sleep assessment methodology (Prinz 1977,

Reynolds *et al* 1985, Speigel *et al* 1990, Hoch *et al* 1994; Dijk *et al* 2001; Gaudreau *et al* 2001).

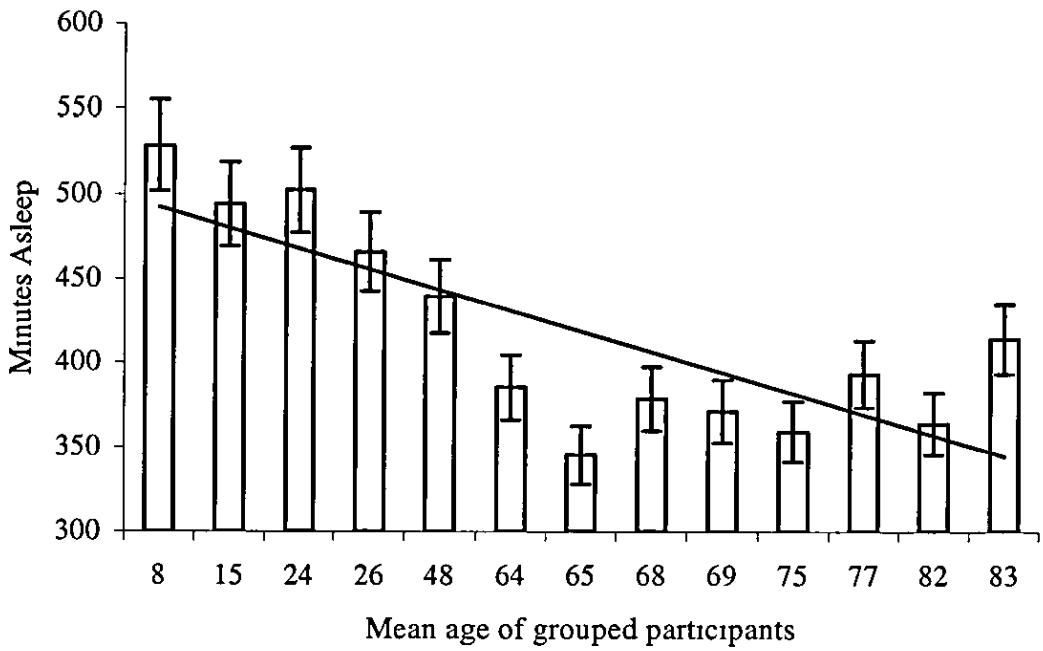
Table 1.1 Comparison of sleep structure between young and older people

Study	Age Range (Years)	Sample Size (n)	TST (mins) (SD)	SOL (mins) (SD)	SE (%) (SD)	SWS (%) (SD)	Arousals (n) (SD)	Time Awake (mins) (SD)
Gaudreau *et al* 2001	6 0 – 10 0	9	528 6 (36 8)	25 04 (12 74)	96 0 (4 8)	34 2 (10 2)	NR	23 0 (7 6)
Gaudreau *et al* 2001	14 0 – 16 0	15	494 2 (23 1)	24 4 (13 9)	95 5 (3 3)	23 6 (6 7)	NR	24 3 (7 0)
Gaudreau *et al* 2001	19 0 – 29 0	15	502 5 (46 3)	9 6 (6 1)	97 3 (1 7)	14 5 (5 8)	NR	14 4 (26 6)
Dijk *et al* 2001	21 0 – 30 0	11	466 0 (10 7)	5 5 (0 7)	83 4 (1 9)	18 3 (2 2)	NR	NR
Gaudreau *et al* 2001	36 0 – 60 0	15	439 5 (34 5)	12 7 (6 2)	92 1 (5 3)	7 8 (6 7)	NR	38 9 (6 5)
Spiegel *et al* 1990	59 8 – 67 2	57	385 4 (98 5)	18 7 (15 0)	NR	20 0 (4 95)	10 6 (7 4)	67 6 (36 1)
Reynolds *et al* 1985	60 0 – 69 0	20	345 3 (57 5)	17 9 (18 6)	79 6 (11 4)	0 85 (2 0)	6 6 (3 0)	96 1 (5 2)
Hoch *et al* 1994	61 1 – 75 0	27	378 6 (40 5)	17 1 (12 3)	83 2 (7 0)	5 4 (6 8)	NR	60 6 (37 2)
Dijk *et al* 2001	64 0 – 74 0	13	371 2 (10 9)	6 1 (0 7)	66 4 (1 9)	15 1 (3 0)	NR	NR
Spiegel *et al* 1990	67 0 – 87 2	30	393 2 (97 9)	14 1 (8 6)	NR	18 79 (5 20)	10 3 (6 5)	60 2 (30 5)
Reynolds *et al* 1985	70 0 – 80 0	20	359 3 (44 5)	27 9 (24 5)	78 5 (10 6)	0 90 (2 1)	7 1 (2 3)	98 3 (4 2)
Hoch *et al* 1994	75 1 – 89 2	23	363 9 (57 4)	20 8 (17 3)	82 0 (8 1)	5 5 (4 8)	NR	60 7 (33 1)
Prinz 1977	76 0 – 90 0	12	414 1 (12 0)	12 6 (8 6)	94 2 (2 3)	24 3 (2 4)	6 8 (3 3)	61 5 (40 0)

TST = Total Sleep Time, SOL = Sleep Onset Latency, SE = Sleep Efficiency, SWS = Slow Wave Sleep
NR = Not Reported

These data are presented with the youngest age groups sleeping EEG characteristics presented first (Gaudreau *et al* 2001) and finishing with the study of the oldest adults (Hoch *et al* 1994, Prinz 1977) From inspection of Table 1 1: TST can be seen to decline with advancing age, similarly sleep efficiency and the amount of SWS also diminishes with advancing age. Conversely, sleep onset latency (SOL), or the time taken to initiate sleep from lights-out, and the number and duration of nocturnal arousals seem to increase with advancing age TST and SOL data are presented graphically in Figures 1 4 and 1 5. The duration of nocturnal arousals, also referred to as wake-time after sleep onset (WASO), from Table 1.1 is presented in Figure 1.6.

Figure 1.4 Decreasing total sleep time across the lifespan



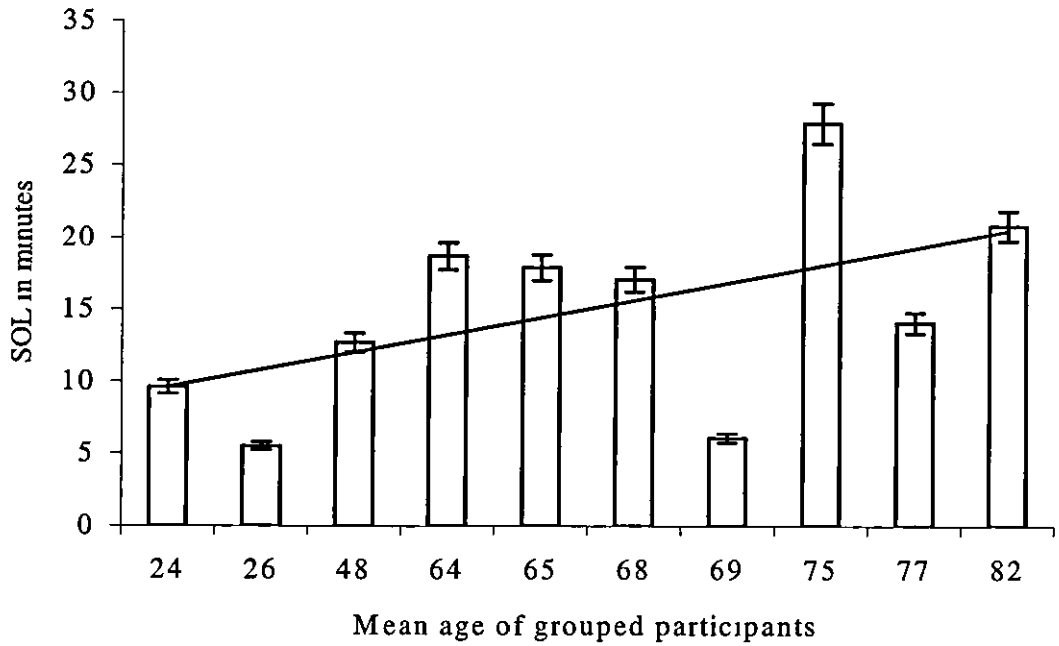
Data from Table 1 1

Figure 1.4 is a graphical presentation of the TST data in Table 1.1 and shows some between age-group variation in the results from these six studies (Prinz 1977;

Reynolds *et al* 1985; Speigel *et al* 1990; Hoch *et al* 1994; Dijk *et al* 2001; Gaudreau *et al* 2001). Differences in methodology, cohort selection and participant characteristics are possible explanations for these differing, between age-group results, nevertheless a clear relationship between advancing age and reduced TST is displayed. From examination of the trend-line superimposed on these data in Figure 1.4 it can be seen that, as far as data from these six studies can suggest, TST reduces at a rate of approximately two minutes per-year of life This is congruent with Caulters's *et al* (2000) findings of a 27-minute decrease per decade, i.e. a 2.7-minute reduction per-year.

Time taken to get to sleep (SOL) is also an important sleep outcome measurement and published widely in the sleep research literature Sleep onset latency data from Table 1.1 is represented graphically in Figure 1.5.

Figure 1.5 Sleep onset latency with advancing age.



Data from Table 1 1

There are some more marked between age-group variations in the data presented in Figure 1.5. This may be due to differing methodologies and the differing characteristics of the cohorts selected by these six research groups (Prinz 1977; Reynolds *et al* 1985; Speigel *et al* 1990, Hoch *et al* 1994, Dijk *et al* 2001; Gaudreau *et al* 2001) The trend-line superimposed on this graph shows equivocal changes in SOL across the lifespan Although there is a suggestion that SOL does increase with age (albeit by only 10 minutes between the ages of 24 and 82). Foley *et al* (1995) and Maggi *et al* (1998) both suggest that difficulties in getting to sleep (i e high SOL) are more common in younger adults than in older adults; it is more that older adults have difficulties with maintaining their sleep (see Section 1 3 for a review of the insomnia literature). These findings may explain the equivocal changes seen in SOL across the human lifespan. It should be noted that the individuals in the above mentioned studies (Table 1.1) were all healthy volunteers and were not experiencing insomnia, dementia or any other syndrome that might

affect their sleep. The data thus presented are representative of normal, healthy sleep across the lifespan.

1.2.5 Spectral analysis

The analysis of EEG measurement has developed from visual scoring techniques to a more advanced, computer-assisted means of assessment This computer assisted assessment of sleep has evolved from simple sleep stage hypnographic information (i e time spent in the various sleep stages as defined by Rechtschaffen and Kales 1968) to a more detailed examination of the amount of EEG power, i e. the amount of EEG energy per-minute (Astrom and Trojaborg 1992; Waterman *et al* 1993; Landholt *et al* 1996) This advanced method of EEG assessment is termed power spectrum analysis. Computer assisted EEG examinations automatically separate EEG readouts into the proportions of the various sleep stages (Rechtschaffen and Kales 1968) and calculates the power densities of brain activity in each sleep stage (Astrom and Trojaborg 1992). This power spectrum analysis of human sleep has revealed significantly reduced EEG power in older adults than in the young and EEG powers in delta sleep have been reported to show an inverse relationship with age (Astrom and Trojaborg 1992; Waterman *et al* 1993, Landholt *et al* 1996). There is a tendency for high-frequency powers (i e sleep stages 1 and 2) to increase and lower frequency powers (i.e. SWS) to decrease with advancing age (Dijk *et al* 1989, Waterman *et al* 1993, Larsen *et al* 1995). These findings are congruent with previously reported EEG analyses of the human sleep cycle (see Figure 1.1)

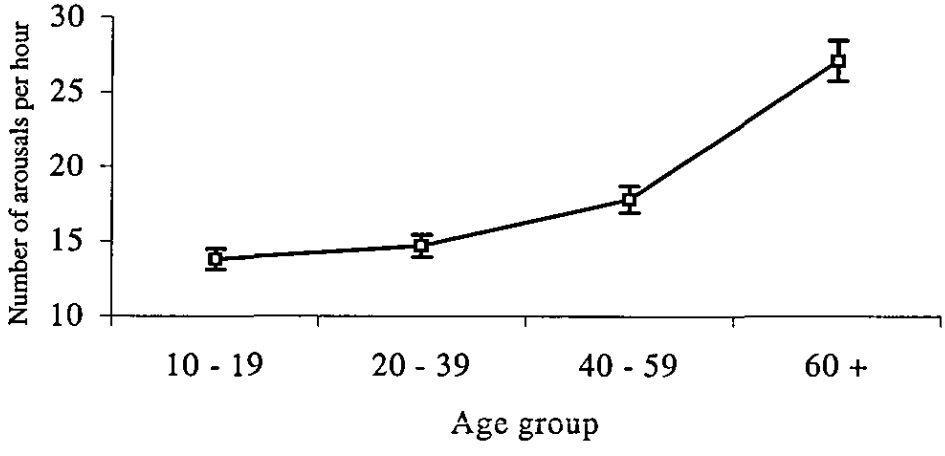
The electrical activity of the brain has been widely examined across all age groups and the amplitude and frequency of the EEG (particularly in SWS) have been shown to diminish with advancing age (Feinberg *et al* 1967; Kales *et al* 1967; Prinz 1977). In a study investigating the sleeping EEGs of 123 men and 191 women (age range 45 – 90) Larsen *et al* (1995) reported a trend of –0.05dB/year reduction in the spectral power of the alpha, theta and delta bandwidths. Conversely, a similarly powerful increase was reported in the beta bandwidth with advancing age (Larsen *et*

al 1995) The structural organisation of the nocturnal sleep period also undergoes changes with advancing chronological age.

1.2.6 Age-related changes in the continuity of sleep

Clear increases in nocturnal EEG defined arousals have been reported with advancing age. Boselli *et al* (1998) examined the number of EEG defined arousals per-night in 40 volunteers separated into four age groups teenagers (10 to 19 years), young adults (20 – 39 years), middle-aged adults (40 – 59 years) and older adults (60 years or greater). The number of EEG defined arousals per hour of sleep was shown to increase with age ($r = 0.852$; $p < 0.0001$) This research group reported 13.8 arousals per-hour in their group of teenagers, 14.7 in their younger adult group, 17.8 arousals in their middle-aged group and 27 1 EEG arousals in their group of older (60+ years) adults (Boselli *et al* 1998). The findings of Boselli *et al* (1998) complement those of Zepelin *et al* (1984) previously presented in Section 1.2.2 describing the diminished depth of sleep encountered with advancing age. Boselli *et al* (1998) data are presented in Figure 1.6.

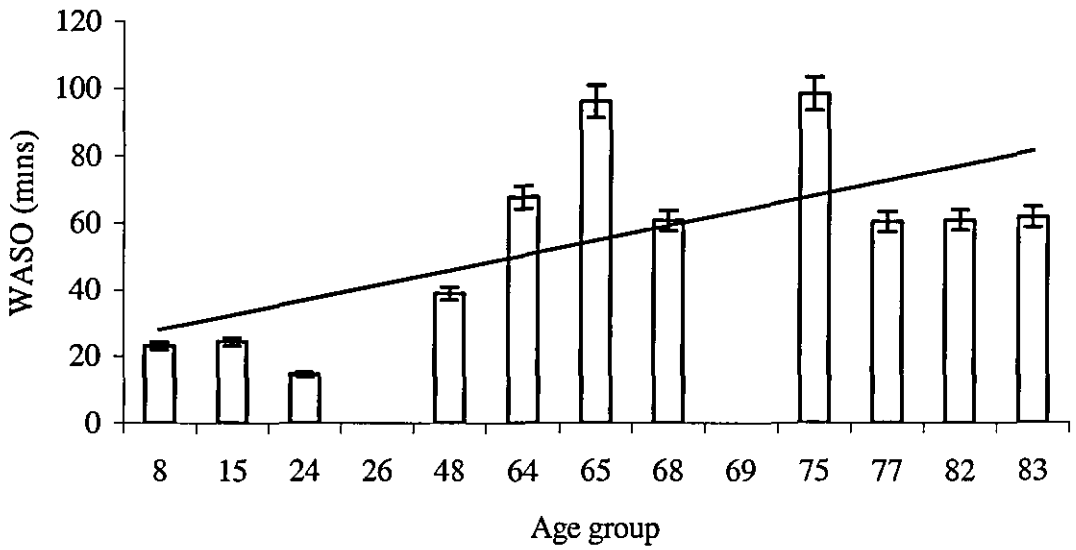
Figure 1.6 The number of EEG assessed nocturnal arousals per hour by age (n = 40).



Data for Figure 1 6 from Boselli *et al* 1998

From inspection of these findings· the continuity of sleep changes with advancing age, with older adults describing increased difficulty in the maintenance of their sleep (Landholt 1996; Cauter *et al* 2000) corroborating the findings of Foley *et al* (1995) and Maggi *et al* (1998) These age-related changes have been reported to progress gradually throughout the lifespan (Boselli *et al* 1998). Time spent awake at night has also been widely assessed in the literature and has been shown to be a good indicator of how the continuity of sleep is disrupted. Time spent awake at night and the number of nocturnal arousals (see Figure 1.7) have been shown to increase throughout life. Data reported in Table 1 1 on the amount of nocturnal wake time (WASO) throughout the lifespan are presented in Figure 1.7:

Figure 1.7 Wake-time after sleep onset (WASO) across the lifespan.



Data for Figure 1 7 is taken from Table 1 1

From inspection of Figure 1.7 it is again possible that there are some discrepancies between research group methodologies and cohort selections which may explain some of the between age-group variations in the presented data However, a reliable increase in nocturnal arousals is evident from these pooled data. From examination of the trendline superimposed on this histogram: time spent awake at night rises from approximately 25 minutes in children to nearly 80 minutes in the oldest adults. This equates to an increase in nocturnal wakefulness of approximately 7.5 minutes per-decade of life. However, as with decreases in TST, these increases in nocturnal wakefulness are likely to be more pronounced from middle age onwards (Caulter *et al* 2000) as sleep becomes significantly lighter and more easily disturbed from middle to older age, see figure 1.7 (Boselli *et al* 1998).

Sleep then, becomes shorter (e g Roffwarg *et al* 1966), lighter (e g. Zeppelin *et al* 1984) and more fragmented (e g Boselli *et al* 1998) with advancing age and it is likely that these changes are more pronounced from middle-age onwards (Caulter *et al* 2000). These sections have reviewed what are ostensibly normal age-related

changes in the structure, organisation, continuity and depth of human sleep. The following sections will firstly examine changes in feelings about sleep (i e satisfaction with sleep and age-related changes in the prevalence of insomnia) before reviewing the literature on sleep in older people with dementia

1.3 CHANGES IN SLEEP QUALITY WITH ADVANCING AGE

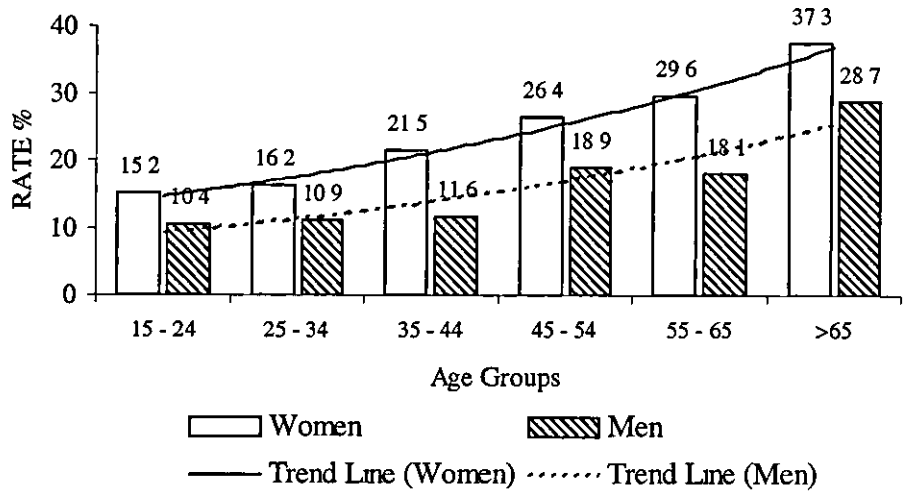
Chronic insomnia is defined as occurring on an average of three or more nights per week for more than one month This form of insomnia is usually associated with a variety of neuropsychiatric conditions, medical disorders or treatments, substance abuse and/or environmental conditions When a complete evaluation reveals no specific aetiology, this type of insomnia is termed primary insomnia. In order to be recognised clinically, sleep disturbances must *"be associated with daytime fatigue or impaired functioning."* Furthermore, for a diagnosis of chronic insomnia the sleep disturbance must: *"cause significant impairment in social or occupational functioning, or cause marked distress, over a period of at least one month"* (DSM-IV; APA 1994; p 1157).

Complaints of disturbed nocturnal sleep can be divided into three separate categories: difficulties in getting to sleep or difficulties with initiating sleep (DIS), problems staying asleep or difficulties with maintaining sleep (DMS) and early morning awakening (EMA). Older adults have been reported to complain more frequently about the quality of their sleep experiences than do younger persons (Foley *et al* 1995, Maggi *et al* 1998) These changes in reported insomnia with advancing age are reported in the following section.

1.3.1 Gradual increases in complaints of insomnia with advancing age

Ohayon *et al* (1996) collected insomnia information from over 5,600 people across different age-groups. Their data are presented in Figure 1.8.

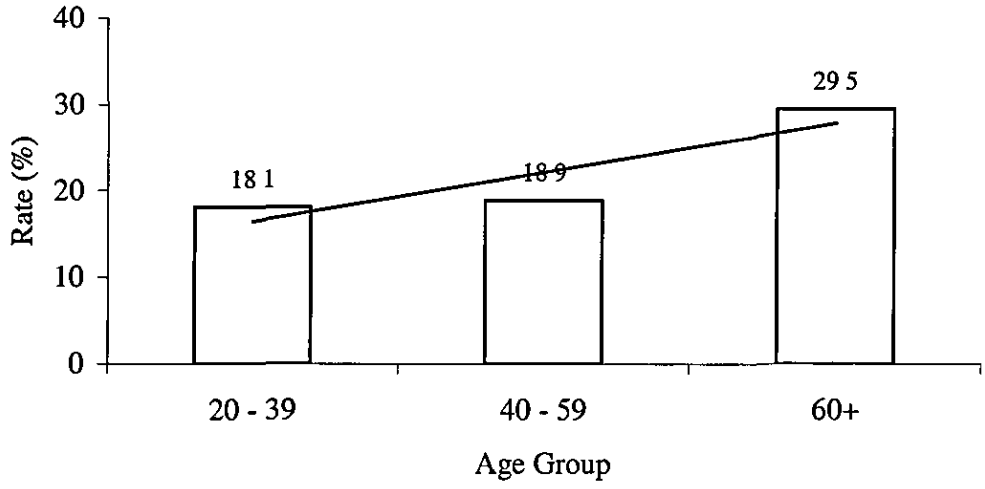
Figure 1.8 Increasing reports of insomnia (both sexes) with increasing age in the general population of France (n = 5,622).



Reproduced from Ohayon *et al* 1996

These data from France (Ohayon *et al* 1996) have been replicated by data from Japan (Kim *et al* 2000), suggesting little variation in reported insomnia rates in Caucasian and Asian general populations These data from Japan are presented in Figure 1 9.

Figure 1.9 Increasing reports of insomnia (both sexes) with increasing age in the general population of Japan (n = 3,030).



Reproduced from Kim *et al* 2000

Kim *et al* (2000) reported that difficulties with initiating sleep (DIS) occurred in 8 3% of their group of older Japanese adults from the general population, difficulties in maintaining sleep (DMS) occurred in 15.0% and early morning awakenings (EMA) in 8 0%. These rates are comparable to those reported in European (Morgan *et al* 1988; Hohagan *et al* 1994; Ford and Kamerow 1989) and American (Foley *et al* 1995) general populations. A comprehensive review of late-life insomnia conducted by Morgan (2001) derived from 12 studies on the prevalence of insomnia in communities from the UK, the USA, Sweden, Italy and Japan reported that 42% of older adults with insomnia (OAWI) present with DIS, 53% with DMS and 24% with problems of EMA. Complaints and dissatisfaction with sleep seem to increase with advancing age (Morgan *et al* 1988, Hohagan *et al* 1994; Foley *et al* 1995; Ohayon *et al* 1996; Maggi *et al* 1998; Kim *et al* 2000). These changes are consonant with age-related changes reported in the sleeping EEG (Feinberg *et al* 1967, Kales *et al* 1967; Prinz 1977; Zepelin *et al* 1984; Dijk *et al* 1989; Astrom and Trojaborg 1992; Waterman *et al* 1993, Larsen *et al* 1995; Landholt 1996; Boselli *et al* 1998). Collectively, these accumulated findings

suggest that older age brings with it a greater risk of developing insomnia as a result of ostensibly normal ageing processes, and pathology.

1.3.2 Age-related changes in incidence rates of insomnia

The insomnia study conducted by Ford and Kamerow (1989) identified the annual incidence rate for older adults developing insomnia as 5.7% in young adults (18 – 25 years) rising to 7 3% in those aged 65 years or older These findings have been supported by Foley *et al* (1999), from their sample of 6,899 older adults (over 65 years), the annual incidence rates for developing insomnia were estimated to be approximately 5%. Risk factors associated with the development of insomnia in this group included: depressed mood, physical disability, poor self-perception of health, widowhood, the use of prescribed sedatives and respiratory complaints (Foley *et al* 1999). As older adults are more exposed to poor health, bereavement and drug consumption than younger adults, this places the older adult population at a greater risk of developing insomnia than younger adults.

1.3.3 Prevalence rates of insomnia in older adults

Numerous studies have examined the prevalence rates of insomnia among older adults with insomnia (OAWI) in the community; nine of these studies (with particularly large sample sizes) conducted over the last fifteen years are summarised in Table 1.2. These accumulated data come from America, Europe and Japan and present prevalence rates of insomnia in the older adult population across the globe

Table 1.2. Findings from nine studies into the prevalence of insomnia (%) in community-dwelling adults from Europe, Japan and the USA.

Study	Age Range	Sample size (n)	Overall (%)	Women (%)	Men (%)
Ohayon *et al* 1996	65+	NR	NR	37 3	28 7
Kim *et al* 2000	65+	766	29 5	NR	NR
Morgan *et al* 1988	65+	1,023	22 5	27 7	14 6
Ford & Kamerow 1989	65+	1,801	12 0	NR	NR
Hohagen *et al* 1994	66 – 92	330	23 0	29 1	7 9
Maggi *et al* 1998	65+	2,398	NR	54 0	35 6
Foley *et al* 1995 (Boston)	65+	3,537	33 7	36 4	29 4
Foley *et al* 1995 (New Haven)	65+	2,717	27 5	31 1	21 2
Foley *et al* 1995 (Iowa)	65+	3,028	23 2	25 4	19 5
Combined outcomes from 9 studies of older adults	65+	> 15,600	**24.5 % Mean**	34 4 % Mean	22 4 % Mean

NR = Not Reported

From the studies reported in Table 1.2; around a third of older women complained of difficulties with their sleep compared to around a fifth of older men (Morgan *et al* 1988; Hohagan *et al* 1994; Foley *et al* 1995; Ohayon *et al* 1996, Maggi *et al* 1998, Kim *et al* 2000). From Table 1.2 it can be seen that approximately one quarter of older adults, over the age of 65 years, experience some form of insomnia

1.4 SUMMARY OF AGE-RELATED CHANGES IN SLEEP QUANTITY AND QUALITY

As we age, sleep gradually reduces in duration and depth (Feinberg *et al* 1967; Kales *et al* 1967; Prinz 1977; Zepelin *et al* 1984; Dijk *et al* 1989; Astrom and Trojaborg 1992; Waterman *et al* 1993, Larsen *et al* 1995; Landholt 1996; Boselli *et al* 1998). Our satisfaction with the sleep experience also gradually declines (Ford and Kamerow 1989; Hohagan *et al* 1994, Foley *et al* 1995; Ohayon *et al* 1996, Maggi *et al* 1998, Kim *et al* 2000). The experience of insomnia also changes with age, OAWI describe increased difficulties in remaining asleep or maintaining their sleep, whereas younger people with insomnia complain more frequently with difficulties initiating their sleep (Foley *et al* 1995; Maggi *et al* 1998).

Insomnia is highly prevalent in later life with approximately 28% of older adults (65+) complaining of disturbed sleep [approximately 34.4% of women and approximately 22 4% of men] (Morgan *et al* 1988; Hohagan *et al* 1994, Foley *et al* 1995; Ohayon *et al* 1996; Maggi *et al* 1998; Kim *et al* 2000). Incidence rates for new cases of insomnia are also greater in older adults; with around 5% per year of young adults developing insomnia compared to 7.3% in those aged 65 or more (Ford and Kamerow 1989). Insomnia is both precipitated and perpetuated by disorders, diseases and lifestyle factors which are particularly prevalent in older age e g. chronic disease, physical disability, widowhood, depression, unemployment, lack of regular exercise, poor self perception of health and psychological stress (Maggi *et al* 1998; Foley *et al* 1999; Kim *et al* 2000). Considering these concomitants, which can precipitate and perpetuate insomnia at any age, these factors place the older adult population at particular risk for the development of a longstanding sleep disorder.

Studies reviewed in the following section indicate that many of the structural changes, which characterise sleep in otherwise healthy older people, are amplified in dementia.

1.5 DEMENTIA: DIAGNOSES, EPIDEMIOLOGY AND SLEEP DISTURBANCES.

The most widely accepted diagnostic criteria for dementia are those offered by the National Institute of Neurological and Communicative Disorders and Stroke and by the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA; McKhann *et al* 1984) These criteria include the presence of dementia established by clinical examination and confirmed by neuropsychological testing. Dementia is described as:

"Involving multiple, progressive cognitive deficits in older persons in the absence of disturbances of consciousness, presence of psychoactive substances, or any other medical, neurological, or psychiatric conditions that might in and of themselves account for these progressive deficits" (DSM IV; APA 1994, p 275)

Diagnosis of dementia of the Alzheimer type is made where cognitive deficits progress gradually and diffusely throughout the cortices. Diagnosis of dementia of the vascular type (or multi infarct dementia; MID) is made where there is a step-wise progression of cognitive deficits associated with focal deterioration within the cortices as a result of strokes (APA 1994).

1.5.1 Epidemiology of dementia

In the UK the Department of Health and the Medical Research Council (MRC) have been conducting a study into Cognitive Function and Ageing (CFAS) Using standardised tests of cognitive function, they reported that the prevalence of cognitive impairment and dementia appeared not to vary widely across the six regions of the UK which they investigated (Liverpool, Newcastle, Nottingham, Oxford, Cambridge and Gwynedd). The MRC-CFAS established that the major influences on scores of cognitive function were confirmed as age, sex, social class and educational level. The MRC-CFAS also estimated that the size of the

population affected with dementia of mild or greater severity in England and Wales was around 550,000 individuals (MRC-CFAS 1998). In another study performed by the MRC-CFAS, it was estimated that around 53% of those individuals with cognitive impairment and limitations to daily activity were reported to be living in institutions (MRC-CFAS 1999). This left a remaining 47% being cared for in the community in 1999. The MRC emphasises that very elderly people and those with cognitive impairments make up a large proportion of those in need of long term care. .

The prevalence of dementia in community dwelling adults over the age of 65 years was reported in a pan-European study that pooled data from 11 separate epidemiological studies, including data from 2346 older adults (Lobo *et al* 2000) The findings from this study identified the prevalence of dementia in population-based cohorts of 6.4%, for all cases of dementia in adults aged 65 years or older. They reported 4.4% of these cases diagnosed with Alzheimer's disease (AD) and 1.6% with vascular or multi-infarct dementia (MID). Lobo *et al* (2000) described increasing prevalence of dementia with advancing age, from 0 8% in the 65 – 69 year-old age group, rising to 28 5% at age 90 years or older. For those diagnosed with AD the figures were 0 6% in the 65 – 69 year age group rising to 22.2% in people aged over 90 years. In people with MID 0.3% were diagnosed in the 65 – 69 age group, rising to 5.2% of those aged over 90 years. They reported increased prevalence of dementia in women than in men (Lobo *et al* 2000). These gender-related findings have been supported by Matthews and Denning (2002), who reported that the prevalence of dementia in older people living in institutions was 62% They also reported a higher prevalence of dementia in older women than older men.

In a study of 510 older adults from Finland aged over 85 years, Juva *et al* (2000) described an increased risk of developing dementia in those with the Apolipoprotein E epsilon 4 (APOE-E4) allele compared to those without this allele, odds ratio 2.36 (95% CI, 1.58 – 3.53). They also described an increased risk in their sample of

older adult women (OR 3 23, 95% CI, 2.20 – 5.17), whereas the odds ratio for their sample of older adult men was not significant (Juva *et al* 2000) Fitzpatrick *et al* (2004) also described an increasing prevalence of dementia in older adult women (16%) than men (14.7%) with age scaled to 80 years and reported an increased incidence rate of dementia in those with the APOE-E4 allele (56.4%) compared with those who did not have this allele (29 6%) also at age scaled to 80-years ($p<0.001$), their sample included 3,602 older adults (Fitzpatrick *et al* 2004) In the general population the incidence of dementia in the over 65 years age-group has been reported to be in the region of 2.6% (Livingston *et al* 1992), of which 0.8% were diagnosed with AD, 0.4% with MID and the remainder with other, mixed or undefined dementias (Boothby *et al* 1994).

1.5.2 Sleep in dementia

In addition to changes in memory, personality and self-care, dementia has been associated with characteristic sleep disturbances which appear to amplify those age-related changes in sleep observed in healthy older people. Compared to age-matched controls, people with dementia take longer to initiate their sleep, experience lighter sleep and wake up more frequently during the night (Prinz *et al* 1982). They also stay awake for longer when aroused and they show increased impairments in their activities of daily living (ADL) as a result (Prinz *et al* 1982; Allen 1987) People with dementia have also been shown to sleep during the day (or nap) more frequently than healthy older people (Ancoli-Israel *et al* 1989; Van Someren *et al* 1993). Table 1 3 compares the total sleep time (TST), sleep onset latency (SOL), sleep efficiency (SE), wake-time after sleep onset (WASO), percentage of slow wave sleep (SWS) and the number of nocturnal arousals in older adults with dementia and age-matched non-dementing controls. These data originate from five sleep studies comparing the sleeping EEG characteristics of older adults with dementia and age-matched controls conducted over the last 22 years (Prinz *et al* 1982; Allen *et al* 1987, Aharon-Peretz *et al* 1991; Moe *et al* 1995; Ancoli-Israel *et al* 1997).

Table 1.3 Comparison of TST, SOL, SE, WASO and the number of nocturnal arousals in older adults with dementia and controls

Study	Age Range	Sample Size (n)	TST mins (SD)	SOL mins (SD)	SE % (SD)	Arousals (n) (SD)	WASO (mins) (SD)	SWS % (SD)
Aharon-Peretz *et al* 1991[a]	65 6 – 72 4	11	434 (62 0)	NR	81 9 (5 1)	NR	NR	NR
Moe *et al* 1995[a]	67 0 – 69 2	38	379 (7 8)	11 0 (1 3)	80 6 (2 0)	18 0 (0 9)	91 0 (9 4)	6 0 (0 8)
Prinz *et al* 1982[a]	58 0 – 85 0	11	371 (55 9)	15 3 (13 6)	82 2 (7 0)	10 5 (4 3)	66 0 (10 0)	17 4 (4 6)
Allen *et al* 1987[a]	63 0 – 89 0	14	483 (32 5)	NR	67 4 (16 3)	17 3 (5 5)	234 4 (56)	9 1 (1 7)
Ancoli-Israel *et al* 1997[b]	74 0 – 96 0	22	348 (97)	NR	60 0 (16)	30 0 (8 2)	1019 (159)	NR
Aharon-Peretz *et al* 1991[c]	66 5 – 79 1	15	524 (84)	NR	61 7 (23 7)	NR	NR	NR
Allen *et al* 1987[d]	69 0 – 96 0	30	334 (43 8)	NR	48 8 (21 9)	25 5 (13 6)	351 0 (134 4)	9 0 (2 3)
Moe *et al* 1995[c]	69 2 – 71 0	78	299 (7 4)	15 3 (1 4)	66 2 (1 7)	20 2 (0 9)	133 0 (8 2)	3 9 (0 5)
Prinz 1982[c]	56 0 – 88 0	10	374 (45 9)	10 0 (5 2)	64 5 (15 8)	33 3 (15 7)	133 0 (16 3)	2 1 (4 2)
Allen *et al* 1987[c]	69 0 – 73 0	16	371 (56 8)	NR	55 8 (28 4)	21 5 (14 6)	293 5 (183 7)	12 0 (1 5)
Ancoli-Israel *et al* 1997[e]	60 0 – 100 0	55	540 (142)	NR	87 0 (21)	35 0 (8 4)	839 0 (150)	NR
Aharon-Peretz *et al* 1991[f]	67 8 – 84 2	10	513 (116)	NR	82 9 (8 0)	NR	NR	NR
Allen *et al* 1987[f]	71 0 – 92 0	8	314 (55 9)	NR	46 3 (28 0)	31 0 (12 2)	364 0 (125 9)	15 3 (3 5)

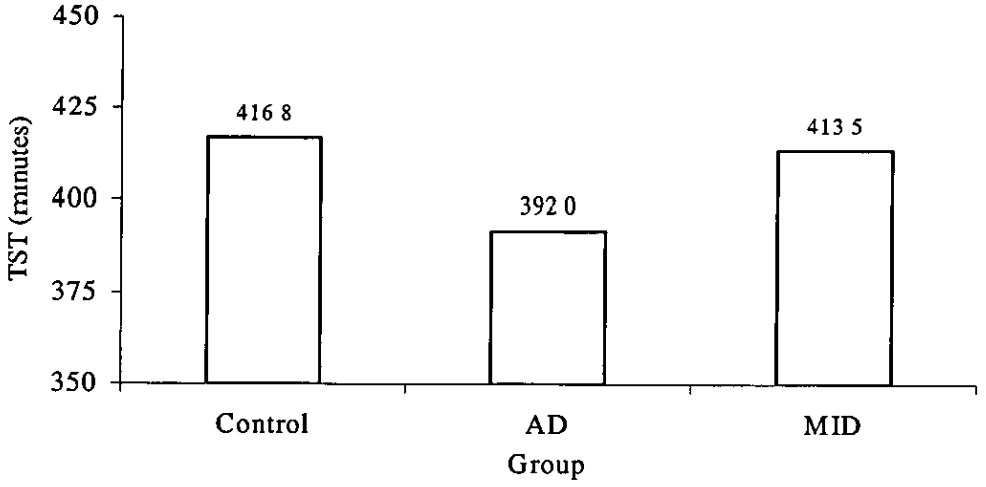
TST = Total Sleep Time, SOL = Sleep Onset Latency, SE = Sleep Efficiency, WASO = Wake-time After Sleep Onset, SWS = Slow Wave Sleep
NR Not Reported, [a] Control group, [b] Mild, moderate or no dementia group nighttime + daytime data, [c] SDAT group, [d] Dementia group, [e] Severe dementia group nighttime + daytime data, [f] MID group

The data presented in Table 1.3 are represented graphically in Figures 1 10 – 1.13 in the following sections

1.5.3 Total sleep time in older adults with dementia.

Figure 1.10 displays information on the total sleep time (TST) of the older people sampled in these five studies across dementia types and compared to controls (Prinz *et al* 1982; Allen *et al* 1987; Aharon-Peretz *et al* 1991; Moe *et al* 1995; Ancoli-Israel *et al* 1997a).

Figure 1.10 Total sleep time in normal ageing and dementia



AD = Alzheimer's disease, MID = Multi-Infarct Dementia

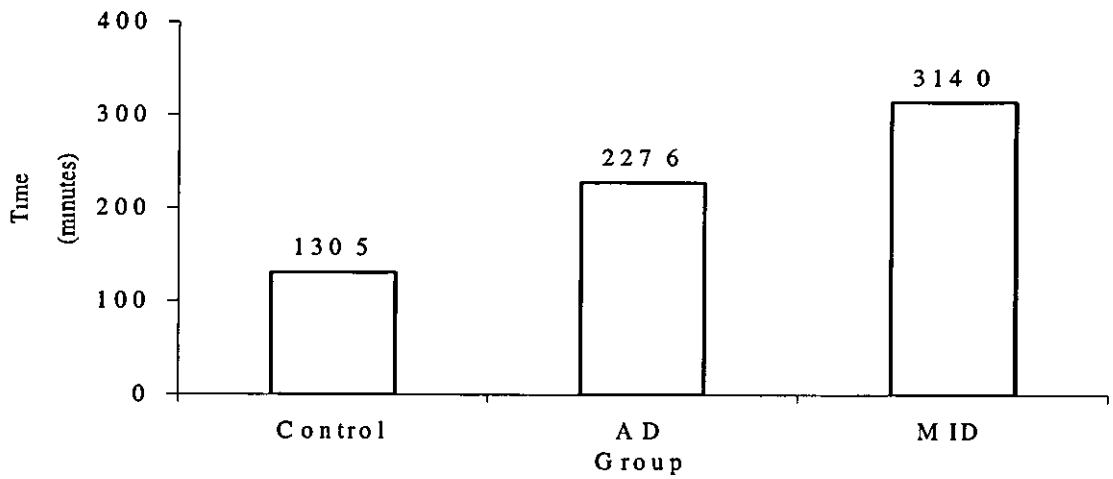
Data for Figure 1 10 compiled from Table 1 3

As can be seen from Figure 1.10, TST is reduced in dementia and particularly in Alzheimer's disease.

1.5.4 Wake-time after sleep onset in older adults with dementia.

The following figure (Figure 1 11) describes wake after sleep onset (WASO) from data presented in Table 1.3.

Figure 1.11 Nocturnal wake time (WASO) in normal ageing and dementia



AD = Alzheimer's disease, MID = Multi-Infarct Dementia

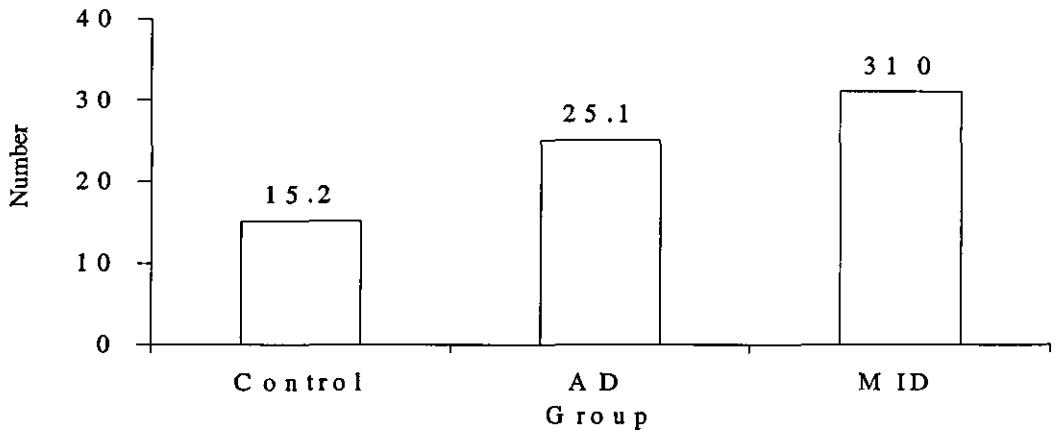
Data for Figure 1 11 compiled from Table 1 3

From Figure 1 11; WASO is increased in older people with dementia and particularly in people with multi-infarct dementia. WASO in people with Alzheimer's disease experienced nocturnal wake times approaching double those seen in healthy, age-matched controls. In people with vascular dementia these nocturnal wake times approach 2.5 times those reported in healthy age-matched controls.

1.5.5 Frequency of nocturnal arousals in older adults with dementia.

The following figure (Figure 1.12) describes the number of nocturnal arousals per-night across dementia types from data presented in Table 1.3.

Figure 1.12 Number of nocturnal arousals in normal ageing and dementia



AD = Alzheimer's disease MID = Multi-Infarct Dementia

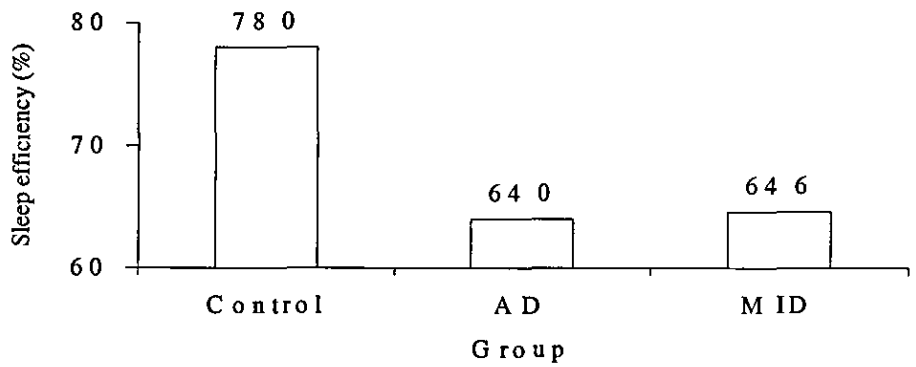
Data for Figure 1 12 compiled from Table 1 3

From Figure 1 12· the number of nocturnal arousals per-night was increased greatly in dementia and particularly in multi-infarct dementia, with around a two-fold increase in the number of EEG assessed nocturnal awakenings reported in MID patients compared to their controls.

1.5.6 Sleep efficiencies of older adults with dementia

The following figure (Figure 1.13) describes the sleep efficiencies of these older adults with dementia from data presented in Table 1 3.

Figure 1.13 Nocturnal sleep efficiency in normal ageing and dementia



AD = Alzheimer's disease, MID = Multi-Infarct Dementia

Data for Figure 1 13 compiled from Table 1 3

From Figure 1.13: SE was reported to be reduced in dementia compared to age-matched non-demented control participants. Sleep efficiency was profoundly affected by dementia with these five studies indicating a 12% reduction in the SE of older people with dementia compared to controls.

1.5.7 Comparison of the sleep characteristics of older adults with dementia and age-matched controls.

Collective examination of the previous four figures (Figures 1.10, 1.11, 1.12 and 1.13) from these five studies (Prinz *et al* 1982; Allen *et al* 1987; Aharon-Peretz *et al* 1991, Moe *et al* 1995; Ancoli-Israel *et al* 1997) shows that older adults with dementia experience less TST, increased nocturnal time awake (WASO), a greater number of nocturnal arousals and diminished sleep efficiencies when compared with age-matched non-dementing control volunteers.

In addition to these general changes in the EEG structure of sleep and alterations in the duration and maintenance of sleep, dementia has also been associated with two specific sleep-wake disorders, Sundowning and REM Sleep Behaviour Disorder (RBD).

1.5.8 Sundowning

Sundowning type behaviours in dementia present as increased levels of wandering and agitation without any specific origin or purpose. Sundowning has been defined as:

"An exacerbation of symptoms indicating increased arousal or impairment in the late afternoon, evening or at night, among elderly demented individuals" (Rindlisbacher and Hopkins 1992; pp. 15).

This 'exacerbation of symptoms' includes the presence of some or all of the following disruptive behaviours: combativeness; agitated / purposeless movement; wandering; prolonged incoherent vocalisation (over 5 minutes); hallucinations (misinterpretations of the environment), confusion, and disorientation (Gallagher-Thompson *et al* 1992). The deterioration of the circadian rhythm (discussed more fully in Chapter 3, Section 3.7), commonly seen in people with dementia (Witting *et al* 1990, Vitiello *et al* 1992; Bliwise *et al* 1993) has been implicated in the phenomenon of sundowning It has been estimated that between 10 – 25% of the nursing home population display behaviours of the sundowning type (Martin *et al* 2000) of which, wandering behaviours have been estimated to occur in around 17% of people with dementia (Klein *et al* 1999). Wandering was found to be more prevalent in males, long-term users of neuroleptic medications, people with dementia of the Alzheimer type and in older adults with dementia who have experienced an increased duration and severity of the disease. Moreover, sleep disturbances have been implicated as significant predictors of wandering behaviours

(Klein *et al* 1999) and as instrumental in the acceleration of cognitive decline (Bliwise *et al* 1993)

Sometimes a person with dementia has such a fragmented sleep/wake cycle that agitated behaviour, social dysfunction, wandering at night and pacing during the day becomes a common part of their everyday lives (Ancoli-Israel *et al* 1997). In extreme cases certain individuals have been seen to be asleep more during the daylight hours than they are at night – the so called day-night reversal, although this feature of reversed 24-hour activity distribution is rare (Allen *et al* 1987; Vitiello *et al* 1992).

1.5.9 REM sleep Behaviour Disorder (RBD)

REM sleep Behaviour Disorder (RBD) is a parasomnia which is characterised by the loss of REM sleep atonia (a principle feature of REM sleep), i e. people with RBD lose REM sleep-associated paralysis and can move (sometimes quite violently) during periods of REM and NREM sleep. People with RBD have been found to display generalised REM and NREM sleep motor dyscontrol (Shenck *et al* 1986). People with RBD commonly display bursts of vigorous and uncontrolled limb movements and vocalisation during sleep which is associated with dream recall (Boeve *et al* 1998). The loss of brainstem neurons in the locus coereleus and the substantia nigra have been shown to be characteristic of idiopathic RBD in older people (Uchiyama *et al* 1995). Recent findings have examined a male predominance for the disease in the order of 87 – 92 % (Schenk *et al* 1993, Boeve *et al* 1998). Furthermore, evidence suggests that RBD is symptomatic of Lewy body dementia (DLB) with many people (92%) who display RBD going on to develop DLB (Uchiyama *et al* 1995; Boeve *et al* 1998; Schenk and Mahowald 2002).

The following section will review the literature which addresses the impact of sleep disturbances in dementia on cognitive function and the rate of cognitive decline

1.6 RELATIONSHIP BETWEEN SLEEP DISTURBANCES IN DEMENTIA AND COGNITIVE FUNCTION

In sleep studies of institutionalised people with AD, frequent, lengthy awakenings, reduced EEG SWS and decreased amounts of REM sleep have been observed compared to age matched controls (Prinz *et al* 1982; Moe *et al* 1995) The quantity of nocturnal REM sleep has been reported to correlate in a positive direction with cognitive function in older adults (Prinz 1977) suggesting a possible diagnostic tool for the identification of older adults with dementia.

Prinz *et al* (1982) conducted the first comparative descriptive EEG study on the sleep and wakefulness of ten older adults with dementia and eleven control participants. This research reported that, although older adults with dementia spent as much time in bed as the control group, they experienced significantly less REM sleep (34.5 minutes compared to 70 2 minutes, $p < 0.0001$) and significantly less SWS (7.73 minutes compared to 63.7 minutes, $p < 0.0001$) The older adults with dementia in this study also experienced a greater number of EEG measured nocturnal arousals than in the control group (33.3 compared to 10 5, $p<0.0001$). These findings have been supported by further work conducted by Allen *et al* (1987) who reported significant reductions in REM sleep (56 9 minutes compared to 102.3 minutes, $p < 0$ 001), and the number of nocturnal arousals (10.3 compared to 4.0, $p = 0$ 03) between their older adults with dementia ($n = 30$) and their fourteen control participants (Allen *et al* 1987).

Moe *et al* (1995) assessed the sleep/wake patterns and levels of cognitive and daily functioning in a group of people with AD. Their assessment of 78 people with dementia of the Alzheimer type and 38 control subjects matched for age included examination with the Mini Mental State Examination (MMSE); Folstein *et al* (1975), the Dementia Rating Scale (DRS), Mattis (1976) and various measurements of Activities of Daily Living (ADL). Sleep was examined by EEG analysis over three consecutive nights. This research team reported that people with dementia

were found to be more wakeful than their control group during the night; that they had decreased amounts of REM sleep, and that their REM latency (REM latency is measured as the time from sleep onset to the first bout of REM sleep measured in minutes) was increased. These three phenomena (increased total nocturnal wake-time, decreased percentage of REM sleep and prolonged REM latency) were all shown to correlate with diminished cognitive and functional abilities during the day and with lower MMSE and DRS scores. These findings suggest that either,

1. Increasing cognitive deterioration influences sleep disruptions in dementia, i e. the more the dementia has progressed, the more disturbed the sleep Or,

2 Increasing sleep disturbance impacts on increased cognitive decline, i.e. the more disturbed the sleep, the greater the rate of cognitive decline.

These three research groups have all reported wide variations in the sleep of older adults with dementia, levels of REM sleep and SWS have been reported to be highly variable, as have nocturnal arousal times (Prinz *et al* 1982; Allen *et al* 1987; Moe *et al* 1995). These findings suggest that, although older adults with dementia experience more sleep disruption than people without dementia, some older adults with dementia can still sleep comparatively well. Indeed, Vitiello *et al* (1990) examined the sleep of a group of 44 older adults with mild dementia and 45 age-matched controls. Their findings were equivocal, with differences in sleep outcome measurements between the two groups failing to meet the required specificity for use as a clinical diagnostic tool. Regestein and Morris (1987) examined the sleep and wakefulness patterns of 16 institutionalised older women with dementia. Their findings described wide variations in the sleep characteristics of their participants. The findings of these two studies suggest that aetiological factors are not alone in influencing sleep disruptions in dementia This conclusion is supported by the findings of Meguro *et al* (1995) This group reported that dementia severity (indexed by computerised tomography of the extent of cortical white matter lesions) and lowered daytime activity levels (assessed by Activities of Daily Living [ADL]

scores) interacted to increase sleep fragmentation. These findings imply that whatever the organic origin of dementia, sleep disruption in older adults with dementia may be amplified by behavioural factors which are known to promote insomnia at all ages (Vitiello *et al* 1990; Regestein and Morris 1987; Meguro *et al* 1995).

1.7 SUMMARY OF SLEEP IN OLDER ADULTS WITH DEMENTIA.

Older adults with dementia show reduced quantities of REM sleep and SWS (Prinz *et al* 1982; Allen *et al* 1987; Moe *et al* 1995) The sleep taken by older adults with dementia has also been reported to be much more variable than their age-matched controls, with some older adults with dementia displaying comparatively 'normal' sleep for their age with others showing particularly disturbed and fragmented sleep. These findings suggest that the organic progression of dementia, although highly significant in the impact that the associated neuronal degeneration has on sleep, does not completely explain the sleep disturbance. The findings of Meguro *et al* (1995) suggest that levels of activities of daily living combine with cognitive impairment in disturbing the sleep/wake cycle in dementia. Moreover, the work of Vitiello *et al* (1990) who reported that sleep disturbance factors failed to distinguish between mildly dementing older adults and non-dementing controls suggests that cognitive impairment *per se* does not completely explain sleep disturbances in these older people (Vitiello *et al* 1990; Meguro *et al* 1995). Collectively, these findings suggest that the relationship between the severity of dementia and sleep are complex and warrant further investigation (Feinberg *et al* 1967; Prinz 1977; Prinz *et al* 1982, Vitiello *et al* 1990; Moe *et al* 1995; Meguro *et al* 1995)

1.7.1 Main summary points from the sleep in older people and dementia literature

- Generally the sleep of older people is: shorter, lighter, more easily disturbed, more fragmented, more difficult to initiate and less satisfying than sleep experienced by younger people.

- People with dementia experience more fragmented sleep-wake cycles, with more sleep occurring during the day and less at night, than in healthy older people.

- People with dementia experience sleep which is shorter, lighter and more easily disturbed than healthy older people.

- People with dementia display such a variation in measured sleep outcomes that the effects of dementia in isolation cannot completely explain the sleep disruption characteristic of this group

This chapter has reviewed sleep in ageing and in dementia, presented information regarding the numbers of people affected by the various types of dementia and the distribution of these individuals across community and institutional environments. As a large proportion of these people with dementia are community-dwelling and therefore being cared for by caregivers who were either family members or friends it is reasonable to assume that the sleep of community-dwelling caregivers is at high risk of being disturbed as a direct result of living with and caring for an older person with dementia. The sleep of dementia caregivers will therefore be reviewed in the following chapter.

CHAPTER TWO

The impact of caregiving on dementia caregivers' sleep

2.1 INTRODUCTION

The previous chapter reviewed evidence for changes in sleep structure and quality in relation to normal ageing and dementia. After a definition of personal care, a demographic analysis of the caregiving population and an examination of the literature pertaining to the impact of caregiving on caregiver wellbeing, the present chapter will detail the research investigating the impact of caregiving on the sleep of caregivers.

2.2 DEFINITION OF THE PERSONAL CARE OF OLDER PEOPLE

Those providing care have been variously described as "informal carers", "carers" or, more recently, "caregivers". The term "caregivers" will be used here. Older people with dementia who are receiving long-term care from their caregivers will be referred to as "care recipients".

The Royal Commission on Long Term Care of the Elderly (1999) defines domiciliary or home care as:

"Personal care or practical help provided to older people in their own homes."

The commission goes on to define personal care more fully as providing assistance or supervision with:

"Personal toileting. eating and drinking... managing urinary and bowel functions.. managing problems associated with immobility; management of

prescribed treatment.. behaviour management and ensuring personal safety (for example, for those with cognitive impairment - minimising stress and risk) "
Section 6.43 – 6.48; The Royal Commission on the Long Term Care of the Elderly (1999). It should be considered that this is the definition for professional caregivers. However, these are the elements of care provided by informal, community caregivers for their dependent dementia care recipients. The following section will report on caregiver demography.

2.3 CAREGIVER DEMOGRAPHY

According to the Office of National Statistics Carers 2000 report (ONS 2002) approximately 16% of the older adult population in the UK provides some form of long-term community-based care to a friend or relative. In real terms this amounted to around 1.07 million people (16% of the total of 6.7 million people providing long-term care in the UK in 2000 (ONS 2002)). The age distribution of these caregivers is presented in Table 2.1.

Table 2.1 Caregiver distribution by age*

Age group	% of caregivers	Percentage of total population(%)
Under 16	4	NR
16 – 44	10	11 5
45 – 64	16	24
65 – 74	18	
75- 84	33	16
85+	19	

*data are presented for caregivers who share the same household as their care recipient
NR = Not reported

From Table 2.1 it can be seen that 70% of caregivers are older than 65. The percentage of the population providing care was higher in the 45 – 64 age-group

than in the over 65 age group However, the percentage of the population of caregivers in the UK providing long-term community-based care has risen by 3% in the over 65 age-group between 1995 and 2000 (ONS 2002). With regard to dementia caregivers approximately 47% of older adults with dementia are estimated to be cared for in the community (as reported in Chapter 1) by family or friend caregivers, amounting to around 250,000 older people with dementia and a similar number of caregivers (MRC-CFAS 1998; MRC-CFAS 1999) The following section will examine the caregiver sleep literature and report on the demands of caregiving and the effects of these demands on caregiver sleep.

2.4 THE IMPACT OF CAREGIVING ON THE HEALTH AND PSYCHOLOGICAL WELLBEING OF CAREGIVERS

The provision of care to an older dependent person has been reported to impact negatively on the health and wellbeing of caregivers. Opie (1994) stated that *"To care is to experience stress"* p. 39, and this has been echoed by more a recent report by Cheung and Hocking (2004) who identified caring as "worrying" about their dependents, about their relationships now and in the future, about their own health, lack of governmental support and institutional care. Smith *et al* (2004) have described a lack of knowledge, skills and preparation of new caregivers that was a cause for concern and distress in their sample. Indeed, the emotional distress (measured using the General Health Questionnaire) of caregivers has been reported to be associated with the degree of self-assessed difficulty with the caring role, dissatisfaction with caregiving, both at $p < 0.001$, and the dependency of the patient, $p = 0.038$ (Mafullul and Morris 2000).

These findings have been corroborated by Blake and Lincoln (2000) who described 'significant strain' in 37% of their sample of 222 caregivers that was correlated with perceptions of the dependency of their patients and with caregiver mood in spouses of stroke patients. These findings also support those of Moniz-Cook *et al* (1998), who reported a relationship between memory ability in people with

dementia and caregiver strain and Cullen *et al* (1997) who described disability and disturbed patient behaviour as strong predictors of caregiver wellbeing. These studies indicate that caregiving *per se* can induce stress and reduce the wellbeing of caregivers regardless of the characteristics of the patient.

In a recent large scale survey Hirst (2005) examined 2900 former caregivers using British Household Panel Survey data and assessed wellbeing using the General Health Questionnaire The findings from this study indicate that caregiver stress was related to providing long hours of care, caregiving for extended periods; being female, increased with severity with increasing time devoted to caregiving each week; providing care in the initial and terminal phases of caregiving; and looking after a spouse (Hirst 2005). These studies indicate the difficulties that caregivers experience whilst providing community-based care for their dependents, however positive experiences of caregiving have been identified and these will be presented in the following section.

2.5 POSITIVE EXPERIENCES OF CAREGIVING

Despite the wealth of evidence on the negative aspects of caregiving there have been several studies that have highlighted positive feelings about caregiving. Positive aspects of caregiving have also been described in terms of successfully maintaining the self-esteem and dignity of a dependent, and engaging in mutually satisfying activities (Nolan and Grant 1992; Grant and Nolan 1993) and feeling satisfied by doing a good job and seeing dependents happy (Cartwright *et al* 1994). Clifford *et al* (1990) described caregiver feelings of closeness to their older adult dependents growing as their caregiving roles progressed in 62% of cases Indeed, Farran *et al* (1991) reported that better family and social relationships were the single most satisfying aspect of providing care as stated by 63% of their sample of caregivers.

Other sources of positive feelings towards caregiving have been described as receiving love and affection from a dependent care recipient (Clifford *et al* 1990), satisfaction from fulfilling a sense of duty (Kane and Penrod 1995) and expressing religious beliefs (Clifford 1990). Repayment of past kindness and positive nurturing feelings of providing physical care needs to a dependent have also been reported (Nolan and Grant 1992; Grant and Nolan 1993). Nolan *et al* (1996) described a number of satisfying elements that can arise from providing care to a dependent and these include: maintenance and provision of 'small pleasures'; seeing happiness in the dependent; maintenance of dignity / self-esteem; nurturing; provision of good quality care; avoiding institutionalisation; assisting in recovery from illness; developing closer caring and family relationships; repaying past kindness; altruism; finding new interests; love, affection and expressions of appreciation; expression of religious beliefs; competency and achievement, fulfilling a sense of duty and the development of personal qualities such as patience and tolerance (Nolan *et al* 1996).

These studies identify caregiving as having potentially life-enhancing attributes despite the commonly reported view that providing care has negative consequences for psychosocial health and the wellbeing of caregivers (Nolan *et al* 1996).

2.5.1 Why someone may take up a caregiving role

The positive elements of caregiving stated above indicate the reasons why people may enter into a caregiving role and not, for example, immediately opt for institutional care placements Caregivers may enter into the caregiving role out of love for their dependent older person; out of a sense of duty to their dependent; or in order to prevent their dependent from becoming institutionalised. In accepting a caregiving role within community settings a large array of services become available to the caregiver in order to support them in their roles as caregivers and these are described in the following section

2.6 RESPITE CARE AS ONE OF A RANGE OF SERVICES AVAILABLE TO CAREGIVERS

There are a number of services available to caregivers of older people aside of the use of respite care. Community nurses, social workers, home help organisers, home care services, day care at day centres and General Practitioners comprise the list of formal health and social support services available to dementia caregivers living in the community. However, there are other support services that are available to the caregiver should they wish to engage with them and these include: sitting services; support groups; counselling, education sessions about care provision and related issues; and training in handling and lifting techniques, for example. These formal and informal services provide the caregiver with a choice of health service provision with which to engage, should they wish, to support them in their community-caregiving roles (Lawton *et al* 1991).

Overnight institutional respite care service provision sits within this range of services, but stands alone as the only service to be provided that involves the physical movement from the community home of a dependent person to an institution for more than one day The impact of respite care, in terms of supporting caregivers and enabling them to provide care for longer in the community and out of institutions, is described in the following section.

2.6.1 Respite care service provision is effective in preventing or at least delaying the breakdown of family care

Institutional overnight respite care service provision has been reported to enable caregivers to continue providing community based care for their dependent older people with dementia Watkins and Redfern (1997) reported that 31% of their sample of 26 caregivers in receipt of respite care continued to provide care in the community until shortly before the death of their care recipient. They suggest that respite care services enabled these caregivers to continue providing community-

based care even into the later stages of their dependents ill-health Pearson (1988) reported caregiver feelings about community based care provision and respite care, of this sample of 26 caregivers, 66% described relief as a result of respite care that made caring for their dependents easier, and more than half of this sample reported that they would not have continued to provide care in the absence of respite care provision, and 33% reported that respite services prevented them from experiencing a nervous breakdown.

Kosloski and Montgomery (1993) examined psychological wellbeing, subjective and objective burden in a group of 47 caregivers who used respite over a period of six months and compared them with a control group of 25 caregivers not receiving such services. They reported significant improvements subjective burden and psychological wellbeing in the respite intervention group compared to the control group at the six month follow-up assessment. The authors conclude that the use of respite care increased psychological wellbeing and reduced feelings of subjective burden in caregivers receiving respite care service provision.

The Service Delivery and Organisation report on respite care (Arksey *et al* 2004) reported a high level of caregiver satisfaction with respite care and stated that many caregivers believe that:

"Respite enabled them to continue caring" (Arksey *et al* 2004, p 103).

The report continued to describe caregivers' appreciation of respite care as:

"It offered a longer period of relief from caring and the particular benefit of being able to sleep without disturbance. Many carers felt it allowed them to go on caring" (Arksey *et al* 2004; p 104).

The authors go on to describe respite care in terms of saving money in the long term as it acts as a mediator by avoiding 'crisis admissions' resulting from

caregiver breakdowns and as an important service which helped caregivers avoid early entry into institutional care, and potentially reduced the risk of caregiver ill-health or mental breakdown (Arksey *et al* 2004)

2.7 THE MULTIFACTORIAL NATURE OF THE BREAKDOWN OF FAMILY CARE

As was reported previously, the psychological wellbeing of caregivers of dependent older people can be impacted by numerous states, traits or conditions and that reduced caregiver wellbeing can precipitate the breakdown of community-based care. Hirst (2005) identified time demands, gender (being female) and spousal caregivers as potentially more at-risk for reducing caregiver wellbeing and thereby the ability to provide community-based care.

The quality of the relationship between caregiver and care recipient has also been reported to impact on caregiver stress (Lyonette and Yardley 2003). Teri (1997) identified depression and anxiety as highly prevalent in community caregivers of dependent older people. A high prevalence of depression in community caregivers was also identified by Livingston *et al* (1996) These conditions are suggested to be influenced by reduced social mobility, physical role limitations (of both the caregiver and the dependent), observing the mental and /or physical deterioration of the patient, financial constraints. Caregiver stress was identified by Jerrom *et al* (1993) as a significant predictor of the breakdown of community based caregiving These findings suggest that there are multiple reasons for the breakdown of caregiving in the community, not just the physical role limitations of caregivers and that any condition or influence that causes distress in community caregivers is likely to lead to accelerated breakdown of community based care provision (Jerrom *et al* 1993; Livingston *et al* 1996; Teri 1997, Lyonette and Yardley 2003; Hirst 2005) The above sections have reviewed definitions of care, the demography of caregiving in the UK and the general experiences of caregiving and service

provision. The following sections of this chapter will continue by examining the impact of caregiving on caregiver sleep.

2.8 THE IMPACT OF CAREGIVING ON CAREGIVERS' SLEEP

Evidence that caregiving has a negative impact on caregiver sleep was reported in the seminal study conducted by Sanford in 1975. Sanford (1975) interviewed 50 caregivers of recently institutionalised older adults (31 of whom were diagnosed with senile dementia). The data described a high level of nocturnal wandering (24%), incontinence (24%) and vocalisation (10%) which caused disturbed sleep in 62% of his sample of caregivers. Sanford (1975) went on to examine the percentage of his sample that felt that they could tolerate each of these challenging behaviours. The disruption of caregiver sleep was only considered tolerable by 16% of the caregivers interviewed in this study (Sanford 1975). Out of 23 different challenging behaviours, 8 supporter limitations and 5 environmental and social problems examined in this study, sleep disturbance was the most frequently cited reason for these caregivers' decisions to institutionalise their dependent older adults. These findings are summarised in Table 2.2.

Table 2.2. Frequency and tolerability of care recipient behaviours by their caregivers, from Sanford (1975).

Behaviour of care recipient	Frequency (% of care recipients)	Tolerance of behaviour (% of caregivers)
Sleep disturbance of caregiver by care recipient	62	16
Night Wandering	24	24
Micturition	24	17
Shouting	10	20
Faecal Incontinence	56	43
Incontinence of urine	54	81
Falls	58	52
Inability to dress	44	77
Inability to wash	54	93

n = 50 caregivers of recently institutionalised older adults, 62% of whom were diagnosed with senile dementia

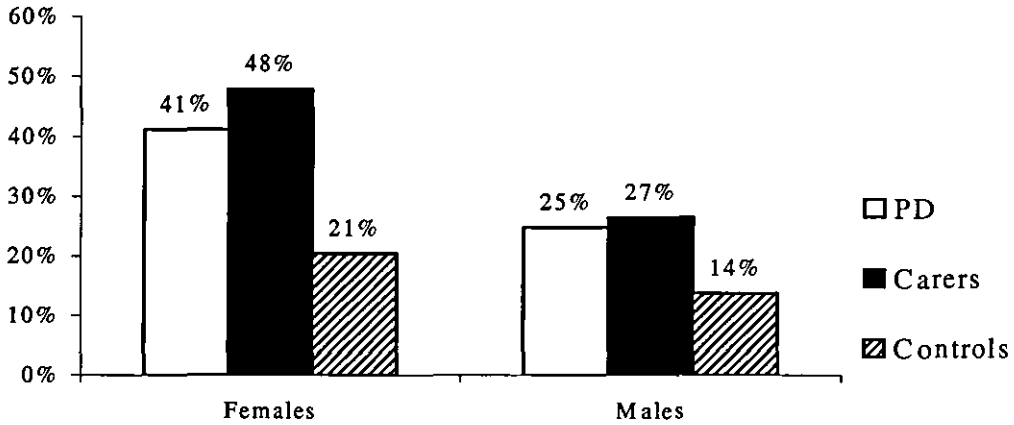
From Table 2.2 it can be seen that sleep disturbances related to care recipient behaviours are common in caregivers and, compared with other care recipient behaviours, are considered to be particularly intolerable by caregivers (Sanford 1975).

The impact of caregiving on caregiver sleep was also reported by Gilleard (1984) In a sample of 119 caregivers of older people with dementia, Gilleard (1984) reported moderate to significant difficulties with caregiving that were solely associated with sleep disturbance in 94% of his sample of dementia caregivers. Gilleard (1984) also described, in three separate studies of older adult caregivers, a mean of 52% of caregivers complaining about their dependent older adult wandering the house at night (total sample n = 301) Gilhooly and colleagues (1984) and Pollak and Perlick (1991) suggest that nocturnal wandering, and the negative impact that this has on the sleep of caregivers, is a significant predictor of

the decision to seek permanent institutional placements for their dependents. Gilhooly (1984) reported on the feelings of 46 caregivers of older adults diagnosed with dementia. She found that *"The supporters in my group also found that night wandering was virtually intolerable"* p. 133 (Gilhooly 1984). Pollak and Perlick (1991) examined reasons reported by 73 community-dwelling dementia caregivers for their decisions to seek a permanent institutional placement for their care recipients. They reported that 80% of these caregivers experienced sleep disturbances from their care recipients and that 65 5% of these caregivers cited sleep disturbance factors as a primary reason for seeking a permanent placement for their care recipients (Pollak and Perlick 1991).

The previous studies (Sanford 1975; Gilhooly 1984, Gilleard 1984; Pollak and Perlick 1991) were not specifically designed to examine sleeping difficulties in caregivers; they were concerned with what upsets caregivers and what their specific difficulties with caring were. It emerged from these studies that caring for an older adult with dementia has serious implications for the chronic disturbance of caregiver sleep. The following studies were specifically designed to examine sleep disruption of older adult caregivers. Smith and colleagues (1997) reported the presence of sleep problems in caregivers, and in people with Parkinson's disease, that were approximately double that found in control subjects matched for age. Their research also described increased problems with sleep in women. The findings of this study are presented in Figure 2.1:

Figure 2.1 Sleep problems in people with Parkinson's Disease (PD), Caregivers and Controls.



Number of persons (%) indicating frequent or continuous sleeping disorders (n = 197 women and n = 212 men) from Smith *et al* 1997.

The findings of Smith *et al* (1997) have been supported by research conducted by Wilcox and King (1999) Their assessment of 90 female caregivers of older adults with dementia described sleep disruption by a care recipient occurred less than once per-week in 8% of their sample, 28% complained of disturbed sleep once to twice per-week and 60% described sleep disturbances occurring three or more times per-week. Overall, 96% of their sample of 90 caregivers stated that a care recipient caused them at least some sleep disruption during the previous month (Wilcox and King 1999).

More recent work has examined the impact of caregiving on caregiver sleep across dementia types. Thommessen and colleagues (2002) described frequent or considerable disturbances of caregiver sleep as a result of the nighttime activities of a care recipient. From their sample of 186 older adult caregivers: 78 caregivers of older adults with vascular dementia, 47 caregivers of older people with mild AD and 28 caregivers of older adults with Parkinson's disease complained of disturbed sleep, 33 caregivers (18%) did not report disturbed sleep. Caring for an older adult with mild dementia, vascular dementia or Parkinson's disease was reported to incur similar levels of psychosocial burden, and the level of cognitive impairment of

dependents has been reported to have particular impact on caregiver sleep disruption, with more advanced cognitive impairment in the care recipient leading to more sleep disruption for both the care recipient and the caregiver (Thommessen *et al* 2002). This research team concluded that caring for older adults with dementia led to pronounced sleep disturbances in dementia caregivers

The findings of Sanford have been replicated by more recent work conducted by Kesselring and colleagues in Switzerland (2001). Their sample of 129 caregivers of infirm older adults revealed that 55% of their sample of caregivers experienced sleep disturbances as a result of providing care. Of their sample, 25% of caregivers were providing care for an older adult with dementia, 68% of caregivers were found to be providing care in excess of 12 hours per-day and 56% were rising during the night to continue to provide care (Kesselring *et al* 2001). On questioning their caregivers on the impact of their sleep disturbances, 55% described a negative impact, 43% described no impact and 2% stated that caregiving had a positive effect on their sleep. In a similar approach to Sanford (1975), this research team assessed the tolerability of certain symptoms and behaviours of these infirm older adults by their caregivers. Sleeplessness and poor sleep was described by 59% of caregivers and was reported to be tolerable by 64% of these caregivers. Restlessness and wandering at night was described by 35% of caregivers, these behaviours however, were only considered tolerable by 47% of the caregivers in this sample (Kesselring *et al* 2001).

More recently, the effects of regularly providing care on an intensive basis have been examined in nationally representative UK surveys. The Office for National Statistics (2002) reported that disturbed caregiver sleep was found among 7% of caregivers providing less than 20-hours of care per-week. In caregivers providing between 20 and 49 hours of care in a week this figure rose to 24%. However, in caregivers who were providing care for more than 50-hours per-week, 47% complained of disturbed sleep as a result of providing of care. Sleep disturbances in caregivers who shared the same house as their care recipient reported a five-fold

increase in sleep disruption, 31% compared to 6% of caregivers who did not share the same house (ONS 2002). This report also described increased hours of care provision in the over 65 age-group with 37% of older caregivers providing care for 50 or more hours per-week (ONS 2002). The Royal Commission on the Long Term Care of the Elderly (2000) estimated that around 800,000 people were providing care for more than 50-hours per-week in 2000.

The Office for National Statistics (2002) also reported that 59% of caregivers who were looking after someone who lived with them experienced physical or mental health problems, 34% reported feeling tired and 31% reported sleep disturbances as a direct result of providing care (ONS 2002). It should be noted that these data are for caregivers across all age-groups and all types of care provision. Collectively these reports indicate that many older people are providing care, many of these older adult caregivers are providing care in excess of 50 hours per-week and that this level of care provision is associated with increased fatigue, mental health problems and sleep disturbances (Royal Commission on the Long Term Care of the Elderly 2000; ONS 2002).

2.9 CAREGIVING AS A RISK FACTOR FOR CHRONIC INSOMNIA

Evidence presented in the previous chapter highlighted the increased risk of developing sleep problems in the older adult population as a result of normal ageing processes and a further increased risk of sleep problems in dementia As caregivers of older adults with dementia are often older adults themselves (spouses or adult children) this places dementia caregivers at particular risk of developing a long-standing sleep disorder (37% of older caregivers provide care for 50 or more hours per-week (ONS 2002)).

2.10 SUMMARY OF SLEEP IN CAREGIVERS OF OLDER ADULTS WITH DEMENTIA

Many caregivers have described pronounced difficulties with their sleep, which result from their caregiving role. Table 2.3 summarises the findings of seven research studies which have examined caregiver sleep over the last 29 years (Sanford 1975, Gilleard 1984, Pollak and Perlick 1991; Smith *et al* 1997; Wilcox and King 1999; Kesselring *et al* 2001; Thommessen *et al* 2002).

Table 2.3 The percentage of caregivers reporting disturbed sleep from seven studies conducted over the last 29 years

Study	n	% of caregivers reporting disturbed sleep	Age range
[a]Sanford 1975	50	62 0	60.0 – 76 0
[b]Gilleard 1984	301	94.0	NR
[c]Pollak & Perlick 1991	73	65.5	53 0 – 102 0
[d]Smith *et al* 1997	407	37 5	NR
[e]Wilcox & King 1999	90	96.0	49 0 – 82 0
[f]Kesselring *et al* 2001	93	53 0	36 0 – 97 0
[g]Thommessen *et al* 2002	186	25 0	70 1 – 76.6

[a] 62% of this sample were caring for older adults with dementia
[b] Caregivers of mentally infirm older adults
[c] Caregivers of patients recently admitted to nursing homes or psychiatric hospitals
[d] Caregivers of older adults with Parkinson's disease
[e] Female caregivers of older adults with dementia
[f] Caregivers of frail or incapacitated older adults.
[g] Caregivers of older adults with mild dementia.

The data presented in Table 2.3 describes high levels of caregiver sleep disturbance. Closer inspection of Table 2.3 also indicates that caregiver sleep disturbances were more frequent in caregivers of older age (Sanford 1975; Pollak and Perlick 1991) and in caregivers who were caring for more cognitively impaired care recipients (Wilcox and King 1999, Thommessen *et al* 2002).

As caregivers report that sleeping difficulties are a major reason for seeking placement of their dependents in a place of permanent institutionalisation (Sanford 1975; Pollak and Perlick 1991) the following sections will review intervention studies on the treatment of dementia caregivers' sleep disturbances after an examination of the literature on caregiver breakdown.

2.11 THE IMPACT OF SLEEP DISTURBANCES ON THE DELIVERY OF COMMUNITY CAREGIVING

Gilhooly and colleagues (1984) and Pollak and Perlick (1991) both suggest that nocturnal wandering, and the negative impact that this has on the sleep of caregivers, were significant predictors of the decision to seek out a place of permanent institutionalisation for their care recipients. Pollak and Perlick (1991) sampled 43 caregivers whose care recipients had been recently admitted to a permanent placement in hospital; they reported that 73% of these caregivers cited nocturnal sleep disruption as a primary reason for seeking a hospital placement for their friend of relative. Pollak and Perlick (1991) go on to suggest that·

"*Further investigations of this process* (sleep disruption of the caregiver in the home) *should assess caregiver-elder interactions and the strain they produce as functions of the time of day.*" pp 209.

Furthermore, they highlighted the importance of learning more about the sleep disturbances of older people with dementia and their caregivers as:

"Most sleep disorders are treatable, providing as-yet unexploited opportunities to reduce caregiver strain and the use of institutional care." (Pollak and Perlick 1991; pp. 209).

The emotional consequences of providing care have also been shown to affect the sleep quality of caregivers. Levels of stress and depression in caregivers have been

shown to be mediated by: subjective care burden; the rate of cognitive decline, and the incidence of sundowning behaviours (Gallagher-Thompson *et al* 1992, Gallagher-Thompson and Powers 1997). It has been suggested that protecting the sleep of caregivers and people with dementia requires further investigation in order to evaluate opportunities for intervention within these groups (Pollak and Perlick 1991; Teri 1997, Cohen-Mansfield *et al* 2000; McCurry *et al* 2000). This can be regarded as important as caregiver burden may induce depression in caregivers and depression, as a diagnostic criterion for insomnia (DSM-IV 1994), may induce caregiver sleep disturbance.

2.12 INTERVENTION STUDIES

The previous sections highlight the frequency with which caregivers cite sleep disruptions as obstructive of their ability to provide care It is evident from the literature that sleep disturbances in people with dementia and their caregivers has received little research attention (McCurry *et al* 2000). The issues of protecting caregivers' sleep and alleviating the sleep disruption seen in people with dementia are important for the preservation of the quality of life for these older people. The protection of sleep in these groups also has implications for the improved management of people with dementia and in enhancing and facilitating community caregiving.

There are only a few reported studies which have assessed the impact of intervention strategies in improving the sleep and wellbeing of caregivers of older adults with dementia. Hinchcliffe and co-workers (1992) described the effectiveness of sleep hygiene and daytime stimulation interventions with an older adult with dementia who was experiencing disturbed sleep and was disturbing her caregiver at night. Intervention consisted of fluid restriction after 8 pm and the prevention of napping during the day in an attempt to consolidate her sleep period. After the implementation of this intervention the caregiver's general health

questionnaire (GHQ) score [any score over 5 indicates clinical morbidity] fell from 26 to zero (Hinchcliffe *et al* 1992).

In another intervention study performed by King and colleagues (2002), a programme of daily physical activity and nutritional education was implemented in a group of 85 caregivers of older people with dementia. Caregivers self-rated sleep quality was assessed with the Pittsburgh Sleep Quality Index (PSQI) at baseline and at follow-up (after 12 months participation in the exercise or control groups). Their exercise group (n =45) experienced significantly better self-rated sleep quality (F =2.9, p <0.045) and significant reductions in perceived stress (Spearman's rank r =0 33, p <0 04) and subjective caregiver burden (Spearman's Rank r =0.33, p <0.04) than the nutrition education control group after the 12-month participation in the programme (King *et al* 2002). More recently, McCurry *et* al (2003) conducted a randomised control trial of sleep hygiene education with a group of caregivers of older adults with dementia, they reported significant improvements in the maintenance of consistent bed and rise times, reduced napping and increased daily exercise (all p<0 01) in their intervention group compared to their control participants (McCurry *et al* 2003).

These studies suggest that behavioural interventions can have positive impacts on caregiver and care recipient sleep The implications of these findings suggest that both caregivers and care recipients maintain some degree of plasticity with regard to their sleep, which could possibly be exploited by such interventions to improve the sleep of these groups (Hinchcliffe *et al* 1992; King *et al* 2002). Indeed, Schultz *et al* (2002) highlight the importance of the assessment of dementia caregiver interventions at a level of clinical rather than statistical significance, as there are currently no intervention studies that have shown clinical significance.

2.13 SUMMARY OF CAREGIVER SLEEP DISRUPTION IN DEMENTIA CAREGIVING

The previous sections have described the low tolerance among caregivers of sleep disturbances, described the increased prevalence and vulnerability, in terms of sleep disruption, of older caregivers and examined the impact of sleep disturbances on the effective delivery of community care. Sleep disruption in older adult caregivers of people with dementia:

- Increases in severity in proportion to the number of care hours provided per-week.
- Accelerates the breakdown of community caregiving

Although sleep and activity intervention studies in these groups are sparse, there is evidence that the manipulation of caregiver / care recipient environments and / or behaviours can have a positive impact on the sleep experienced by these groups (Hinchcliffe *et al* 1992; King *et al* 2002). The following chapter will review the origins of age-related, dementia-related and caregiver-related sleep disturbances and highlight opportunities for intervention and / or the treatment of the sleep disturbances in these older people.

CHAPTER THREE

Sleep disturbances in older people with dementia and in caregivers

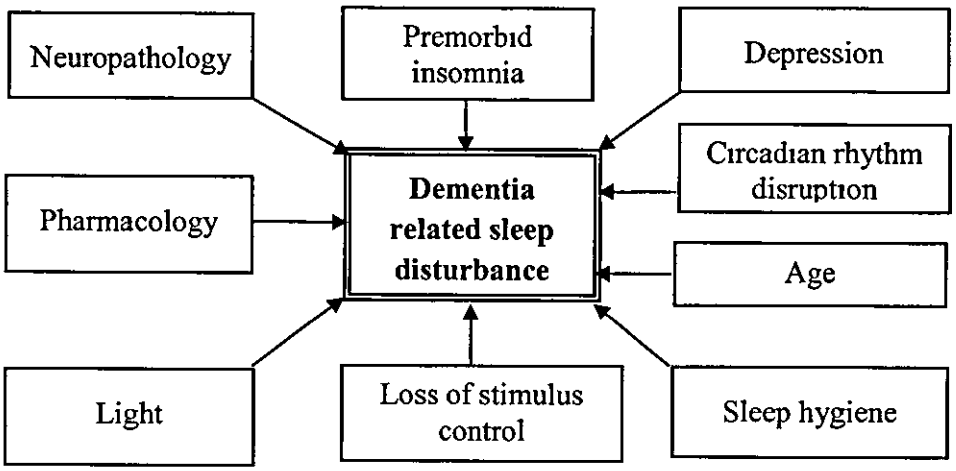
3.1 INTRODUCTION

The previous chapters have examined: i) normal age-related changes in sleep; ii) the amplification of these changes as a result of progressing dementing illnesses, and iii) the impact of providing care on the sleep of caregivers. This chapter aims to explore the origins of sleep disturbances in older adults with dementia and in dementia caregivers.

3.2 THE ORIGINS OF SLEEP DISTURBANCES IN PEOPLE WITH DEMENTIA.

The deterioration of sleep in people with dementia is likely to be associated with several factors. The neurological disease process, premorbid insomnia, depression and mental health issues as well as sleep practices, environmental influences (e g. light exposure), the attenuation of the effects of endogenous *zeitgebers* (or "time-cues" from the German *'zeit'* meaning 'time' and *'geber'* meaning 'giver'), the impact of the circadian rhythm on sleep and drug consumption all have a likely influence on sleep although the relative contribution of each of these factors is unknown. These possible sleep disruption factors in older adults with dementia are summarised in Figure 3 1.

Figure 3.1 The likely contributors of sleep disturbance in older adults with dementia.



Each of these factors will be reviewed in the following sections.

3.3 AETIOLOGY OF THE DEMENTING PROCESS / DETERIORATING NEUROLOGY

A variety of age-related alterations can be seen to occur in the human brain. These changes occur as part of normal, healthy ageing processes. However, the dementing process exacerbates these 'normal' changes and contributes more so to the deterioration of the cortices, brainstem and cognitive functionality than in normal, healthily ageing people (Arendt *et al* 1998).

The neuronal systems involved with 'basic brain functions' (including sleep) such as the hippocampus, the neurons of the basal cholinergic forebrain and the neocortical association areas have been shown to maintain a high degree of plasticity into late adulthood. These particular areas of the brain have also been shown to be particularly affected by the progression of AD (Arendt *et al* 1998). The breakdown of synaptic interconnections and the mechanisms that regulate modifications in synaptic connectivity have been directly implicated in the pathomechanism of AD (Arendt 2001).

The dementing process has been reported to have a negative influence on the suprachiasmatic nucleus (SCN) which is known to affect the timing of the circadian rhythm (Dijk *et al* 1985). Abnormalities in this area of the brain have been reported to impact negatively on the sleep-wake cycle (Harper *et al* 2001; Allen *et al* 1987).

3.3.1 Effects of the aged brain on sleep drivers, distribution and maintenance of sleep

Pathological brain ageing, as seen in neurodegenerative disease, results from impairments in cortical morphoregulatory processes (Arendt 2001). The hippocampus and the medulla oblongata (the lowest level of the brain stem) are critically involved with the initiation of sleep and the maintenance of wakefulness (Gottesmann 1999) and are mediated by the GABAergic, serotonergic and cholinergic neurochemical pathways. Intracerebral neurochemical concentrations of neurotransmitters also show age-related declines, particularly in concentrations of GABA and acetylcholine (Grachev and Apkarian 2001).

The deteriorating regulation of neurochemical concentrations and neuronal structure of the brain therefore, could well explain the decreased quantity, quality, distribution and maintenance of sleep seen in older adults and particularly in the progression of dementia However, there are large variations in the amounts of sleep taken by older adults (Prinz 1977; Miles and Dement 1980) and older adults with dementia (Regestein and Morris 1987; Allen *et al* 1987). Regestein and Morris (1987) examined the polygraphic sleep characteristics of 16 older women with mild to moderate dementia over a two-week period of study. This research group reported total sleep times in the range of 5 hours – 12.1 hours per-night in their sample. Allen *et al* (1987) compared the polygraphic sleep characteristics of 30 older adults with dementia and 15 control participants. Their assessment of sleep in their older adults with dementia concluded *"there was wide inter-individual variation in all sleep parameters in the dementia group"* p 154 The findings from

these studies indicate that similarly demented older adults may experience wide variations in the quantity and integrity of their sleep (Regestein and Morris 1987; Allen *et al* 1987). These findings suggest that the neurological consequences of the dementing process, although important in the maintenance of sleep and wakefulness, do not impact on the sleep of this group in isolation. The implications of these findings are that decrements in sleep experienced by older adults with dementia are not completely explained by their neuropathology *per se.* External influences of the environment (Ancoli-Israel *et al* 1989; Van Someren *et al* 1993), of behaviour (Spielman *et al* 1987, Meguro *et al* 1995) and of individual differences (Allen *et al* 1987; Vitiello *et al* 1990) are also factors which might have an influence on the diminution of the sleep quality and the sleep structure of older adults with dementia Work performed by Meguro *et al* (1995) described activities of daily living (ADL) as a highly significant predictor of sleep quality. Their group of ambulant participants were found to sleep significantly less during the day ($F = 42.5$) and significantly more during the night ($F = 12.1$) than their non-ambulant group (both at: $p < 0.0001$). These results indicate the importance of daily activity and behaviour on the experience of sleep in dementia which was *unrelated* to their level of cognitive impairment (Meguro *et al* 1995)

Insomnia in these groups of older adults (from Figure 3.1) is multifactorial in origin Neurology has an influence, but the experience of sleep is known to be influenced by the external environment, the expectations of the sleep experience and any pre-conditioned responses to these expectations and the environment (Bootzin 1972, Spielman *et al* 1986). As elements other than dementia are likely to be influencing the sleep and daily activity rhythms of this group, the effects of pre-morbid insomnia, mental health issues, pharmacological and the associative conditioning of sleep practices will therefore be reviewed in the following sections.

3.4 PRE–MORBID INSOMNIA

The origins of late-life insomnia may be partly due to difficulties with sleep experienced at a younger age. As reported in Chapter 1, several research teams from across the world have described significant decrements in the experience of sleep with advancing age, with the more advanced years bringing with them an increased likelihood of disturbed sleep (Ford and Kamerow 1989; Foley *et al* 1995; Ohayon *et al* 1996; Kim *et al* 2000). In older adults with dementia a wide variation has been reported in the quantity of sleep (Prinz 1982; Regestein and Morris 1987, Allen *et al* 1987; Vitiello *et al* 1990). This implies that insomnia in dementia may be partially influenced by a previous difficulty sleeping which has developed prior to the onset of dementia. Older adults with dementia who sleep well may do so because they may never have had any difficulty sleeping prior to the onset of their dementia.

3.5 DEPRESSION AND MENTAL HEALTH FACTORS

Mental health status, particularly depression, is well acknowledged to impose negatively on the sleep experience and that untreated, chronic insomnia can precipitate depressive symptomology (Ford and Kamerow 1989) Symptoms of depression, as measured by the Hamilton Rating Scale for Depression and the Clinical Global Impression, have been reported to be common in people with AD (8%) and Multi-Infarct-Dementia (MID) (20%) (Greenwald *et al* 1989). This work has been corroborated by Teri (1997) who, in a series of studies, described depression in 17% – 30% in her sample of older people with AD. These findings suggest that sleep disturbances in dementia may be influenced by symptoms of depression. Indeed, Katona *et al* (1997) identified co-morbid depression in their sample of 700 randomly sampled community-residing older adults as an important consideration, particularly in those with memory impairments, sleep disturbances, somatic complaints, anxiety disorders or limitations with activities of daily living (ADL) Furthermore, Tobianski *et al* (1995) reported a two-fold greater risk of

developing depression in those with memory impairments compared to those without.

3.6 PHARMACOLOGICAL EFFECTS ON SLEEP IN DEMENTIA

The impact of drug consumption on sleep in older adults with dementia is complex for a number of reasons. Firstly, older adults are high level consumers of pharmacological agents used to treat the wide range of diseases and disorders that accompany older age (Giron *et al* 2002) and the risk of consuming these agents (particularly benzodiazepines) increases with age (Egan *et al* 2000). Secondly, older adults and especially older adults with dementia are particularly high consumers of benzodiazepine and neuroleptic drugs (Forsell and Winblad 1997), with one study describing 49.7% of a sample of 330 nonagenarians regularly being prescribed and consuming some type of psychotropic medication (Forsell and Winblad 1997). Sedation of older adults with dementia is common and (if administered during daylight hours) can lead to fragmentation of the sleep-wake cycle with sleep being distributed across the 24-hour day and not consolidated into the nighttime hours (Ancoli-Israel 1997) Ancoli-Israel *et al* (1997) emphasise the significance of over-sedation and excessive daytime sleep in their group of older adults with dementia on the fragmentation of nighttime sleep and its reciprocal increase in nighttime activity. One study described the complete fragmentation of the circadian rhythm of an older man with AD after being prescribed haloperidol that led to an acceleration of his cognitive decline. Improved circadian rhythmicity and a reduced rate of cognitive decline were again seen in this patient after the cessation of haloperidol treatment (Wirz-Justice *et al* 2000). Thirdly, some generic drug brands are known to negatively affect sleep Non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen are commonly prescribed for many older adults for a range of difficulties from headaches to arthritis. These NSAIDs have been reported to negatively impose on both objective and subjective sleep measures, reducing sleep efficiency and increasing the number and duration of nocturnal arousals in 37 healthy adults (Murphy *et al* 1994; Brown *et al* 1995). Finally,

medical professionals have been reported to have a lack of information with regard to sleep and geriatric medicine. One study reported that 40% of 125 physicians would select neuroleptic drugs as the treatment of choice for sleep disturbances in older adults with moderate dementia (Stoppe *et al* 1995), indicating a physician preference for treating sleep problems in dementia pharmacologically.

3.7 CIRCADIAN RHYTHMS

A diurnal rise and fall in activity levels and alertness is common to all mammals and, in young and healthy humans has a period of approximately 90-minutes (Moore-Ede *et al* 1982). Sleep and wakefulness are influenced by the state of the circadian rhythm. If the rhythm is reaching a peak (acrophase) then sleep is difficult to initiate, but easy to terminate. Conversely, where the rhythm is approaching its minima (nadir) sleep is easy to initiate and difficult to terminate. There has been much research conducted into circadian rhythms, initial experimentation was conducted on plants as far back as the 1860s. A seminal work by Moore-Ede *et al* (1982) provides an excellent account of the evolution of circadian rhythm research since initial experimentation began.

3.7.1 Circadian rhythms in dementia.

Levels of daytime and nocturnal activity in people with dementia have been examined and compared with age matched non-dementing control participants. Males with dementia have been shown to exhibit significantly less activity than control groups during the daylight hours and (particularly in men with AD) significantly more activity during the night (Satlin *et al* 1995; Harper *et al* 2001). One research group found that their group of 28 people with AD to be approximately half as active during the daytime and nearly four times more active during the night than their 10 control volunteers (Satlin *et al* 1995).

Levels of light exposure have been reported to positively influence sleep and older adults with dementia have been reported to experience reduced levels of light exposure as a result of impaired mobility (Ancoli-Israel *et al* 1997). Light treatments for sleep disorders have been shown to be effective in older adults with dementia (Van Someren *et al* 1997). A more detailed review of the light therapy literature is presented in the following section which describes the effectiveness of light exposure on the re-entrainment of circadian rhythmicity.

3.8 THE INFLUENCE OF LIGHT ON CIRCADIAN RHYTHMS

The effects of increased environmental light exposure on the circadian rhythm have been investigated as a form of treatment for the circadian disruption of sleep in older people with dementia. This has come as a result of the wealth of literature demonstrating the effectiveness of light exposure in alleviating the symptoms of seasonal affective disorder (SAD), depression, jetlag and night shift problems (see Van Someren *et al* 1993 and McCurry *et al* 2000 for reviews) and the influence that light has on the timing of sleep in OAWI (Campbell *et al* 1995). Bright light therapy has been shown to improve the coupling of the circadian rhythm to environmental *zeitgebers* in older people with dementia (Van Someren *et al* 1997; 1999; 2004). This intervention has been suggested to be a potentially useful means of improving sleep disturbances in this group (Lyketsos *et al* 1999) and in improving nursing home management (Ancoli-Israel *et al* 2002). Bright light treatments have been reported to improve sundowning behaviours (Bliwise 1993, Van Someren *et al* 1997; 2004) and reduce nocturnal agitation (Satlin *et al* 1992). Sundowning behaviours of agitation appear to have strong circadian components in most older adults with dementia, which are related to sleep, medication use and environmental light exposure (Martin *et al* 2000).

Light therapies have become developed more recently as a result of the positive correlative link between the brain hormone melatonin (reported to have hypnotic properties) and exposure to bright light (Haimov *et al* 1994; Van Someren *et al*

1993; 1997 and 1999; Brusco *et al* 1999). Reduced melatonin levels have been reported in OAWI and it has been suggested that these decreased melatonin levels may influence the decreased sleep quality characteristic of older age (Haimov *et al* 1994). Daily oral administration of melatonin, over several months of treatment, has been reported to show significant improvements in nocturnal sleep quality and daytime alertness in elderly insomniacs and decreased sundowning type behaviours and agitation in older adults with dementia (Brusco *et al* 1999; Cohen-Mansfield *et al* 2000) Older adults with AD *and* with sleep disturbances have also been reported to possess melatonin secretion rhythm disorders which may play a role in the irregular sleep-wake schedules of these older adults with dementia (Mishima *et al* 2001)

Two recent studies have shown that bright light and other non-drug treatments may be efficacious in improving two problems associated with ageing; namely the alleviation of sleep disturbances and the reduced rate of cognitive deterioration, without undesirable side effects (Murphy and Campbell 1996; Van Someren *et al* 1996). These findings were corroborated by Ancoli-Israel *et al* (1997) who reported that the circadian rhythms of nursing home patients are disturbed, with more disturbances associated with the severity of the dementia, not just with age. This disturbance, they suggest could be due to a decrease in the amount of environmental light exposure as a result of reduced mobility (an increased frailty) in people with advanced dementia (Ancoli-Israel *et al* 1997).

Van Someren *et al* (1996) have also suggested that circadian rhythm disturbances are influenced by a lack of exposure to environmental light. This research group suggested that reduced exposure to environmental light affects the amount and the timing of endogenously secreted melatonin, known to influence the suprachiasmatic nucleus (SCN) and the entrainment of the circadian rhythm (Dijk *et al* 1985; Lewy *et al* 1992). Several other research groups (Haimov *et al* 1994; Shochat *et al* 2000; Mishima *et al* 2001) have supported these findings.

3.9 THE INFLUENCE OF BEHAVIOUR ON SLEEP

The previous section described the importance of light exposure which may be affecting the sleep of older adults with dementia. Evidence for the existence of important behavioural mechanisms that regulate sleep quality comes from the therapeutic literature where particular psychological therapies have been successfully implemented for the treatment of insomnia. The therapeutic literature will be reviewed in the following sections.

Research into the behavioural treatment of sleep disorders has mostly been conducted on young and middle aged cohorts with little research attending to the over 65 year age-group. Such behavioural interventions involve the reconditioning of sleep behaviour, dispersing poor sleeping practices and reinforcing positive sleep hygiene behaviours. These techniques include: maximising the psychological link between the bedroom and sleep; reduction and elimination of daytime napping; training the patient in relaxation techniques; curtailment of the consumption of caffeine and alcohol in the four-hour period before bed and the effective management of stress and depression during the day (Bootzin *et al* 1972; Spielman *et al* 1987).

Alessi *et al* (1999) implemented a 14-week programme of physical activity coupled with modifications to the nocturnal environment (attenuation of environmental light and noise sources) in a group of 15 older people with moderate dementia and compared this group with a similarly aged group of similarly demented older adults with dementia who did not receive the intervention (n =14). They reported significant improvements in nighttime sleep times (F (27, 1) =4 42; p =0 029) and a reduction in daytime agitation (F (27, 1) =7.86; p =0 009) in the older people with dementia who received the intervention compared with age-matched non-intervention participants (Alessi *et al* 1999). These findings imply that behavioural / environmental interventions can impact positively on the sleep of older adults with dementia.

3.9.1 Stimulus control theory

Stimulus control theory was first described by Bootzin (1972). With regard to sleep this theory states that sleep, although essentially a biological mechanism, is greatly influenced by learning. When positive discriminative sleep stimuli (i.e. environmental cues or conditions which are sleep promoting) become unattended to, stimulus control is effectively lost with regard to sleep and insomnia ensues. This loss of stimulus control is proposed to contribute to both the onset and the maintenance of insomnia (Bootzin 1972).

Behavioural, psychological and environmental treatment modalities for insomnia are grounded in stimulus control theory and learning Two such treatments have been developed to combat insomnia; these are Stimulus Control Therapy and Sleep Restriction Treatment (Bootzin 1972; Spielman *et al* 1987; Morin *et al* 1990). Both of these cognitive behavioural strategies have been shown to be effective in the treatment of insomnia for non-demented, younger adults (Chambers and Alexander 1992) and for non-demented older adults (Friedman *et al* 1991). There is no evidence to suggest that some elements of these cognitive-behavioural treatment methods may not benefit the sleep experienced by older people with dementia; particularly when considering the possibility of maintained brain plasticity in dementia

3.9.2 Stimulus control therapy

Stimulus Control Therapy (SCT) was developed from classical and operant conditioning theories and is one of the most effective psychological treatments for insomnia (Lacks and Morin 1992). The therapy is based on strengthening learned connections between the sleep environment and sleep onset and maximising the sleep promoting properties of the sleeping environment (Bootzin 1972). The essential tenets of this therapy are to propagate the association between the

bedroom and sleep, to eliminate poor sleep practices and to teach a patient with insomnia strategies for optimising their sleep experience (Hauri 1998)

3.10 EFFICACY OF SLEEP HYGIENE AND STIMULUS CONTROL

Several studies have explored psychological, behavioural and environmental treatment modalities which have been successful in treating insomnia throughout all age-groups and levels of cognitive functionality. According to a review of this research area conducted by Morin *et al* (1999) between 70 – 80% of older adults with insomnia (OAWI) benefit from non-pharmacological treatments for insomnia and these interventions produced *"reliable and durable changes in the sleep of patients with chronic and primary insomnia pp 1145 "* (Morin *et al* 1999).

Sleep is affected by a number of environmental and lifestyle factors. Some of these are noise, temperature, light, exercise, diet, alcohol consumption, substance use / abuse, daytime napping, excessive time spent in bed, the use of the bedroom for activities other than sleep or sex, and irregular routines. These factors, which may benefit or impose on sleep, are collectively referred to as 'sleep hygiene' practices (Hauri *et al* 1982). Sleep hygiene in older people dementia will be reviewed in the following section

3.10.1 Sleep hygiene in dementia

Sleep hygiene consists of two essential elements· health practices and environmental influences (Bootzin *et al* 1972) The manipulation of the environment, as stated previously, has been shown to be a useful method of improving the sleep and daily activity rhythms of people with dementia. Reduction of noise levels in nursing homes has also been reported to induce similar benefits in the sleep and daily activity rhythms of people with dementia (Schnelle *et al* 1998; Alessi *et al* 1999). The implications of these studies point further towards the assumption that sleep / wake cycles can be improved, consolidated and maintained via psychological, behavioural and / or environmental interventions. They also

suggest that positive sleep hygiene practices can improve sleep in older adults with dementia (Schnelle *et al* 1998, Alessi *et al* 1999).

3.11 SUMMARY OF THE POSSIBLE ORIGINS OF SLEEP DISTURBANCES IN DEMENTIA

The origins of sleep disturbances in older adults with dementia are complex. Different individuals may be at variable levels of risk for having or developing a sleeping problem. As presented in Figure 3.1 at the beginning of this chapter, there is a possibility that a number of factors influence the sleep quality of these groups, be it their age, previous sleeping difficulties, drug consumption, their level of neurodegenerative impairment, depression, levels of exposure to environmental light, sleep hygiene practices and / or circadian rhythm disturbances. Any of these factors acting in isolation or collectively could precipitate or perpetuate a sleeping problem in dementia. This concludes the literature review on the possible origins of sleep disturbances in older people with dementia. The following section will review the possible origins of sleep disruptions in dementia caregivers

3.12 THE ORIGINS OF SLEEP DISTURBANCES IN CAREGIVING

Chapter 2 presented information regarding the difficulty that dementia caregivers experience with sleep disturbances. The demands of dementia caregiving impacts on caregiver sleep (Sanford 1975, Gilleard 1985) and this imposition on caregiver sleep has been shown to accelerate institutionalisation of their dependent older adults with dementia (Gillhooly 1984; Pollak and Perlick 1993; Kesselring *et al* 2000; Thommassen *et al* 2001).

Of the possible contributors to sleep disturbances in older people with dementia, sleep disturbances in caregiving are likely to be impacted by any of the factors presented in Figure 3.1 with the exception of neuropathology. The sleep of caregivers could be effected by depression, loss of stimulus control as a result of daily routines following the potentially random behaviour of a care recipient, poor

sleep hygiene resulting from excess noise at night from the dementia care recipient, increased environmental light exposure on having to arise during the night to provide care, drug consumption, pre-morbid (i.e. pre-caregiving) insomnia or circadian rhythm disruptions. These factors may influence insomnia at any age or set of circumstances, however, dementia caregivers may be uniquely affected by the activities and behaviours of their care recipients during the daytime and at night, which places them at greater risk for developing and maintaining some form of insomnia. As these factors have been reviewed with respect to older adults with dementia in the previous sections they will not be repeated here, although there are a number of studies which have examined the effects of some of these factors specifically in dementia caregivers.

3.12.1 Depression in dementia caregiving

From the perspective of caregivers, 47% of female caregivers of older people with Parkinson's disease have been reported to show symptoms of depression (Smith *et al* 1987). Depressive symptomology in people with dementia has been reported to correlate with caregiver depression, notably in female caregivers of people with dementia where depression is most common. Depressive symptoms in caregivers of *depressed* older adults with dementia are very common. A study conducted by Teri *et al* (1997) described the prevalence of depression to be present in 75 – 100% of the 201 caregivers sampled who were supporting older adults with dementia with concomitant symptoms of depression (Teri 1997) The 75 – 100% variation was dependent on caregiver circumstances (caregiver gender, severity of the dementia, relationship of the caregiver to the patient and their living arrangements). Insomnia was also reported to be worse in their female caregivers, those caregivers who had been caregiving for longer time periods, worse in spousal caregivers and in those caregivers who were sharing living spaces with their care recipients (Teri 1997). These findings corroborate those of Livingston *et al* (1993), who identified sleep disturbances as an important predictor of future depression in older people, they also identified women, those living alone and those who were unmarried as most

likely to have sleep disturbances and therefore either be depressed or to go on to develop depression. Murray *et al* (1997) identified a high risk for mental health problems in 50% of caregivers of depressed or dementing older adults. Indeed, in a study of 5627 older caregivers of people with moderate to advanced dementia, 32% were classified as depressed. Caregivers of patients who were: younger; Caucasian or Hispanic; those who did not have a secondary education; those who were more dependent; behaviourally disturbed; angry; or aggressive were at significantly greater risk of being depressed Caregiver predictors of depression were identified as: a low income; being a spousal caregiver; caregiving for more than 40-hours per week; and being more dependent (Covinsky *et al* 2003).

3.12.2 Pharmacological effects on sleep in caregivers

With regard to drug consumption in caregivers, only one study was found which reported the prevalence of drug consumption by older adult caregivers compared to age-matched non-caregiving controls. Mort *et al* (1996) reported that 63% of their group of 30 caregivers were regularly being prescribed and consuming significantly more psychotropic agents, compared to just 10% of their controls ($p < 0.001$). This research team also noted *"In all cases these* (pharmacological) *agents were used for sleep pp 585."* (Mort *et al* 1996). These findings exemplify the 'at-risk' nature of the caregiving population for difficulties with their sleep.

3.12.3 Summary of sleep disturbances in caregivers

There is an unknown impact of a loss of stimulus control, poor sleep hygiene, environmental light exposure, pre-morbid (i.e. pre-caregiving) insomnia or circadian rhythm disruptions in caregivers as these research areas have yet to be reported in the literature. Although it seems that caregivers are at particular risk for developing depression (Teri *et al* 1997) and are highly likely to be treated with hypnotic medications for any sleeping difficulties with which they may present (Mort *et al* 1996) despite the reported efficacy and success of behavioural and psychological treatment for sleep disturbances (Morin *et al* 1999; Alessi *et al*

1999). The evidence suggests that the presence of a care recipient with dementia and the demands of long-term community care provision places the dementia caregiver at particular risk for having sleep disturbances (Sanford 1975; Gilleard 1984; Gilhooley 1984; Pollak and Perlick 1991; Kesselring *et al* 2000; Thommessen *et al* 2002).

3.13 RESPITE CARE

Caregivers looking after family or friends in the community are often provided with respite care. This service comprises several types of intervention; daycare, where the older person with dementia goes to a day centre a few mornings or afternoons a week; in-home respite, where a professional caregiver comes into the community home of the older person with dementia and their caregiver for a few hours to a few days; short term respite, whereby the older person with dementia goes into an institution for a few days; video respite, where the older person with dementia is invited to watch a video for a few hours and so give their caregiver some time, and full residential respite care. This latter service comprises a few days to a few weeks of booked hospital, private / local residential care home, or nursing home placements for their dependent older adults to stay whilst their caregivers get some rest. Respite care services are provided as part of the National Health Service framework and are managed by NHS nursing staff on psychogeriatric hospital wards. Dementia care recipients are assessed by clinical psychologists whilst living in the community after an initial diagnosis is made by GPs. Caregivers and their dependant care recipients are visited by district nursing teams (community psychiatric nurses [CPNs]) and social workers from social services. This battery of healthcare professionals monitors the health and living situations of these older adults with dementia and their caregivers in the community. Respite services are provided to caregivers on referral by GPs, social workers or CPNs and periods of booked respite care on psychogeriatric wards are arranged for them. Initially, respite services are provided on a weekly basis every few months, but as the dementia progresses and as caregivers become more familiar with the experience of respite service provision and might need more intensive assistance with the

advancing dementia in their care recipients, periods of respite care are often extended to two-weekly periods and the frequency of bookings may increase. This titration of respite services for dementia caregivers in the later stages of community-based caregiving is also designed to assist the transfer of care in the community to a place of permanent institutionalisation by: i) familiarising caregivers and care recipients with the hospital environment; ii) allowing healthcare professionals to assess dementia care recipients and develop individual care plans; and iii) to allow time for suitable, permanent institutional placements to be identified. However, in the first instance respite care service provision is more often provided as a preventative measure against the breakdown of community based care, by providing short periods of time whereby community caregivers can get some rest.

Considering caregiver requirements from general practitioners and hospital doctors, caregivers have been reported to have three main requirements: recognition, information and support. Support includes the provision of respite services, which are considered to be *"necessary breaks from caring "* p 484 (Travers 1996). The British Medical Association reported in 1995 that caregivers have a right to at least two-weeks of respite care per-year (BMA 1995). However, caregiver knowledge of these services is scant (Audit Commission 2000) with only around one quarter of caregivers informed of, and receiving regular respite services in the UK (Philp *et al* 1995) and in Europe (Kesselring *et al* 2000).

This literature suggests that service providers are ignorant of these caregiver requirements identified by Travers (1996) of recognition, information and support. There is cause for concern here as the Audit Commission (2000) has highlighted respite services as "*essential to enable them* (caregivers) *to continue caring"* p 60 (Audit Commission 2000).

As stated by Opie (1994; p 39); *"To care is to experience stress"* and considering the needs of caregivers (Travers 1996); respite services can be seen as a powerful

intermediary between the community caregiving role and the decision to institutionalise dementia care recipients. The alleviation of caregiver stress as a result of respite provision will therefore keep families together, keep infirm older adults out of institutions and relieve much potential financial burden on the state. Caregivers have been reported to express high levels of satisfaction with overnight respite care services. Watkins and Redfern (1997) examined reports from 28 community caregivers of older people with dementia; they reported that 22 of these caregivers reported positive feelings about the service, both in terms of their own sleep and the treatment of their dementia care recipient. There were only 6 caregivers in this study who reported any negative feelings about the service and these were mostly related to feelings of guilt in the caregiver (Watkins and Redfern 1997) Despite these positive reports of respite care described in this study, other work has been conducted which questions the level of engagement and duration of service use by older adult dementia caregivers. Melzer (1990) evaluated the service use of a respite care unit from 19 caregivers of older people with dementia who spent time at the unit. Melzer (1990) reported high levels of caregiver drop-out from service provision over time. Reasons for caregivers dropping out were reported to be that: dementia care recipients became more confused when moved from home, pre-existing respite arrangements with other agencies (including family) were satisfactory and caregivers felt that they did not require extra respite services; serious illness in the dementia care recipient; caregivers opting for permanent institutional placement as they felt that they could no longer cope with their caregiving roles (Melzer 1990).

These findings are confounded by those reported by Pearson (1988) who described caregiver satisfaction with respite care in terms of sleep outcomes and feelings of being rested by the service. Of the 25 caregivers examined by Pearson (1988), 64% reported that they experienced better quality sleep during respite service provision and 92% stated that they felt more relaxed (Pearson 1988). Although approximately half the caregivers in Pearson's study did cite either; difficulties in visiting their care recipient or; an adverse change in their care recipient's sleep

routines as a result of overnight in-hospital respite care. These findings are supported by Levin *et al* (1994) whose examination of caregiver feelings of respite care (n = 167) revealed that 30% of dementia caregivers felt that the service had a positive impact on their dementia care recipients in terms of medication prescription and sleeping patterns; 70% felt that the intervention was not beneficial to their care recipients, with 10% opting out of future respite service provision. Of these caregivers more than 50% described increased abilities in providing extra-institutional community-based care for their dementia care recipients as a result of the respite care intervention. However, 11% of their sample of caregivers reported deterioration in terms of increased confusion and increased sleep post discharge from the respite hospital (Levin *et al* 1994). Increased caregiver ability to cope with caregiving post-respite as a result of increased sleep during the respite period was also reported in Watkin's and Redfern's (1997) study.

These findings indicate that, despite caregiver concerns about respite care from the perspective of deleterious effects on their dementia care recipients, most caregivers described positive feelings about respite care in terms of improved sleep, opportunities for daytime rest and increased longer-term community caregiving capabilities for themselves. The evidence suggests that respite care provides dementia caregivers with an opportunity to rest and that the service is mostly regarded as an effective means of improving caregiver sleep (Pearson 1988, Meltzer 1990; Levin *et al* 1994; Watkins and Redfern 1997).

3.14 SUMMARY OF SLEEP DISTURBANCES IN OLDER ADULTS WITH DEMENTIA AND THEIR CAREGIVERS

The sleep disturbances of older adults with dementia and their caregivers lead to a reduction in the quality of life in both of these groups. Neurology, sleep history, behaviour, psychology and the environment all have a possible influence on the sleep of these groups of older people.

For a full and informative synopsis of the sleep experienced by these groups research will best be conducted across both community and hospital settings. The neurological component of the dementing process does not appear to completely explain the disruption of sleep in older adults with dementia. Moreover, owing to the positive evidence of environmental and psychological interventions on sleep in healthy older people, there are, at present, unknown effects of any possible environmental impacts on sleep in this group of challenged older adults.

3.14.1 The lack of empirical evidence of caregiver / care recipient sleep disturbances in the community

McCurry *et al* (2000) reported that there have been no empirical studies evaluating the impact of either behavioural or environmental factors on the sleep and nighttime agitation of community-dwelling care recipients. The methodology described in the following chapter aims to test the research hypotheses stated at the end of this chapter. To the knowledge of the author this study is only the second sleep study and the first actigraphic study to be performed concurrently on caregivers and care recipients (Pollak and Stokes 1997) Furthermore, this will be the first actigraphic sleep study to examine the effects of respite care (environmental shift) on the sleep-wakefulness status, circadian rhythmicity, daytime sleepiness and quality of life of care recipients and their caregivers (McCurry *et al* 2000). Further evidence for the lack of information regarding the usefulness of respite care comes from a recent Cochrane review published in 2004. The authors of this report confirm:

"Current evidence does not demonstrate any benefits or adverse effects from the use of respite care for people with dementia or their caregivers [these results]. .should be treated with caution as they may reflect the lack of high quality research in this area rather than a lack of benefit." p 1 (Lee and Cameron 2004) These authors go on to suggest that: *"Given the frequency with which respite care is advocated and provided well designed trials in this area are needed"* p 1.

Due to the demographic age shift we are currently, and predicted to continue, experiencing, it is anticipated that the number of older adults with dementia and the number of adults required to care for these people with dementia will increase steadily over the next forty years (ONS 2002; Royal Commission for the Long-Term Care of the Elderly 2000). Continued assessment and appraisal of the sleep of caregivers and people with dementia is therefore justified and necessary in order to relieve undue stress experienced by caregivers and also to impede the progression of their dependents' dementia, which is possibly being fuelled by compromised sleep / wake patterns. This research is also important in the long-term preparation for the future demands of care for these groups, which can only be expected to increase over the next half century and beyond.

3.15 AIMS OF RESEARCH

The assessment of the sleep of caregivers and of people with dementia in and around booked periods of institutional respite care would offer a natural opportunity to assess the impact of an environmental intervention on the sleep and daily activity patterns of older people with dementia. This examination could also indicate any potential benefits of respite care for caregivers. The investigation of the effects of respite services on the sleep of older people with dementia and their caregivers in these 'natural' settings will go a long way to filling in gaps in the literature as to the efficacy of environmental interventions on the sleep treatment of older people with dementia and their caregivers.

This research aimed.

- To describe and compare caregiver health related quality of life with population norms.

- To present normative sleep data on older adults with dementia and their caregivers in terms of actigraphic sleep and circadian rhythm outcomes and to describe the subjective sleep experience of dementia caregivers.

- To examine any interrelationships between dementia caregiver and care recipient sleep timings and organisation.

- To examine the impact of respite care services on the sleep and circadian rhythms of dementia caregivers.

- To examine the impact of respite care services on the sleep and circadian rhythms of dementia care recipients.

CHAPTER FOUR

Method

4.1 INTRODUCTION

In order to examine the impact of full residential respite care (usually two weeks) data were collected before, during and after periods of booked respite care i e. for a total duration of data collection of six weeks. Data were collected with minimal intrusion into the lives of these caregivers and their care recipients. Data were collected using reliable and valid measurement techniques; these are described in the following sections after presentation of the study design.

4.2 THE STUDY DESIGN

Caregivers and care recipients were measured for 2 weeks prior to periods of booked respite care, for the duration of their respite provision (usually 2 weeks) and for 2 weeks following respite care. Caregiver and care recipient trajectories through and locations during this study are presented in Figure 4.1.

Figure 4.1 The study design

	Baseline (2 wks)	Respite (2 wks)	Follow-Up (2 wks)
Care recipients	Home	Hospital	Home
Caregivers	Home	Home	Home
Timeline = 6 weeks	⟶		

Both caregiver and care recipient sleep outcomes were measured simultaneously during this period and they were considered as care recipient / caregiver dyads. A more detailed figure of the study protocol is presented in Figure 4.2 on Page 92 and includes the information presented in Figure 4.1.

4.3 THE ASSESSMENT AND MEASUREMENT OF SLEEP

Actigraphy measures gross body movements and converts these into a score of physical activity expressed in activity counts per-minute (ac/min) As sleep is essentially a non-active, non-moving state; actigraphic assessment of individuals offers an opportunity to examine the sleep and wakefulness patterns of participants. Actigraphic assessment has the benefit of collecting data unobtrusively and over long periods of time. This form of assessment has been shown to be a useful technology in assessing the timing of sleep (Witting *et al* 1990; Cole *et al* 1992; Sadeh *et al* 1994; Jean-Louis *et al* 1996; Ancoli-Israel *et al* 1997; Blood *et al* 1997) and the effectiveness of treatments for sleep disorders (Haun and Wisbey 1992; Sadeh *et al* 1995; Van Someren 1996). The validity and reliability of actigraphy for the measurement of sleep and daily activity levels in care recipients and their caregivers will be reviewed in the following section.

4.3.1 Validity and reliability of actigraphy

Actigraphy has risen in recent years to the forefront of sleep assessment in a variety of different research settings. These include the assessment of insomnia, sleep related respiratory disorders (SRRDs), and periodic limb movement (PLM) disorder as well as general sleep hygiene, sleep efficiency and circadian rhythm stability. An American Sleep Disorders Association (ASDA) report investigating the validity of actigraphy against EEG studies in the assessment of sleep disorders was produced in 1995. This comprehensive review of actigraphy highlighted the flexibility of the actigraph for assessing a wide variety of sleep disorders. This ASDA report stated that the actigraph is:

"A useful and informative tool for assessing sleep-wake cycles in individuals" p 287.

ASDA (1995) also emphasised that, for optimal assessment, continuous measurement over a long period of time (numbers of days to weeks) is desirabl e,

with longer measurement protocols producing more reliable data (ASDA 1995; Cole *et al* 1992).

Actigraphy has been used since the early 1970's; initial machines were very large and heavy, yet reports from researchers were favourable, stating that these devices were well tolerated by young, older and dementing individuals (Witting *et al* 1990) ASDA (1995) suggested that recording epochs should be set to a maximum of 1 minute for the optimal assessment of sleep and circadian rhythmicity. The software available for analysis of these data is programmed to produce standard sleep variables such as total sleep time (TST), sleep efficiency (SE), wake time after sleep onset (WASO) and sleep onset latency (SOL), the software also derives measures of circadian rhythmicity (Cambridge Neurotechnology™ 1999).

Issues concerning the correlation of actigraphy with polysomnography (PSG – also known as electroencephalography EEG) have been widely addressed in the literature. It has been reported that there is a positive correlation between actigraphy and PSG in assessing TST of around 90-93% (Sadeh *et al* 1994), 91% (Ancoli-Israel *et al* 1997b), 95% (Blood *et al* 1997) and 97% (Jean-Louis *et al* 1996). Other studies have found actigraphic correlation with PSG in the measurement of TST, SOL, SE, sleep onset and wake-time after sleep onset (WASO) for healthy middle aged participants [88% correlation], in healthy older participants [85% correlation] and an 89% correlation in psychiatric care recipients (Mullaney *et al* 1980, Cole *et al* 1992).

The validation of actigraphy against PSG (the gold-standard method of sleep assessment) show high levels of agreement (85 – 97%) in various groups of adults (Mullaney *et al* 1980; Cole *et al* 1992; Jean-Louis *et al* 1996). However, there is incomplete agreement between actigraphically and EEG measured sleep outcomes. Discrepancies between PSG and actigraphy lie in the overestimation of total sleep times and underestimation of wake-times after sleep onset, although these discrepancies are small (Blood *et al* 1997; Sadeh *et al* 1994). The actigraph has

also been shown to be a good predictor of changes in circadian rhythmicity over longer periods of investigation (Chambers 1994; Van Someren *et al* 1997).

The actigraph has also been approved for its ability to take measurements that closely parallel the more expensive and involved process of PSG and in an unobtrusive way (Mullaney *et al* 1980; Cole *et al* 1992). Actigraphy has been shown to be a reliable assessor of such issues as regularity of sleep times, naps during the day, follow through in sleep curtailment procedures (Hauri and Wisbey 1992) and the assessment of entrainment to, or desynchronisation from, the circadian rhythm (Witting *et al* 1990, Van Someren 1996). Sadeh *et al* (1995) suggest that actigraphy maybe a:

"Useful, cost-effective method for assessing sleep disorders such as insomnia and schedule (circadian) disorders, and for monitoring their treatment process" p 301.

4.4 SUMMARY OF SLEEP ASSESSMENT

For valid results, the assessment of sleep across two different environments (home and hospital) must be performed over long collection periods of several days to weeks (Cole *et al* 1992; ASDA 1995) The actigraph can collect data reliably and safely over a large number of days (Van Someren *et al* 1996; 1997) or weeks (Mishima *et al* 1998; Van Someren *et al* 2003). As stated by ASDA (1995):

"Recordings can be conducted for days or weeks on care recipients in their own homes under conditions more natural and typical than can be achieved by polysomnography in the sleep laboratory." (ASDA 1995; p. 286)

4.5 CHOSEN METHODOLOGY

In order to address the research aims stated at the end of the last chapter the actigraph has been selected as the method of choice. When considering the need for recordings to be made over several weeks and in different environments, the technology available to make these recordings must be tolerable, durable, discreet and reliable. Actigraphy is the only available technology to take meaningful measurements of the sleep-wakefulness rhythms (and changes therein) of this vulnerable cohort whilst meeting the above criteria of tolerability, reliability and durability.

The selected actigraphic technology was supplied by Cambridge Neurotechnology™ and comprised a 'wrist-watch' worn device (Actiwatch – Plus™), a telemetric interface which connected with a PC and the necessary software to extract data from the device and derive outcome measurements of sleep and circadian rhythmicity (see Section 4 6 for a full description of these outcome measurements).

4.5.1 Software

Cambridge Neurotechnology™ developed the 'actiwatch' system including actimeter devices, interfaces to connect and download stored actigraphic data into a PC and the relevant computer software for processing these data (Cambridge Neurotechnology™ 1999). Data were generated via the movement of a crystal within the actigraph. As the crystal moved within the device (as the wearer moved) a small electrical charge was generated. This charge was then stored and read after a preset epoch of time has elapsed [1 minute epochs are recommended as a maximum by ASDA (1995)]. The actiwatch software, using previously tested and standardised algorithms, then computed the sleep / wakefulness status of the participant.

4.5.2 Scoring algorithms

Identification of sleep and wakefulness from the actiwatch sleep analysis software incorporated an algorithm which assessed each data point from each epoch (one minute epochs in the current study) and those data points directly surrounding that epoch. Adjacent activity scores influenced the total score in the following way:

- Within one minute of the scored epoch, activity levels were reduced by a factor of 5 and then added to the epoch being scored.

- Within 2 minutes of the scored epoch, activity values were reduced by a factor of 25 and, again then added to the scored epoch.

Medium sensitivity of the software defines a cutoff score of 40 activity counts per-minute, above which the epoch was scored as wakefulness. Automatic detection of the initiation of sleep by the actiwatch software was made by the software automatically searching for 10 consecutive immobile (score under 40) epochs or minutes around the user defined bedtime, with no more than one epoch of movement (score > 40) in that time. Similarly, the termination of sleep was automatically identified by the software where 10 consecutive epochs or minutes (around the user defined get up time) scored over 40 were registered with no more than one of these epochs scoring less than 40 (Cambridge Neurotechnology™ 1999). The higher sensitivity cutoff threshold was 20 activity counts per-minute

The setting of these actigraphs to medium sensitivity was recommended by the manufacturer (Cambridge Neurotechnology™ 1999). However, recent research conducted by Van Someren *et al* (2003) has suggested, for these Cambridge Neurotechnology™ actimeters that sensitivity levels should be set to a higher sensitivity when assessing the sleep of dementia care recipients.

The higher sensitivity levels recommended by Van Someren (2003) for assessing the sleep / wakefulness of care recipients stipulated a cutoff threshold of 20 activity counts per-minute. Van Someren *et al* (2003) contend that actigraphic assessment at this higher sensitivity level counteracts actigraphic overestimations of TST and underestimations of WASO (as mentioned in Section 4 3.1). To examine any differences between these higher and medium sensitivity settings in the present study, a paired-samples comparison was conducted, the findings from this analysis will be presented in Chapter 5 Thereafter all sleep / wakefulness analyses for these groups of care recipients and their caregivers will be performed on data coded at the higher sensitivity levels, as recommended by Van Someren (2003).

It should be noted that these sensitivity thresholds only affect the scoring of sleep and wakefulness outcome variables; circadian rhythm outcome measurements (as these are calculated across 24-hour periods or more and do not include the detection of sleep and wakefulness) were unaffected by any changes in this threshold sensitivity.

4.6 OUTCOME MEASUREMENT VARIABLES

Measurements collected in this study protocol can be subdivided into two categories from care recipients and caregivers Both caregivers and care recipients were measured actigraphically and the relevant actigraphic outcome measurements taken will be described in Section 4.6.1. Caregivers were also measured with questionnaires and sleep diaries These subjective outcome measurements will be described in Section 4.6 2. The application of the sleep diary augmented care recipient and caregiver actigraphic data for analysis as well as providing subjective sleep outcomes for caregivers.

4.6.1 Actigraphic outcome measurements

The sleep parameters generated by the Cambridge Neurotechnology™ software are presented in Table 4.1.

Table 4.1 Sleep and circadian rhythm outcome measurements collected for analysis.

	Outcome measurement	Units	Abbreviation
Sleep Measurements	Total sleep time	Minutes	TST
	Sleep onset latency	Minutes	SOL
	Wake-time after sleep onset	Minutes	WASO
	Sleep efficiency	%	SE
	Total daily nap time	Minutes	TNT
	24-hour sleep time	Minutes	24ST
Circadian Rhythm Measurements	Interdaily stability	Score	IS
	Intradaily variability	Score	IV
	Lowest five hours of nocturnal activity levels	Score	L5
	Relative amplitude of the circadian rhythm	Score	RA

Total sleep time (TST) is measured in minutes and is a measure of the duration of nocturnal sleep time from sleep onset to sleep offset Sleep onset latency (SOL) is the time, measured in minutes from lights-out until sleep onset. Wake time after sleep onset (WASO) is a measure of the length of time, in minutes, an individual was awake during the night from initial sleep onset until morning wake-up and arise time. Sleep efficiency (SE) is measured as the length of time spent in bed asleep, divided by the total length of time in bed (i e. including SOL and WASO) multiplied by 100 to convert to a percentage. Total daily nap time (TNT) is a measure (in minutes) of the length of time spent asleep during the day and 24 hour sleep time (24ST) is TST + TNT, also measured in minutes

A description of the circadian rhythm outcome measurements follows in Section 4.6.1.1 through to Section 4.6.1 4.

4.6.1 1 Interdaily stability (IS)

The IS, first described by Witting *et al* (1990), quantifies the invariability of the circadian rhythm between days. IS is derived by normalising for the number of data points within the 24-hour value from the chi-square periodogram (Sokolove and Bushel 1978).

$$IS = \frac{n\sum_{h=1}^{p}(\bar{x}_h - \bar{x})^2}{p\sum_{i=1}^{n}(x_i - \bar{x})^2}$$

Where n = the total number of data points

p = the number of data per day

$\bar{x}$ = the mean of all data

$\bar{x_h}$ = the hourly means

x_i = the individual data points

Decreases in the value of IS over time may reflect a loose coupling between the circadian rhythm and its entraining zeitgebers (Moore-Ede *et al* 1982). IS is calculated as a value between zero and one, an IS approaching one indicates perfectly stable levels of activity (rises and falls) between days, i.e. one day's activity exactly mirroring the following and the preceding days, for example. However, an IS approaching zero is indicative of a completely random routine across days with one day's activity levels being completely unrelated to the activity patterns of surrounding days.

4.6.1 2 Intradaily variability (IV)

The IV, also first described by Witting *et al* (1990), quantifies the fragmentation of the circadian rhythm within days. IV is defined as the ratio of the mean squared first derivative of the data and the overall variance of the data:

$$IV = \frac{n\sum_{i=2}^{n}(x_i - x_{(i-1)})^2}{(n-1)\sum_{i=1}^{n}(x_i - \bar{x})^2}$$

Where n = the total number of data points

$\bar{x}$ = the mean of all data

x_i = the individual data points

Increases in the value of IV over time may be indicative of increases in agitation, wandering, daytime napping and nocturnal arousal (Witting *et al* 1990). IV is calculated as a value between zero and two (although a score of greater than two is possible in people with extremely disrupted circadian rhythms), an IV of 2 or more is indicative of a highly fragmented daily rhythm with frequent shifts from activity to rest and back again. However, an IV approaching zero indicates slow, stable and gradual shifts from rest to activity and back again. The IV, then, gives an indication of the disruption of the circadian rhythm i.e. the frequency and extent of transitions between rest and activity (Van Someren *et al* 1997).

4.6.1.3 Lowest five consecutive hours of activity (L5)

The lowest five consecutive hours of activity (L5) is a measure of nighttime activity levels measured in activity counts per-five hours. Activity levels are compared across 24-hour periods and the least active five hours (within each 24-hour period) activity scores are added cumulatively. This yields a score of activity counts for

that five hour window of least activity during the 24-hour day. As would be expected this accumulated score of activity relates to movement occurring during the night and indicates amounts of physical nighttime movement, i.e. the more disturbed a persons' sleep, the more active they will be at night. In care recipients and their caregivers who were possibly experiencing disturbed nighttime sleep, this measure of L5 informed the nature of their nocturnal activity levels before during and after periods of booked respite care Increased nighttime activity levels are indicative of disturbed sleep with high L5 scores linked to high wake-times after sleep onset (Van Someren *et al* 1997).

4 6.1.4 Relative amplitude (RA)

The activity score describes the amount of gross body movement or activity and can be calculated over all the data points. Although, for the sake of separating diurnal and nocturnal activity levels, the RA is often separated into the most active 10 consecutive hours of activity (M10) and the least active five consecutive hours of activity (L5) (Witting *et al* 1990). Daytime napping behaviours will influence (decrease) mean M10 values and nocturnal activity will invoke changes (increases) in L5 mean values.

RA is calculated from M10 and L5 using the formula:

$$RA = \frac{(M10 - L5)}{(M10 + L5)}$$

As L5 → zero, RA → 1.

A relative amplitude approaching 1 is associated with activity centralised into the daytime hours, with very little nighttime activity. Conversely, a reduced RA indicates higher nighttime activity levels, characteristic of disturbed nighttime sleep.

4 6 1.5 Summary of actigraphic outcome measurements

These measures are considered informative when measuring vulnerable cohorts and have been shown to be valid and reliable indicators of sleep timing and circadian rhythmicity (function and dysfunction) within these groups (Witting *et al* 1990, Van Someren *et al* 1997). IS and IV have been shown to be sensitive indicators of circadian rhythmicity in this cohort displaying improvement in the patterning of activity (i.e. coupling to zeitgebers) from chronobiological treatments (Van Someren *et al* 1999). These measures are informative in the assessment of circadian rhythmicity particularly over-time when comparing environmental treatment effects (Van Someren *et al* 1997 and 1999). IS has also been shown to be more sensitive than any other current circadian variable (RA, IV, cosinor-derived goodness of fit and phase) at distinguishing older adults with AD from normal, healthy older people (Satlin 1995). Recommendations regarding the circadian rhythm outcome measurements IS and IV suggest that calculations are made over as long a time period as possible (preferably in excess of one week) in order to obtain reliable, within-period data (Cole *et al* 1992; ASDA 1995). It should be noted that the other circadian rhythm outcome measurements (RA and L5) are calculated on a 24-hour basis as with the other sleep outcome measurements.

4.6.2 Subjective and questionnaire outcome measurements

Data collected from caregivers in the form of written documentation will be described in the following Sections (4.6 2.1 – 4.6 2.6) These included the Epworth sleepiness scale (Johns 1991), the Pittsburgh sleep quality index (Buysee 1989), the Short Form – 36 (SF-36) Health-Related Quality of Life Questionnaire (Brazier *et al* 1992), sleep diaries, the Loughborough University sleep diary and a post-study questionnaire. Copies of all these documents can be found in the Appendices (3 – 7 respectively).

4.6.2.1 The Epworth sleepiness scale (ESS)

The ESS was developed by Johns (1991) as a means of assessing the subjective daytime sleepiness of individuals. It has become a standard metric for assessing the subjective daytime sleepiness of participants. The ESS is a self-completed questionnaire assessing the subjective likelihood of falling asleep in eight different situations (e.g. sitting and reading or talking to someone). Ratings are given on a four-point scale. A response of zero indicates that the participant would 'never' fall asleep in a given situation. A response of one indicates a slight chance of dozing, two a moderate chance and three a high chance of falling asleep. Final scores are added cumulatively yielding a score in the range 0 – 24. The higher the score the more likely a participant feels that they could fall asleep during the day and so they would be considered to be experiencing high levels of subjective daytime sleepiness. Scores greater than ten on the ESS indicate excessive daytime sleepiness (Johns 2000). See Appendix 4 for a copy of the Epworth Sleepiness Scale.

4.6 2.2 Pittsburgh sleep quality index (PSQI)

The PSQI is an eleven item questionnaire which assesses daytime fatigue, subjective ratings of the sleep experience and subjective estimation of TST, SE, WASO and SOL. On scoring, the PSQI generates both a global (total) score and seven component scores. These component scores included sleep quality, sleep latency, the use of medication, daytime dysfunction, sleep duration, sleep efficiency and sleep disturbances Global scores are in the range 0 – 21 with higher scores indicating an increased dissatisfaction with sleep and a greater severity of sleep disturbance. Any score over 5 on the PSQI represents a clinically recognised level of sleep disruption (Buysee 1989). The PSQI has shown good validity for use in care recipients with primary insomnia (Backhaus *et al* 2002) See Appendix 3 for a copy of the Pittsburgh Sleep Quality Index.

4.6.2.3 The Short Form – 36 (SF-36) Health-Related Quality of Life Questionnaire

The SF-36 is a 36-item questionnaire assessing the physical and emotional health of the respondent. The questionnaire generates validated scores highlighting health-related quality of life across eight domains. These domains included general health perception, energy/ vitality, emotional role limitation, social functioning, physical functioning, physical role limitation, pain and mental health. The SF-36 has shown good reliability (Cronbach's $\alpha > 0.85$) at distinguishing between groups with expected health differences, good response rates and ease of use (Brazier *et al* 1992) This questionnaire has also been reported to be practical and valid for use in the assessment of the quality of life of older adults [9897 older adults aged 65 – 104 (Walters *et al* 2001)]. The questionnaire has also been reported to have greater consistency when applied by an interviewer rather than solo completion of the questionnaire by volunteers (particularly in older adults) (Brazier *et al* 1996). See Appendix 5 for a copy of the SF-36 health-related quality of life questionnaire.

4 6.2.4 Sleep diaries

Sleep diaries require participants to answer simple questions regarding their sleep practices and also to rate the quality of their sleep and daytime alertness. Times at which participants go to bed, initiate sleep, terminate sleep and arise from bed are the most fundamental measures taken from the sleep diary, although nighttime fragmentation of sleep and feelings of wellbeing during the nighttime and the following morning can also be recorded Sleep diaries and actigraphy have shown significant levels of correlation (Brooks *et al* 1993; Lockley *et al* 1999). Correlation between sleep diaries and actigraphically measured sleep / wakefulness has been found with Pearson's r =0 69 for total sleep time (Brooks *et al* 1993), for sleep onset Pearson's r =0.77 and for sleep offset Pearson's r =0 88 (Lockley *et al* 1999).

4.6.2.5 The Loughborough University sleep diary

The Loughborough University sleep diary comprised a 15-item questionnaire across three domains. Firstly, caregiver sleep was examined with questions of bedtimes, sleep onset latencies (SOL), wake time after sleep onset (WASO) information, wake times, rise times and hypnotic consumption data. Secondly, care recipient information was recorded; including bedtimes, wake times, whether the care recipient had disturbed the caregiver during the night and for how long any disturbance had occurred. The final 5 items on this questionnaire were rating scales on: how well the participant felt that morning (wellbeing), how much they enjoyed their sleep on the previous night, how active their mind was in bed on the previous night, how tense and how anxious they felt in bed on the previous night. These 5 items were scored as whole integers on the scale: 0 – not at all, to 4 – very much. See Appendix 6 for a copy of the Loughborough University Sleep Diary.

4.6.2.6 Post-study questionnaire

After completion of the study protocol caregivers were assessed with a post study questionnaire to obtain information about themselves, their care recipient and their relationship. These data included the sexes and ages of the participants, the duration of the caring role, the duration of the dementing illness, the diagnosis, the number of respite admissions received, and medications prescribed for both the caregiver and the care recipient. These data were collected from caregivers at the end of the study protocol and for care recipients from case notes on the ward obtained during their respite admission. See Appendix 7 for a copy of the post-study questionnaire.

4 6.2.7 Summary of subjective sleep quality outcome measurements

The subjective outcome measurements collected using the previously reported methodology aimed to examine the effects of respite service provision on the

subjectively reported sleep quality of dementia caregivers. These results described the extent to which sleep quality was affected by dementia caregiving and examined the effectiveness of respite service provision on improving caregiver subjective sleep quality.

4.7 POWER CALCULATIONS

For the present study power calculations were based on Van Someren *et al* (1997) examination of IS and IV in a group of dementia care recipients assessing the impact of bright light treatment on these outcome measurements. Van Someren *et al* (1997) reported a clinically significant change in these two measurements of circadian rhythmicity (IS and IV), significant at the $p < 0.05$ level, in their treatment cohort of 17 institutionalised, care recipients

In order to estimate a suitable sample size for the present study, the effect of an intervention on these values of IS and IV in a similar repeated-measures design was established. Once the effect size (also referred to as the standardised effect size) was estimated for these variables under such design constraints, statistical tables were used to estimate a suitable sample size for the present study. Van Someren *et al* (1997) reported clinically significant changes in the outcome measurements of IS and IV after four days of bright light treatment in a group of 17 care recipients with severe dementia. This research teams' data are summarised in Table 4.2.

Table 4.2 Summary of Van Someren *et al* (1997) clinically significant changes in IS and IV in a group of care recipients with severe dementia.

Outcome Measurement	Baseline Mean (SD)	Treatment Mean (SD)	t	p
IS	0.50 (0.05)	0.65 (0.04)	3.79	0.002
IV	1.01 (0.10)	0 80 (0.07)	2 92	0.010

t = paired samples t-test value; p = level of significance, n = 17 older people with severe dementia

The standardised effect size (sd) is derived from the following equation:

$$sd = \frac{2t}{\sqrt{df}}$$

Where the *t* statistic is a measure of the differences between the baseline and treatment means divided by the standard error of the difference, i.e. a measure of the treatment effect (from Table 4.1) and *df* are the degrees of freedom from the Van Someren *et al* (1997) study. Degrees of freedom are expressed as (n-1), in this case there were 16 degrees of freedom.

For IS:

$t = 3\ 79$ and $df = 16$

The standardised effect size (sd) was therefore:

$$sd = \frac{2(3.79)}{\sqrt{16}}$$

$$sd = \frac{7.58}{4}$$

Therefore:

sd = 1.895 for IS.

For IV:

$t = 2.92$ and $df = 16$

The standardised effect size (sd) is therefore:

$$sd = \frac{2(2.92)}{\sqrt{16}}$$

$$sd = \frac{5.84}{4}$$

Therefore:

sd = 1.460 for IV.

From Tables: using standardised effect sizes for IS and IV from Van Someren *et al* (1997) and setting power (d) at 0.8 and α at 0 05:

From IS sd = 1.895; using statistical tables; n was estimated to be 12 older people for the present study to reach significance in differences between IS in baseline and treatment periods at a power of 80% (d =0.8).

From IV: sd = 1.460, using statistical tables; n was estimated to be 18 older people for the present study to reach significance in differences between IV in baseline and treatment periods at a power of 80% (d =0.8)

4.7.1 Summary of power calculations

From the calculations performed in the previous section and from guidance from Van Someren *et al* (1997) data, the present study was estimated to require at least 18 participants to derive significant changes in circadian rhythm outcomes measurements in care recipients. However, the present study was also interested in the circadian rhythms of caregivers, which have yet to be assessed in the literature. Actigraphically measured sleep times and sleep efficiencies have also yet to be

reported in enough detail to perform power calculations for these groups of older adults and for this type of study design (repeated measures). With the difficulty in estimating sample sizes required for significant changes to be measured in caregivers circadian rhythmicity and caregiver and care recipient sleep outcomes, the present study aimed to recruit and measure thirty caregiver / care recipient dyads. It should be noted that these power calculations have been designed to test for the sample size required to detect significant main effect changes in sleep and circadian rhythm outcome measurements as a result of respite care at $p < 0.05$ with d at 0.8. Any interactions or sub-group analyses conducted in the results section may therefore be under-powered as no adjustments have been made for multiple statistical testing and that acceptance of a higher rate of Type I errors has been accepted.

4.8 CONSENT

Participant suitability was initially assessed by consultant psychogeriatricians who suggested names of potential participants to the researcher. Informed consent was obtained from the caregivers in this study after initial introductions between potential participants and the researcher by senior ward staff on the respite wards of local community hospitals were made. On meeting with community-residing dementia caregivers' consent was obtained in writing after a full explanation of the study protocol, the reasons for conducting the research and the answering of any queries they may have had. Ethical approval did not allow consent to be taken from the older adults with dementia as it was not considered efficacious to ask someone with moderate to severe dementia to participate in a complex study and sign a consent form. Instead, ethical approval stipulated that caregivers providing assent for their care recipients to participate was sufficient for them to participate. See Appendices 1 and 2 for caregiver and care recipient consent and assent forms respectively. This protocol met with the Leicestershire Mental Health Services, NHS Trust, Nottinghamshire Healthcare NHS Trust and Derbyshire Mental Health

NHS Trust Local Research Ethical Committees (LREC) and Loughborough University Research Ethics Committee (LUREC) approval

4.9 PROCEDURES

Participants were selected from four hospitals providing respite care in the midlands (Loughborough, Coalville, South Nottinghamshire and South Derbyshire). Eligibility for entry into the study included:

- A care recipient meeting DSM-IV (APA 1994) criteria for moderate to severe dementia

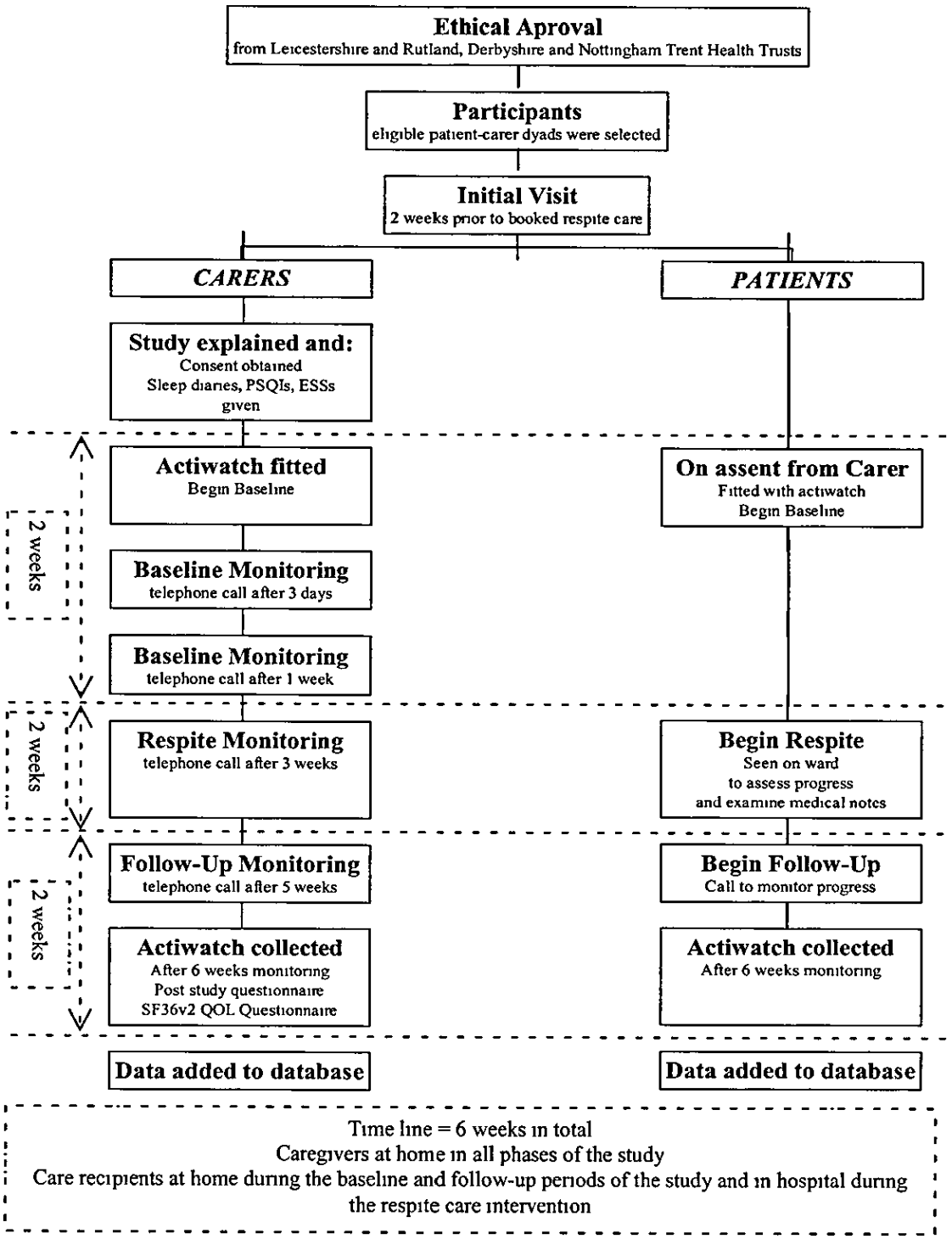
- The care recipient having a principal community caregiver and,

- The care recipient and their caregiver being in receipt of regularly booked periods of respite care.

The care recipients and their principal caregivers who met these inclusion criteria were then invited to enter the study and were considered as caregiver-care recipient dyads. Cases were identified by consultant psychogeriatricians and participants were contacted by hospital ward-staff who sent an invitation to be contacted by the researcher. On agreement to meet via telephone, the researcher visited the homes of potential dyads and briefed caregivers on the nature and demands of the project. If the caregiver provided consent to participate, and assent was provided from the caregiver to fit an actiwatch to their care recipient, a baseline meeting was arranged 2-weeks prior to their respite booking. At this baseline meeting both the caregiver and the care recipient were fitted with one Cambridge Neurotechnology™ Actiwatch each and caregivers provided with the paperwork Paperwork included 6 week-long sleep diaries (and one spare), six Epworth Sleepiness Scales (Johns *et al* 1991) including one spare, one Pittsburgh Sleep Quality Index (Buysee *et* al 1989) and one SF-36 Health-Related Quality of Life Questionnaire (Brazier *et al* 1993).

After two days caregivers were telephoned to check initial progress and tolerability of the technology and paperwork demands, hospital staff were then informed that the care recipient would be arriving for their period of respite care in the hospital wearing an actiwatch. Prior to the engagement of participants all participating hospital staff attended a seminar which briefly described the study and explained how to take care of the technology and record care recipient sleep information. Care recipients were visited on the hospital ward after 2 5 – 3 weeks whilst they were receiving respite care and their notes examined for personal information regarding age, diagnosis and the number of respite admissions received. After 5 weeks of the study caregivers were telephoned again, to check progress and to arrange a time for recollection of the actiwatches and the completed paperwork. After 6 weeks the follow-up meeting was conducted with caregivers and care recipients at home together. The actiwatches were recollected along with the completed sleep diaries and the sleep and health-related quality of life questionnaires. At this stage the post-study questionnaire was applied in order to retrieve personal information from the caregiver regarding their age and the duration of their caregiving role. The three stages of the study protocol for each volunteer were the baseline, respite (treatment) and follow-up periods. The outcome measurements TST, SOL, SE, WASO, L5, 24-hour sleep time, TNT, IS, IV and RA generated by Cambridge Neurotechnology™ Software were compared across these three stages. See Figure 4.2 for a flow diagram of participant acquisition and the study protocol.

Figure 4.2. Flow diagram of the study protocol



4.10 DATA ANALYSES

4.10.1 Group Size

At baseline; 38 caregivers successfully provided subjective sleep outcome data, 36 caregivers and 34 care recipients respectively successfully provided actigraphic sleep outcome data. At respite; 34 dyads successfully provided sleep and circadian rhythm outcome data and in follow – up, 30 dyads successfully completed the entire study protocol. PSQI and ESS data was provided by 40 caregivers and 37 caregivers completed the SF-36 Health-Related Quality of Life Questionnaire. In order to optimise use of the available data, initial descriptive statistics were based on all available data for that phase of the study, irrespective of whether or not a given participant subsequently withdrew. Conversely, multivariate models requiring complete datasets for a given variable are based only on the participants who completed all phases of the study. These variations in 'n' size are made clear in the text.

4.10.2 Statistical Analyses

Actigraphic, questionnaire and sleep diary variables were combined in a single database, and all data were analysed using SPSS for Windows ™ (Version 10 0). Actigraphic data were then averaged across the caregiver / care recipient groups for each phase (baseline, respite, follow-up) of the study, prior to a series of preliminary analyses to assess the stability of the baseline period (see Chapter 5). For these and subsequent analyses, appropriate parametric statistics were used. However, since scores from the 4-point caregiver wellbeing scale departed from the normal distribution, these ratings were analysed using Friedman's non-parametric test for related samples across more than two conditions. Relationships between variables were examined using Pearson's product-moment correlation coefficients. Baseline analyses of caregiver and care recipient sleep and circadian rhythm outcomes between sub-groups of bedroom sharing and separately sleeping dyads

and from caregivers who rated their sleep as good and those who rated their sleep as poor (and their care recipients), independent samples t-tests were used with bedroom partnership status and PSQI group (good versus poor) entered as grouping variables

In separate analyses for the caregiver and care-recipient groups, actigraphic and subjective sleep variables for the baseline, respite and follow-up periods were compared in a series of repeated measures multivariate ANOVA models adjusted for sleeping arrangements (sharing / not sharing a bedroom with a care recipient). Between-subjects factors by sharing and non-sharing dyads were introduced into these multivariate ANOVAs as sharing caregivers showed significant correlations in their sleep outcomes compared to those who were not sharing bedrooms with their care recipients (See Tables 5 15 and 5.16 in Chapter 5). For each model, therefore, outcome measurements were entered as within-subjects factors, while bedroom sharing / not-sharing status was entered as a between-subjects variable. These results, presented in Chapters 6 and 7, are summarised in separate tables for the principal effects of the respite care intervention (for each outcome measurement), contrasts between conditions, and interaction effects (between the outcome measurements and dyadic sleeping arrangements). Other variables considered as covariates for inclusion in these multivariate ANOVAs included age, gender, medication consumption and diagnosis. However, these covariates were not included in multivariate ANOVAs for various reasons. The predominant factor attached to excluding these other potential covariates was the heterogeneity of groups, i.e. the breakdown of the sample into sub-groups may have reduced the power of analyses, for example by controlling for gender or for the diagnoses of care recipients. Medication usage would also have formed an interesting basis for running sub-analyses; however the range and type of medications prescribed to both caregivers and older people with dementia negated this possibility. As the overall main effects of the impact of respite care are the primary focus of this thesis, and of particular relevance to policy makers and practitioners, the selected analyses were performed in the absence of sub-analyses that would have been

difficult to perform (as sub-group numbers would have been uneven) and may lack relevance to policy or practice. Full multivariate ANOVA tables are reproduced in Appendices 9 and 10 for caregivers and care recipients respectively. Contrast ANOVA tables, testing for significant differences between conditions are presented in Appendix 11.

4.10.3 Single case-study qualitative data

In examining community healthcare it is sometimes useful to consider single cases which, for one reason or another are interesting in their own right. Their interest may lie in their exemplification of expected trends or behaviours, or be of interest as, for some reason, their trends or behaviours confound results by appearing to contradict experimental expectations. Two single case studies from two caregivers are presented at the end of Chapter 6 and, similarly, two single case-studies from two dementia care recipients are presented at the end of Chapter 7. These single case-studies are included as they form a qualitative analysis of the experience of respite care in caregiving and in dementia. These qualitative data are presented in order to examine the experiences of caregivers and older people with dementia in and around booked periods of respite care. The qualitative data was gathered from field notes of conversations with caregivers and observation of their (and their dependents) questionnaire, sleep diary and actigraphic outcome measurements.

This concludes the method constructed to examine the sleep and circadian rhythmicity of older people with dementia; their caregivers and the impact of the respite care intervention on their sleep and circadian rhythmicity The following chapters will describe the results from this study. Chapter 5 will detail baseline descriptive data from these dyads; Chapter 6 will present intervention data from the caregivers who participated in the entire study protocol and; Chapter 7 will present intervention data from the dementia care recipients who completed the entire study protocol Discussions and conclusions from this study will be presented in Chapter 8.

CHAPTER FIVE

Descriptive Results

5.1 INTRODUCTION

This chapter will present the trajectories of the participants through the study protocol, describing the numbers of dyads contacted, the numbers of those who withdrew or were not included in the study and the reasons for their non-participation. The examination of the actigraphic data for possible first-night and preadmission effects will be made in order to examine whether the study protocol or respite service admission had significant impact of any outcome measurements. Following these initial analyses actigraphic sensitivities will be explored in order to examine whether significant differences in outcomes existed between the medium and higher sensitivity level settings of the technology on sleep outcomes, as described in Chapter 4. These analyses were conducted in order to identify how data should be aggregated and described in the following descriptive analyses of caregiver and care recipient sleep outcomes.

Caregiver and care recipient profile data will then be presented in line with the first research aims stated at the end of Chapter 3. Caregiver health-related quality of life and descriptive, baseline sleep and circadian rhythm data from caregivers and care recipients will then be the focus of the remainder of this chapter.

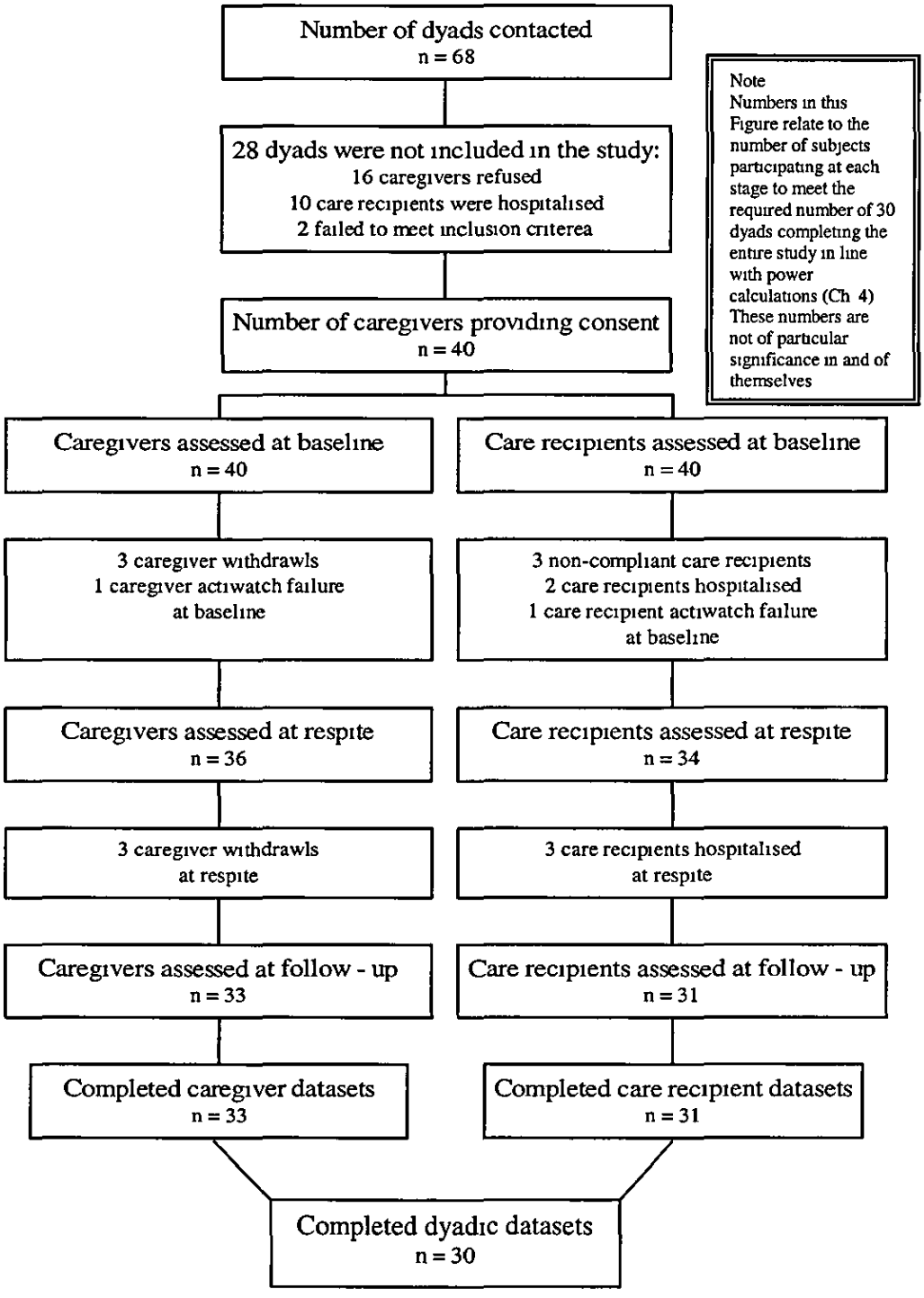
Data will be presented from the whole group of caregivers and care recipients before a breakdown by bedroom partnership (sharers and non-sharers) These data will be presented for caregivers first and care recipients second Dyadic interrelationships will then be explored in the same manner, i.e. as a whole group, followed by dyadic sleeping arrangements. Data collection spanned 2.5 years from

November 2000 to June 2003. A description of caregiver and care recipient trajectories through the study protocol is summarised in Section 5.2.

5.2 CARE RECIPIENT AND CAREGIVER TRAJECTORIES THROUGH THE STUDY PROTOCOL

Recruitment and the progress of the care recipients and caregivers who joined the study protocol are summarised in Figure 5.1.

Figure 5.1 Recruitment, baseline, respite and follow-up of dyads



Data were continuously collected until the completed dyadic dataset reached 30 pairs of complete actigraphic data (i e. 30 paired datasets from the baseline, respite and follow-up periods of the study) in line with the power calculations described in Chapter 4. This required contacting and inviting 68 caregivers to consent to taking part in the study and assent for the care recipients to do so. Discrepancies in sample sizes in the following analyses were due to the removal of excessively outlying data (over 3 standard deviations (SDs) from the mean) from the dataset *or* incomplete questionnaire or sleep diary data. It should be noted that these discrepancies were small, amounting to only one care recipient describing excessively (over 3 SDs from the mean) short nighttime sleep times and long daytime naptimes. No caregiver data was considered as excessively outlying as their data were all within the bounds of 3 SDs from mean values.

5.3 THE POSSIBLE IMPACT OF FIRST NIGHT EFFECTS AND PREADMISSION EFFECTS

In order to examine the impact of respite care on these caregiver / care recipient dyads, paired samples t-tests on the sleep outcome measurements of these groups was performed. Variability of caregiver and care recipient sleep data across the baseline period of the study required assessment in order to identify how baseline data should be presented, such that these data were typical of sleep in the home environment. There were two factors that may have led to variation in sleep outcomes during the baseline period, firstly; first night effects (FNE) resulting from the use of actigraphy (i.e. the novelty of actigraphic sleep assessment in some way imposing on the sleep outcomes of participants) or; secondly, preadmission anxiety of the impending respite care intervention may have impacted on caregiver and / or care recipient sleep and circadian rhythmicity. There was a possibility that these caregivers or their care recipients may have experienced some impact on their sleep around these times as a result of pre-admission anxiety causing sleep disturbances As a result, comparison between the first and last days of baseline and the grand baseline mean were conducted to examine whether the aggregated 2-week baseline

period data were typical of the baseline period and that baseline period outcomes were not distorted by untypical nights sleep. The comparison of the first and last days of the baseline period with the complete baseline mean sleep data was made in order to examine the possibility of any FNE or pre-respite admission effects on the sleep of these groups and therefore to decide how baseline data were aggregated for further analysis. Should there have been no significant FNE or pre-admission effects (i e. the first and last days of baseline not being significantly different from the baseline grand mean) then data would be aggregated for the whole of the baseline period. Conversely, should either the first or last days of the baseline period be significantly different from the baseline mean values then FNE or pre-admission effects may have been obscuring true baseline values, these days would then be removed from baseline calculations.

As FNE have only been reported on nocturnal sleep outcome measurements, and considering the way in which the circadian rhythm outcome measurements were calculated (i e binned data comparing multiple days). These correlated paired-samples t-tests were only conducted on the sleep outcome measurements and are presented for caregivers in Table 5 1 and for care recipients in Table 5 2.

Table 5.1 Examination of baseline sleep outcome measurements for first night effects and pre-admission effects on caregivers.

Outcome measurement	**Day 1** **Mean (SD)**	**Day 14** **Mean (SD)**	**Baseline [B]** **Mean (SD)**	**Day 1 – B** **t (p)**	**Day 14 – B** **t (p)**
TST	422 9 (53 1)	428 7 (64 2)	422 6 (52 1)	0 04 (0 972)	0 77 (0 444)
WASO	65 9 (42 1)	57 3 (42 1)	59 2 (30 9)	1 87 (0 070)	-1 05 (0 302)
SOL	20 6 (31 1)	24 5 (34 8)	22 5 (17.3)	-0 43 (0 672)	0 41 (0 683)
SE	83 3 (8 9)	82 6 (12 3)	81 9 (10 0)	1 12 (0 272)	0 45 (0 659)

B = Baseline, t = paired samples t statistic, p = significance value, n = 36 caregivers

Table 5.2 Examination of baseline sleep outcome measurements for first night effects and pre-admission effects on care recipients.

Outcome measurement	Day 1 Mean (SD)	Day 14 Mean (SD)	Baseline [B] Mean (SD)	Day 1 – B t (p)	Day 14 – B t (p)
TST	468 9 (135 5)	432 3 (156 6)	453 9 (132 6)	1 20 (0 237)	-1 55 (0 130)
WASO	47 4 (42 4)	77 1 (83 0)	60 8 (47 0)	-2 189 (**0.036**)	0 58 (0 565)
SOL	24 1 (59 3)	33 6 (56 1)	23 9 (30 0)	0 04 (0 969)	1 74 (0 091)
SE	84 7 (17 7)	77.1 (23 5)	82 3 (17 1)	1 47 (0 143)	-1 31 (0 231)

B = Baseline, t = paired samples t statistic, p = significance value, n = 34 care recipients

Results from these paired-samples t-tests showed no significant differences between the first day or the last day of the baseline period and the aggregated baseline period data for caregivers. Care recipients experienced significant differences between day 1 of the baseline period and average baseline period values for WASO. Care recipients experienced no significant differences between day 14 of the baseline period and average baseline period levels in any of these outcome measurements. There is little evidence from Table 5.1 and Table 5 2 that caregiver or care recipient sleep outcome data were influenced by FNE or pre-admission anxiety. Considering this in the further analyses of these data, baseline period data were aggregated from all baseline days. Any further references to the baseline period in the results and discussion chapters presented in this thesis will be data aggregated from all baseline days

5.3.1 Actigraphic sleep/wake detection sensitivity thresholds

Sleep outcome measurement data will be presented for actigraphic sensitivities of medium (cutoff threshold of 40 activity counts per-minute) and for the higher actigraphic sensitivity (cutoff threshold of 20 activity counts per-minute) as stated in Chapter 4. Statistical analyses of the differences between these outcome measurements were also performed. It should be noted that the circadian rhythm outcome measurements were unaffected by these sensitivity thresholds as they were

only implemented for the detection of sleep and wakefulness. The sleep outcome measurements at medium and higher sleep / wake sensitivity detection levels are presented for caregivers in Table 5.3 and for care recipients in Table 5.4

Table 5.3 Comparison of medium and higher sleep/wake sensitivity thresholds for actigraphic sleep data from caregivers (n = 36) at baseline

		Medium Sensitivity	High Sensitivity	
Outcome measurement	**Units**	**Mean (SD)**	**Mean (SD)**	**t (p)**
Total nocturnal sleep time (TST)	Mins	422 6 (52 1)	401 5 (52 6)	7 3 (<0 001)
Wake after sleep onset (WASO)	Mins	59 2 (30 9)	85 3 (40 5)	-13 2 (<0 001)
Sleep efficiency (SE)	%age	81 9 (10 0)	77 6 (8 7)	4 3 (<0 001)
Sleep onset latency (SOL)	Mins	22 6 (17 5)	22 8 (15 3)	-0 2 (0 829)
24 hour Total sleep time (24ST)	Mins	501 0 (74 7)	476 6 (78 4)	7 2 (<0 001)
Total daytime naptime (TNT)	Mins	78 4 (41 6)	75 2 (41 2)	5 7 (<0 001)

t = paired samples t statistic, p = significance value

Table 5.4 Comparison of medium and higher sleep/wake sensitivity thresholds for actigraphic baseline period sleep data from care recipients (n = 34).

		Medium Sensitivity	High Sensitivity	
Outcome measurement	**Units**	**Mean (SD)**	**Mean (SD)**	**t (p)**
Total nocturnal sleep time (TST)	Mins	453 9 (132 6)	422 1 (132 4)	7 8 (<0 001)
Wake after sleep onset (WASO)	Mins	60 8 (47 0)	81 6 (48 8)	-6 0 (<0 001)
Sleep efficiency (SE)	%age	82 3 (17 1)	76 0 (18 1)	7 8 (<0 001)
Sleep onset latency (SOL)	Mins	24 1 (29 9)	23 6 (30 2)	0 2 (0 868)
24 hour Total sleep time (24ST)	Mins	638 8 (185 7)	590 7 (186 4)	7 8 (<0 001)
Total daytime naptime (TNT)	Mins	191 8 (109 7)	176 3 (103 2)	5 1 (<0 001)

t = paired samples t statistic, p = significance value

Paired samples t-tests between these data revealed that highly significant differences between all these sleep outcome measurements (with the exception of sleep onset latency - SOL) were found between the medium and higher sensitivity cutoff thresholds. In light of Van Someren's (2003) suggestion of using higher

sensitivity thresholds for analysing data from dementia care recipients and from the highly significant differences found between these sensitivity thresholds, all future actigraphic sleep outcome data presented in this thesis will be data analysed using these higher sensitivity thresholds i.e. a level of sleep / wake detection at a cutoff threshold of 20 activity counts per-minute for both the care recipients and the caregivers who participated in this study.

5.4 THE STUDY SAMPLE

Altogether 34 care recipient-caregiver dyads, completed the baseline period of the study protocol, consistent with the minimum sample size requirements for 80% power detailed at the end of Chapter 4. Profiles of the caregivers and care recipients who participated in this study are presented in Table 5.5 and Table 5 6 respectively. This section will report the descriptive findings from these caregivers and their care recipients. The reported data were collected and analysed from the baseline period of the study only, where caregivers and care recipients were at-home together. These data provide a detailed examination of the state-of-affairs of sleep in these groups in a usual, at-home environment.

Table 5.5 Profiles of caregivers participating in the study

Variable	Mean (SD)	Range
Number of caregivers	36	-
Caregiver age	67.4 (12.5)	34 – 87
PSQI score	8.7 (3.8)	1 – 17
ESS score	6 1 (3.7)	0 – 15
SF 36 scores (100% scale)*		
Physical functioning	67.3 (24.1)	20 – 100
Role-physical functioning	72.2 (23 2)	20 – 100
Bodily pain	67.9 (26 8)	11 – 100
General health perceptions	62 5 (19.1)	25 – 97
Vitality	43.4 (13.6)	20 – 70
Social functioning	55.0 (31.9)	0 – 89
Role-emotional functioning	69 9 (26.2)	20 – 100
Mental health	58.7 (16.1)	20 – 88
Health change	38.5 (15.1)	0 – 75
Reported number of years caring	4 8 (3.5)	1 – 17
Number of respite episodes received	7.9 (9.3)	1 – 50
Number (%) of male caregivers	12 (33.3%)	-
Number of female caregivers	24 (66.6%)	-

* SF-36 questionnaires were successfully completed and returned by 37 caregivers

From Table 5.5, the 36 caregivers who agreed to participate in this study had a mean age of 67.4 years. Questionnaire information revealed that 77.5% of these caregivers had PSQI scores in the clinical range for disturbed sleep (i.e. greater than 5 (Buysee *et al* 1989)), their daytime sleepiness (ESS) levels were a mean of 6 1. The caregivers in this study had received a mean of 7.9 respite breaks from caring across a mean caregiving time of 4.8 years before entry into the study. Caregivers were predominantly female (n = 24; 66 6%), mostly looked after their spouses (n = 27; 75.0%) and were mostly providing care to older adults with Alzheimer's

disease (n = 25; 69.4%). The baseline characteristics of care recipients are presented in Table 5.6

Table 5.6 Profiles of care recipients receiving respite care.

Variable	Mean (SD)	Range
Number of care recipients	34	-
Care recipient age	76.2 (8.0)	49 – 93
Years since diagnosis	4.8 (3.5)	1 – 17
Number of respite episodes received	7.8 (9 3)	1 – 50
Number (%) of male care recipients	21 (61.8%)	-
Number (%) of female care recipients	13 (38.2%)	-
Number (%) of care recipients diagnosed with AD	23 (67 6%)	-
Number (%) of care recipients diagnosed with other dementias	11 (32 4%)	-

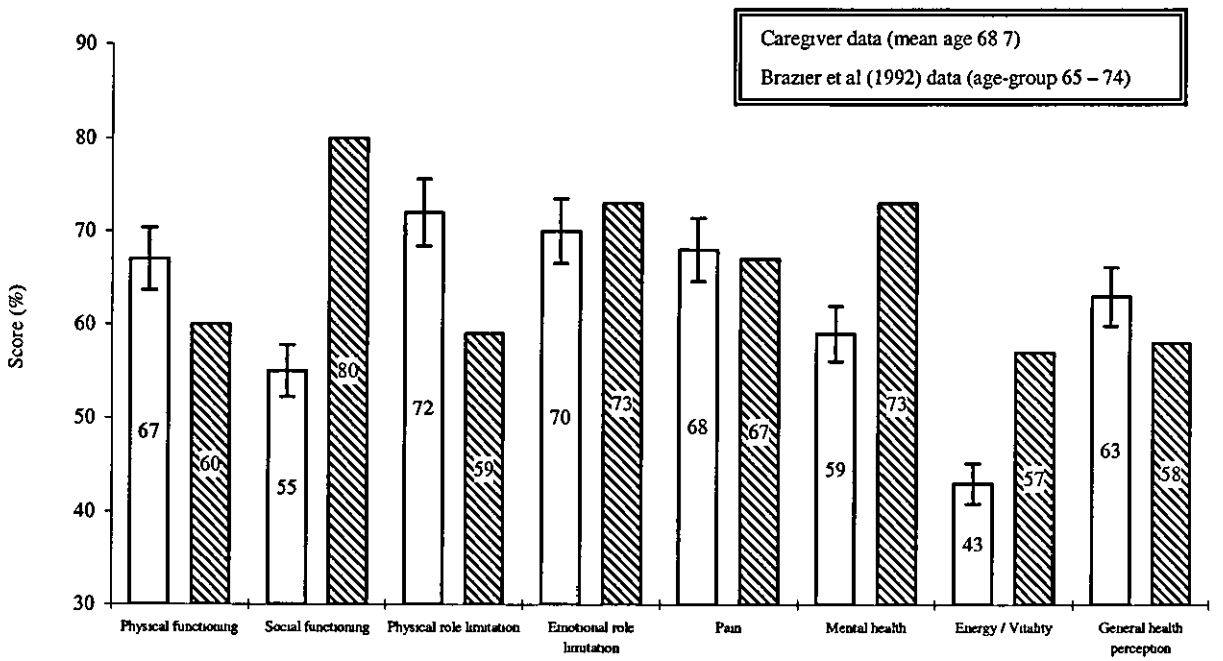
From Table 5 6, the 34 care recipients who participated in this study had a mean age of 76.2 years. The care recipients in this study had received a mean of 7 8 respite breaks in a hospital or a social service residential home across a mean time since diagnosis of 4 8 years before entry into the study. Care recipients were predominantly male (n = 21; 61.8%) and were mostly diagnosed with Alzheimer's disease (n = 23; 67.6%).

5.5 CAREGIVER HEALTH-RELATED QUALITY OF LIFE

This section will present the SF-36 data alongside normative population data for the over 65 year-old age group reported by Brazier and colleagues in 1992 (Figure 5.2). The SF-36 domains presented in Figure 5.2 indicate greater health-related quality of life with higher domain scores with the exception of physical role limitation; emotional role limitation and pain where higher scores indicate reduced health-related quality of life.

These data are presented graphically in Figure 5.2

Figure 5.2 Histogram showing caregiver SF-36 health-related quality of life scores alongside normative scores.



☐ Caregivers (n = 37) ☒ Normative sample (n = 103)

Error bars refer to standard deviations in the current sample

From Figure 5.2, the caregivers in this study expressed similar levels of pain, general health perception, emotional role limitation and levels of physical functioning as a normative non-caregiving group (Brazier *et al* 1992). However, energy / vitality, social functioning and mental health scores were much reduced in these caregivers compared with a non-caregiving group. The caregivers who participated in this study also reported more physical role limitations than a normative sample of older adults.

5.6 CAREGIVER AND CARE RECIPIENT BASELINE SLEEP AND CIRCADIAN RHYTHM OUTCOMES

Descriptive baseline actigraphic sleep and circadian rhythm data for caregivers and care recipients are presented in Table 5 8.

Table 5.8 Actigraphic baseline period sleep and circadian rhythm outcomes between caregivers (n = 36) and their care recipients (n = 34).

Outcome measurement	Units	Caregiver Mean (SD)	Care recipient Mean (SD)
Total nocturnal sleep time (TST)	Mins	398 2 (54 5)	419 5 (133 8)
Wake after sleep onset (WASO)	Mins	83 9 (39 1)	83 6 (50 5)
Sleep efficiency (SE)	%age	77 7 (9 0)	75 6 (18 2)
Sleep onset latency (SOL)	Mins	22 6 (15 6)	24 1 (30 2)
Lowest 5 hour activity (L5)	Index	855 8 (673 0)	850 6 (1147 7)
24 hour Total sleep time (24ST)	Mins	473 8 (79 4)	589 4 (188 0)
Total nap time (TNT)	Mins	73 3 (41 5)	175 9 (104 2)
Interdaily stability (IS)	Index	0 787 (0 065)	0 693 (0 095)
Intradaily Variability (IV)	Index	0 905 (0 230)	1 270 (0 397)
Relative Amplitude (RA)	Index	0 907 (0 071)	0 777 (0 173)

Description of caregiver and care recipient sleep outcome measurements revealed no notable differences between the two groups with the exception of 24-hour sleep time and total nap time. Care recipients slept for longer than their caregivers in average 24-hour periods by 116 minutes and napped for longer during the day by a mean of 103 minutes at baseline. Caregiver and care recipient circadian rhythm outcome measurements revealed differences in IS, IV and RA with these dementia care recipients displaying reduced circadian rhythmicity of sleep and wakefulness than was seen in their caregivers.

Subjectively reported caregiver data from the baseline period of the study are presented in Table 5 9

Table 5.9 Subjective descriptive sleep data from caregivers of care recipients (n=36).

Outcome measurement	Units	Mean	SD
Caregiver bedtime (range)	Time	(19.50 – 01.58)	
Caregiver sleep onset latency	Mins	37.7	32.6
Caregiver nocturnal wake-time	Mins	42.5	41.3
Morning caregiver wake time (range)	Time	(04:22 – 08·37)	
Morning caregiver get-up time (range)	Time	(05:30 – 08:53)	
Caregiver wellbeing score	Scale	2.28	0.65
Caregiver time in bed	Mins	512 8	55.9
Caregiver subjective sleep time	Mins	394.1	63.9
Caregiver subjective sleep efficiency	%	76.8	11.3
Care recipient bedtime (range)	Time	(18:17 – 00:14)	
Care recipient wake time (range)	Time	(05.43 – 08.28)	
% Caregivers who woke before care recipient	%	77 8	-
Number of disturbances by care recipient	No.	1.08	0.97
Duration of disturbances by care recipient	Mins	19.5	23.9

Sleep diary information revealed that these caregivers went to bed between 19:50 and 01:58, they described a mean sleep onset latency of 38 minutes and reported waking during the night (WASO) for a mean of 43 minutes. They reported waking between 04·22 and 08:37 and arising between 05.30 and 08·53. They described remaining in bed for a mean 513 minutes at baseline and reported sleeping for 394 minutes and described a subjective sleep efficiency of 76 8%. These caregivers assisted their care recipients into bed between 18:17 and 00.14 and reported hearing their care recipients awaking between 05:43 and 08:28 and 77 8% of these caregivers awoke before their care recipient. Caregivers reported being disturbed by their care recipients, on average, 1 08 times per-night at baseline and that the

total time of these disturbances amounted to 19 5 minutes per-night as a direct result of care recipient disturbance factors.

The possibility of differential effects of caregiving by sleeping arrangements was suggested in Chapter 3 of this thesis. The following Section (5.6.1) will present caregiver actigraphic and subjective data split by bedroom partnership (sharing and non-sharing caregivers). Care recipient data will be presented by bedroom partnership in Section 5.6.2. These data are presented in order to test the possible impact of bedroom partnership on the sleep and circadian rhythm outcomes of caregivers and care recipients.

5.6.1 Comparison between caregivers sharing bedrooms and those not sharing bedrooms with their care recipients

Comparison between actigraphic sleep and circadian rhythm data for caregivers sharing the same bedroom and those not sharing the same bedroom as their care recipients are presented in Table 5.10.

Table 5.10 Actigraphic baseline period sleep and circadian rhythm outcomes from caregivers sharing (n = 19; 52 8%) and not sharing (n = 17; 47.2%) a bedroom with a care recipient

Outcome measurement	Units	Sharing Mean (SD)	Not sharing Mean (SD)	Mean Difference	t (p)
Total nocturnal sleep time (TST)	Mins	410 4 (52 9)	386 2 (53 3)	24 2	1 4 (0 165)
Wake after sleep onset (WASO)	Mins	88.3 (43 5)	81 9 (37 9)	6 4	0 48 (0 633)
Sleep efficiency (SE)	%	77 5 (8 9)	76 8 (9 6)	0 78	0 26 (0 796)
Sleep onset latency (SOL)	Mins	21 3 (14 5)	26 7 (17 8)	-5 5	-1 0 (0 302)
Lowest 5 hour activity (L5)	Index	885 2 (709 1)	846.3 (623 5)	38 9	0 2 (0 859)
24 hour Total sleep time (24ST)	Mins	491 6 (58 9)	460 0 (94 7)	31 6	1 2 (0 233)
Total nap time (TNT)	Mins	76 4 (31 2)	73 8 (51 1)	2 5	0 2 (0 852)
Interdaily stability (IS)	Index	0 80 (0 04)	0 77 (0 09)	0 03	1 4 (0 176)
Intradaily Variability (IV)	Index	0 98 (0 21)	0 90 (0 26)	0 08	1 0 (0 314)
Relative Amplitude (RA)	Index	0 89 (0 09)	0 91 (0 07)	-0 02	-0 6 (0 536)

t = independent samples t statistic, p = significance value

From these independent samples t-tests there were no significant differences in any sleep or circadian rhythm outcome measurements for caregivers sharing bedrooms and those not sharing bedrooms with their care recipients. Caregiver subjective data from baseline, by bedroom sharers and non-sharers are presented in Table 5.11.

Table 5.11 Subjective descriptive sleep outcomes from caregivers sharing (n = 19; 52.8%) and not sharing (n = 17; 47.2%) a bedroom with a care recipient.

Outcome measurement	Units	Sharing Mean (SD)	Not Sharing Mean (SD)	Mean Diff	t (p)
Age	Years	73 5 (7 7)	60 4 (13 6)	13 2	3 8 (**<0.001**)
Pittsburgh sleep quality index (PSQI)	Index	8 6 (4 3)	8 7 (3 3)	-0 1	-0 1 (0 943)
Epworth sleepiness scale (ESS)	Index	5 5 (3 7)	6 6 (3 6)	-1 0	-0 9 (0 393)
Caregiver sleep onset latency	Mins	32 0 (33 5)	44 5 (29 4)	-12 4	-1 2 (0 226)
Caregiver nocturnal wake-time	Mins	48 0 (47 6)	36 4 (28 4)	11 6	1 0 (0 349)
Morning caregiver wellbeing	Index	2 21 (0 58)	2 26 (0 78)	-0 05	-0 2 (0 830)
Caregiver time in bed	Mins	524 4 (52 8)	501 2 (60 7)	23 2	1 2 (0 229)
Caregiver sleep time	Mins	399 3 (72 5)	388 9 (52 0)	10 4	0 5 (0 620)
Caregiver subjective sleep efficiency	%age	76 6 (12 7)	77 2 (9 1)	-0 6	-0 2 (0 880)
Number of care recipient disturbances	#	0 45 (0 36)	1 1	-0 6	-1 6 (0 143)
Duration of care recipient disturbances	Mins	17 3 (22 6)	21 4	-4 2	-0 4 (0 670)

t = independent samples t statistic, p = significance value

From these independent samples t-tests: there were no significant differences in any subjective outcome measurements for caregivers sharing bedrooms and those not sharing bedrooms with their care recipients with the exception of caregiver age. Those sharing bedrooms were significantly older than caregivers not sharing bedrooms with their care recipients by a mean of 13.2 years ($t = 3\ 8$; $p < 0.001$). There was a relationship effect influencing this latter result as those caregivers who were sharing a bedroom with their care recipients were all spousal caregivers (n =19; 52.7%), whereas the non-bedroom sharing caregivers were split by spouses (n =10, 27 7%) and adult child caregivers (n =7; 19.4%), thus reducing the age of those non-sharing caregivers.

Baseline sleep and circadian rhythm data from care recipients who were sharing bedrooms and those not sharing bedrooms with their caregivers are presented in the following section.

5.6.2 Comparison between care recipients who were sharing bedrooms and those who were not sharing bedrooms with their caregivers.

Table 5.12 Actigraphic baseline period sleep and circadian rhythm outcomes from care recipients sharing (n = 17; 50.0%) and not sharing (n = 17, 50.0%) a bedroom with a caregiver.

Outcome measurement	Units	Sharing Mean (SD)	Not Sharing Mean (SD)	Mean Difference	t (p)
Total nocturnal sleep time (TST)	Mins	453 6 (99 2)	390 6 (156 1)	62 9	1 4 (0 166)
Wake after sleep onset (WASO)	Mins	66 6 (29 5)	102 1 (59 0)	-35 5	-2 3 **(0.026)**
Sleep efficiency (SE)	%age	81.3 (9 9)	69 7 (22 2)	11 6	2 0 (0 061)
Sleep onset latency (SOL)	Mins	19 3 (20 4)	28 8 (37 4)	-4 3	-0 4 (0 677)
Lowest 5 hour activity (L5)	Index	631 2 (574 4)	1133 (1494)	-501 4	-1 3 (0 220)
24 hour Total sleep time (24ST)	Mins	633 6 (179 8)	542 7 (168 9)	90 8	1 6 (0 128)
Total nap time (TNT)	Mins	188 2 (125 8)	161 9 (68 8)	26 3	0 8 (0 453)
Interdaily stability (IS)	Index	0.70 (0 1)	0 68 (0 09)	0 03	0 8 (0 404)
Intradaily Variability (IV)	Index	1 25 (0 44)	1 29 (0 33)	-0 04	-0 3 (0 752)
Relative Amplitude (RA)	Index	0 79 (0 18)	0 77 (0 17)	0 01	0 2 (0 837)

t = independent samples t statistic, p = significance value

From these independent samples t-tests: there was significantly greater WASO for those care recipients who were not sharing bedrooms with their caregivers compared to those sleeping with their caregivers by a mean of 35 5 minutes (t = -2.3, p = 0 026) There were no other significant differences between any other sleep or circadian rhythm outcome measurements for the care recipients who participated in this study by bedroom partnership.

5.7 DYADIC INTERRELATIONSHIPS

The potential for care recipient sleep disturbance factors to impose on the sleep of their community-residing caregivers was reported in Chapter 2 and one of the aims of this research was to examine the impact of care recipient sleep and circadian

rhythm characteristics on those of their caregivers This section will present data from caregivers and care recipients in order to examine whether any dyadic interrelationships were present and what the resultant impact of these possible interrelating sleep and circadian rhythm patterns had on caregiver sleep.

Interrelationships between care recipient and caregiver actigraphic outcome measurements will be reported in the latter sections of this chapter after first describing the subjective reports from caregivers about their sleep and the habitual sleep patterns of their dependent care recipients.

5.7.1 Subjective sleep reports: interrelationships between caregivers and care recipients

As with the previous chapter, data presented are from the baseline period of the study protocol only, providing a detailed examination of the usual, state-of-affairs with regard to the sleep of community dwelling care recipients and their caregivers whilst they were at-home together. The routines of caregivers and care recipients in terms of bedtimes, wake-times and sleep disturbance factors are presented in Table 5.14.

Table 5.14 Calculated contrasts between subjective outcome measurements of care recipient and caregiver sleep times during baseline.

Subjective outcome measurement	Mean differences
Caregiver bedtime	40 mins after care recipient bedtime
Caregiver wake-time	39 mins before care recipient wake-time
Caregiver get up time	6 mins after care recipient wake-time

n = 36 caregivers subjective sleep diary reports

The caregivers who participated in this study described going to bed an average of 40 minutes after assisting their care recipient to bed, many described this time as

'their own' quiet time in the evening away from the caregiving role. Similarly, in the mornings caregivers reported waking around 39 minutes before their care recipients and described this again as their own time. Caregivers arose, on average, 6 minutes after their care recipient had awakened in the morning These findings indicate that caregivers did not arise until the awakening of their care recipient in some way prompted them to do so.

The following section reports on the level of correlation between care recipient and caregiver sleep organisation and characteristics of the 34 dyads that completed the baseline period of the study protocol.

5.8 ACTIGRAPHIC OUTCOME MEASUREMENT INTERRELATIONSHIPS BETWEEN CARE RECIPIENTS AND CAREGIVERS.

The dyadic interrelationships of sleep organisation and characteristics between care recipients and caregivers are presented in the following sections. Care recipient and caregiver actigraphic sleep and circadian rhythm outcome measurements were presented previously in Table 5.8 (page 102). Pearson's product moments correlations between these actigraphic sleep outcome measurements from these care recipients and caregivers will be presented in Table 5.15.

Table 5.15 Correlation between care recipients and caregivers actigraphic sleep and circadian rhythm outcome measurements at baseline.

Outcome measurements	Pearson's r	p
Total sleep time (TST)	0.47	**0.005**
Wake-time after sleep onset (WASO)	0 09	0 606
Sleep efficiency (SE)	0.14	0.417
Sleep onset latency (SOL)	-0 03	0.873
Lowest 5-hours of activity (L5)	0.11	0.561
24-hour sleep time (24ST)	0 31	0 086
Total nap time (TNT)	-0 04	0 821
Interdaily stability (IS)	0.12	0.540
Intradaily variability (IV)	0.51	**0.004**
Relative amplitude (RA)	0.26	0.160

r = Pearson's product moment correlation coefficient, p = significance value, n = 34 dyads

The correlation data presented in Table 5.15 shows mixed associations between care recipient and caregiver baseline circadian rhythm outcome measurements Care recipient and caregiver total sleep time correlated highly (r =0 47; p =0 005). Care recipient and caregiver circadian rhythm intradaily variability also showed significant correlation (r =0.51, p =0 004)

5.8.1 Interrelationships between dyads who were sharing bedrooms and those not sharing bedrooms.

These data are presented for all caregivers and care recipients, however, as with the previous chapter, the separation of dyads who were sharing the same sleeping environment from those sleeping in different bedrooms may indicate whether sleeping arrangements in dementia and dementia care have any impact on dyadic

sleep outcomes. The breakdown of sharing dyads and non-sharing dyads are presented in Table 5.16 and Table 5.17 respectively.

Table 5.16 Correlation between care recipients and caregivers sharing the same bedroom, actigraphic sleep and circadian rhythm outcome measurements at baseline.

Outcome measurements	Pearson's r	p
Total sleep time (TST)	0 57	**0.013**
Wake-time after sleep onset (WASO)	0.25	0 331
Sleep efficiency (SE)	0.58	**0.012**
Sleep onset latency (SOL)	0.33	0.217
Lowest 5-hours of activity (L5)	0.63	**0.008**
24-hour sleep time (24ST)	0 34	0 205
Total nap time (TNT)	-0.02	0.941
Interdaily stability (IS)	0 08	0 762
Intradaily variability (IV)	0 67	**0.004**
Relative amplitude (RA)	0.45	0.083

r = Pearson's product moment correlation coefficient, p = significance value, n = 17 dyads (50%)

For those dyads sharing the same bedroom; caregiver and care recipient total sleep time correlated highly (r = 0.57; p = 0.013) as did caregiver and care recipient sleep efficiency (r = 0 58; p = 0.012). Caregiver and care recipient nighttime activity levels also correlated highly (r = 0 63; p = 0 008) Caregiver and care recipient intradaily variabilities were also significantly correlated (r = 0 67; p = 0 004). There were no other significant correlations between any other caregiver and care recipient outcome measurements.

Table 5.17 Correlation between care recipients and caregivers not sharing bedrooms; actigraphic sleep and circadian rhythm outcome measurements at baseline.

Outcome measurements	Pearson's r	p
Total sleep time (TST)	0.369	0 145
Wake-time after sleep onset (WASO)	0.124	0.635
Sleep efficiency (SE)	-0.014	0.958
Sleep onset latency (SOL)	-0.184	0.494
Lowest 5-hours of activity (L5)	-0 155	0 567
24-hour sleep time (24ST)	0.217	0.437
Total nap time (TNT)	-0.147	0.600
Interdaily stability (IS)	0.112	0.680
Intradaily variability (IV)	0 362	0 169
Relative amplitude (RA)	-0 052	0 850

r = Pearson's product moment correlation coefficient, p = significance value, n = 17 dyads (50%)

There were no significant correlations between any sleep or circadian rhythm outcome measurements for those dyads that were not sharing the same bedrooms at baseline.

5.9 COMPARISON BETWEEN GOOD AND POORLY SLEEPING CAREGIVERS

Examination of those caregivers who reported that they slept comparatively well at baseline and those who described significant sleep disruption on their PSQI questionnaires at baseline is addressed in this section. A median split of PSQI scores, divided into good sleepers (PSQI score of 8 or less) and those who stated that they slept poorly at baseline (PSQI scores greater than 8) was conducted and independent paired samples t-tests on the actigraphic and questionnaire data were performed. Data from this comparison is presented in Table 5.18.

Table 5.18 Independent samples t-tests from a median split of good (PSQI <=8) and poorly (PSQI >8) sleeping caregivers at baseline.

		Good sleepers		Poor sleepers		
Outcome Measurement	**Units**	**Mean**	**SD**	**Mean**	**SD**	**t (p)**
ESS Score	Score	5 8	3 8	6.2	3.6	0.28 (0.778)
Total sleep time (TST)	Mins	403.3	54.9	394.9	53.7	0.49 (0.629)
Wake time after sleep onset (WASO)	Mins	67.9	28 3	102.6	44.1	2.89 (**0.006**)
Sleep onset latency (SOL)	Mins	20 6	15.1	26.9	16.8	1.22 (0 230)
Sleep efficiency (SE)	%	80 0	7 9	74.2	9.5	-2 10 (**0.042**)
Total nap time (TNT)	Mins	73.7	37.4	76 6	45 7	0.22 (0 830)
24 hour sleep time (24ST)	Mins	481.8	75.9	471.5	82.6	-0.40 (0.692)
Lowest 5 hours activity (L5)	Index	634 9	340 2	1098	818.1	2.28 (**0.029**)
Interdaily stability (IS)	Index	0.81	0 07	0.77	0 07	-1.54 (0.132)
Intradaily variability (IV)	Index	0.86	0.17	1 02	0.26	2 26 (**0.030**)
Energy (En)	Score	50 0	12 0	35.6	11.4	-0.38 (**0.001**)
Wellbeing (Well)	Index	2 4	0 7	2.1	0.6	-1 67 (0 101)

t= independent samples t statistic, p = significance value,
n = 18 (50 0%) good sleepers and 18 (50 0%) poor sleepers at baseline

The results from these independent paired-samples t-tests indicate that poorly sleeping caregivers experienced significantly increased (by around 30 minutes at baseline) WASO, significantly reduced (by approximately 6%) sleep efficiencies and significantly increased levels of nighttime activity (by over 400 activity counts during their least active consecutive 5 hours of activity) compared to those caregivers who rated their sleep as good. Furthermore, the poorly sleeping caregivers described increased intradaily variability of their activity patterning across the baseline period of the study and significantly reduced energy / vitality scores on their SF-36 questionnaire outcomes.

The question of how these caregivers' actigraphic and questionnaire outcomes correlated during the baseline period of the study was also addressed in order to examine the relationship between subjective questionnaire reports and actigraphic

sleep and circadian rhythm outcome measurements. These tests were performed to examine the relationship between objective measurement and subjective reporting of sleep in caregivers of older people with dementia. Correlation matrix data are presented in Table 5.19

Table 5.19 Correlations between baseline actigraphic and subjective questionnaire outcome measurements from caregivers.

	TST	WASO	SE	SOL	TNT	24ST	L5	IS	IV	En	Well
PSQI	-0 11 0 475	0 32 **0.026**	-0 16 0 164	0 08 0 308	-0 13 0 227	-0 14 0 207	0 23 0 078	-0 21 0 104	0 09 0 299	-0 41 **0 006**	-0 37 **0 010**
TST	-	-0 36 **0.014**	0 58 *	-0 26 0 058	0 38 **0 008**	0 88 *	-0 52 *	-0 13 0 213	-0 03 0 426	-0 02 0 463	-0 17 0 150
WASO		-	-0 93 *	0 56 *	-0 23 0 085	0 36 **0 014**	0 70 *	0 04 0 395	0 11 0 257	-0 18 0148	-0 22 0 091
SE			-	-0 72 *	0 36 **0.014**	0 55 *	-0 69 *	-0 17 0 160	0 02 0 464	0 13 0 228	0 12 0 239
SOL				-	0 33 **0.023**	-0 03 **0.037**	0 18 0 138	0 16 0 167	-0 35 **0 017**	-0 14 0 215	-0 14 0 201
TNT					-	0 79 *	-0 16 0 162	-0 26 0 059	0 28 **0.043**	-0 15 0 196	-0 11 0 245
24ST						-	-0 01 0 481	-0 23 0 087	0 13 0 223	-0 06 0 359	-0 14 0 212
L5							-	0 03 0 431	0 28 **0 042**	-0 03 0 436	-18 0 142
IS								-	-0 45 **0.002**	-0 12 0 250	-0 13 0 215
IV									-	-0 07 0 355	-0 02 0 453
En										-	0 41 **0 006**

PSQI = Pittsburgh Sleep Quality Index, TST = Total Sleep Time, WASO= Wake-time After Sleep Onset, SE = Sleep Efficiency, SOL = Sleep Onset Latency, TNT = Total daily Nap Time, 24ST = 24-hour Sleep Time, L5 = Lowest Five Consecutive Hours of Activity, IS = Interdaily Stability, IV = Intradaily Variability, En = Energy and vitality domain from the SF-36 questionnaire

n = 36 caregivers, numbers at 2 decimal places represent Pearson's r correlation coefficients and are presented above numbers at three decimal places that represent significance values Emboldened numbers represent significance at p<0 05 and * indicates p< 0 001

Caregiver PSQI scores correlated with objectively recorded WASO and subjectively examined wellbeing and energy / vitality scores from the sleep diary and SF-36 questionnaires respectively. Total sleep time correlated highly with all sleep outcome measurements (with the exception of SOL) and with nocturnal activity levels (L5) but not with other circadian rhythm or subjective outcomes. Wake time after sleep onset correlated highly with sleep efficiency; sleep onset latency; 24-hour sleep times; and nocturnal activity levels (L5). Sleep efficiencies correlated significantly with sleep onset latency; daily nap times and 24-hour sleep times as well as nocturnal activity levels (L5). Sleep onset latency correlated highly with total nap times, 24-hour sleep times and intradaily variability (IV) of caregiver circadian rhythmicity. Nap times and 24-hour sleep times and IV were also significantly correlated as were nocturnal activity levels (L5), IV and interdaily stabilities (IS). The subjectively reported energy/vitality and wellbeing scores also correlated highly.

5.10 Nocturnal wake times and activity levels in care recipients of caregivers describing their sleep as good and those describing poor sleep

Examination of nocturnal wake times and activity levels in care recipients of good and poorly sleeping caregivers was conducted in order to explore any relationship between these outcomes and sleep disruption in caregivers. Wake time after sleep onset (WASO) and nocturnal activity levels (L5) were significantly greater in those caregivers who rated their sleep as poor compared to those who described comparatively good sleep at baseline. Independent samples t-tests of those care recipients of 'good' sleeping caregivers and care recipients of those caregivers describing their sleep as poor on WASO and L5 outcomes are presented in Table 5.20.

Table 5.20 Independent samples t-tests from a median split of care recipients of good (PSQI <=8) and care recipients of poorly (PSQI >8) sleeping caregivers at baseline.

		Care recipients of Good sleepers		Care recipients of Poor sleepers		
Outcome Measurement	**Units**	**Mean**	**SD**	**Mean**	**SD**	**t (p)**
Wake time after sleep onset (WASO)	Mins	52.3	35.6	68 3	55.2	0 99 (0 330)
Nocturnal activity (L5)	Score	587.0	575.0	1121	1410	1.49 (0 146)

t = independent samples t statistic, p = significance value, n = 16 (47 1%) care recipients of good sleeping caregivers and 18 (52 9%) care recipients of poorly sleeping caregivers at baseline

There were no significant differences between care recipients of good and poorly sleeping caregivers on WASO or L5, although those care recipients of poorly sleeping caregivers were awake for approximately 16 minutes and were more active at night by more than 500 activity counts in their least active consecutive five hours of activity compared to those care recipients of caregivers who rated their sleep as good at baseline.

These findings conclude the data presentation from the baseline period of this study

5.11 SUMMARY OF DESCRIPTIVE AND INTERRELATING DYADIC OUTCOME MEASUREMENTS

This chapter has presented descriptive actigraphic, subjective and interrelating data from the dyads that participated in the baseline period of the study only. The following chapter (Chapter 6) will present data from the intervention and follow – up periods of the study for the caregivers who participated in the whole study protocol. Care recipient data for the whole study protocol in Chapter 7. Chapter 8 will then discuss the findings from this Chapter and from Chapters 6 and 7

CHAPTER SIX

Intervention Results

The impact of respite care on dementia caregivers

6.1 INTRODUCTION

The analyses presented in this chapter will comprise repeated measures multivariate analysis of variance (MANOVA) comparing the baseline, respite and follow – up periods of the study in order to examine any impact of respite care on dementia caregivers. Analyses will be split by sleeping arrangements (caregivers sharing and those not sharing bedrooms with their care recipients) as presented in the previous chapter Analyses will be conducted using multivariate ANOVAs between the three study periods for each outcome measurement (except caregiver wellbeing scores) with sleeping arrangements (sharing or not sharing bedrooms with care recipients) included in the models as a between-subjects factor. Models will therefore be repeated measures, within-subjects analyses with interactions between outcome measurements and sleeping arrangements included. Initial presentation of these data will include whole-group mean data for each period of the study and standard deviation information.

The principal effects of the respite care intervention on these whole-group sleep and circadian rhythm outcomes will be presented before data from bedroom sharers and non-sharers. These are presented to explore any interactions between caregiver sleep and circadian rhythm outcome measurements and their sleeping arrangements Caregiver wellbeing scores will be examined following these multivariate analyses of the sleep and circadian rhythm data. These wellbeing analyses will comprise Freidman Ranks tests for non-parametric data.

The following chapter (Chapter 7) will present data from the care recipients who participated in the whole study protocol in a similar fashion to the caregiver data presented herein.

6.2 COMPARISON BETWEEN THE BASELINE, RESPITE AND FOLLOW – UP PERIODS FOR CAREGIVERS

The impact of the respite care intervention on caregivers between the baseline, respite and follow – up periods of the study are presented in Table 6.1. These analyses comprise 15 separate multivariate ANOVA models controlling for caregivers sharing bedrooms and those not sharing bedrooms with their care recipients for the 15 separate outcome measurements described in previous chapters A significant change in outcomes during the respite period of the study compared to the baseline and follow – up periods of the study will be considered where $p < 0.05$.

Table 6 1 will present group mean scores and examine the principal effects of the respite care intervention for all outcome measurements from caregivers. Table 6 2 will examine the interactions between bedroom sharing and non-sharing caregivers on their actigraphic sleep and circadian rhythm outcome measurements. Table 6.3 will present data split by bedroom sharers and non-sharers for caregiver subjectively reported sleep outcome data Caregiver wellbeing analyses will be presented in Section 6.3 in Tables 6 4 and 6.5.

Table 6.1 The principal effects from multivariate ANOVAs of caregiver actigraphic sleep, circadian rhythm and subjective sleep outcomes resulting from the respite care intervention*.

Outcome measurement	Units	n	Baseline mean (SD)	Respite mean (SD)	Follow-Up mean (SD)	F (df)	p
Actigraphic TST	Mins	33	403 0 (48 8)	413 0 (50 9)	392 2 (54 4)	7 11 (2,62)	**0.002**
Actigraphic WASO	Mins	32	83 4 (38 9)	79 9 (32 6)	83 4 (37.1)	0 77 (2,60)	0 468
Actigraphic SE	%	33	78.5 (8 4)	78 2 (7 7)	75.7 (9 0)	4.73 (2,62)	**0.012**
Actigraphic SOL	Mins	28	23.2 (14 8)	22 8 (16 8)	25 6 (20 1)	0 73 (52,2)	0 488
Actigraphic L5	Index	32	828 8 (530 1)	642 4 (334 3)	826 3 (478.3)	8 06 (2,60)	**0.001**
Actigraphic 24-hr TST	Mins	32	471 2 (71 8)	474 3 (67 1)	460 8 (71 6)	2 30 (2,60)	0 109
Actigraphic TNT	Mins	33	72 5 (41 6)	66 1 (29.1)	73 0 (34 2)	1 60 (2,62)	0 210
Actigraphic IS	Index	32	0 79 (0 06)	0 77 (0 06)	0 76 (0 08)	3 84 (2,60)	**0.027**
Actigraphic IV	Index	32	0 95 (0 24)	0 93 (0 25)	0 94 (0 23)	0 32 (2,60)	0 728
Actigraphic RA	Index	32	0 90 (0 07)	0 91 (0 07)	0 90 (0 08)	2 24 (2,60)	0 115
Subjective TST	Mins	26	397 3 (56 9)	413 4 (70 8)	399 5 (61.8)	1 44 (2,48)	0 246
Subjective TIB	Mins	32	516 0 (60 3)	525 1 (50 3)	518 6 (50.5)	1.50 (2,60)	0 232
Subjective WASO	Mins	32	45 0 (42 6)	34 4 (35.3)	50 3 (51 1)	3 15 (2,60)	**0.050**
Subjective SE	%	25	77 3 (9 2)	78 6 (11 9)	77 4 (11 0)	0 50 (2,46)	0 608
Subjective SOL	Mins	33	39 4 (33 8)	34 1 (25 8)	33 1 (24 3)	1 41 (2,62)	0 253

TST= Total Sleep Time, WASO = Wake time After Sleep Onset, SE = Sleep Efficiency, SOL = Sleep Onset Latency, L5 = Lowest five hours of activity score, IS = Interdaily Stability, IV = Intradaily Variability, RA = Relative Amplitude

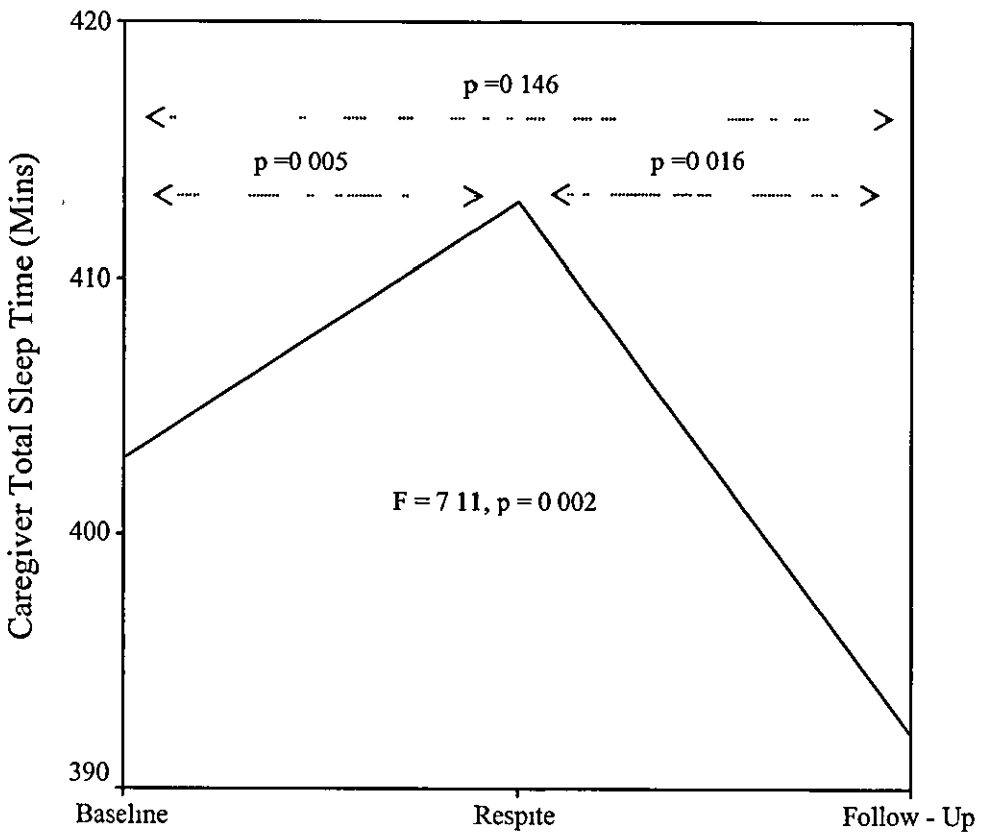
* Analyses comprised 15 MANOVAs for each outcome measurement controlling for sleeping arrangements (caregivers sharing and those not sharing bedrooms with their care recipients) Group means, standard deviations, F ratios and significance estimations are presented here Interactions between outcomes and sleeping arrangements are presented in Tables 6 2 and 6 3

6.2.1 Significant findings for caregivers from the respite care intervention

Analysis of caregiver sleep and circadian rhythm outcome measurements between the baseline, respite and follow – up periods of the study revealed that:

Caregivers' total sleep time, as examined actigraphically, was significantly increased over baseline levels during respite, but reduced significantly at follow – up ($F(2, 62) = 7.11$; $p = 0.002$). These data are described graphically in Figure 6.1.

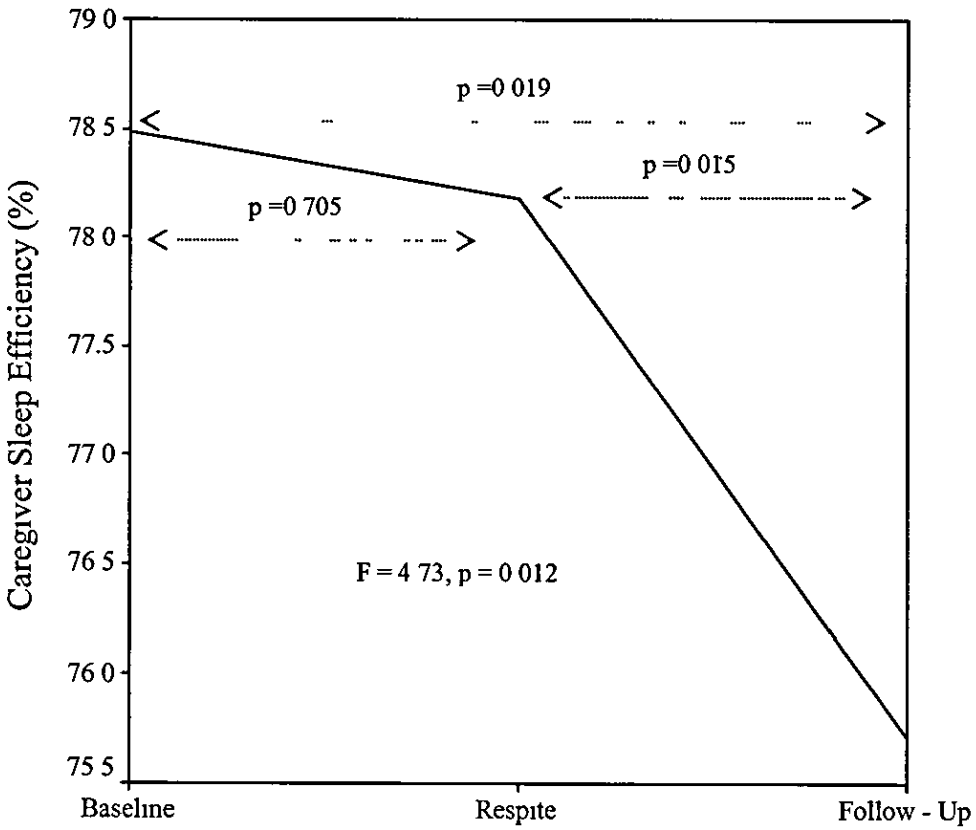
Figure 6.1 Caregiver total sleep time across the three study periods



Arrows <---------> on graphs with accompanying p values show contrast ANOVAs between conditions i e baseline and respite; respite and follow- up; and baseline and follow - up

Actigraphic caregiver sleep efficiencies were significantly increased in the baseline and respite periods compared to the follow – up period (F (2, 62) =4.73; p =0.012). These data are described graphically in Figure 6.2.

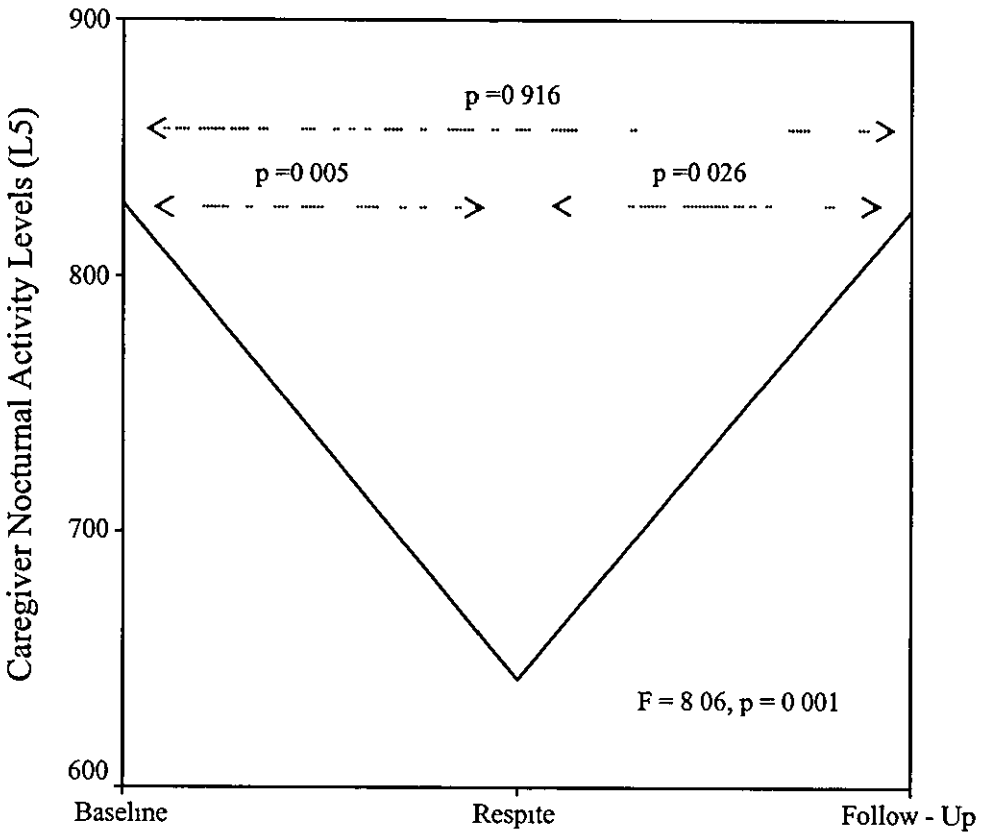
Figure 6.2 Caregiver sleep efficiency across the three study periods.



Arrows <----------> on graphs with accompanying p values show contrast ANOVAs between conditions i e baseline and respite, respite and follow- up, and baseline and follow - up

Caregiver nocturnal activity levels (L5) were significantly reduced during periods of respite care compared to baseline and follow – up levels (F (2, 60) =8.06; p =0.001). These data are presented graphically in Figure 6.3.

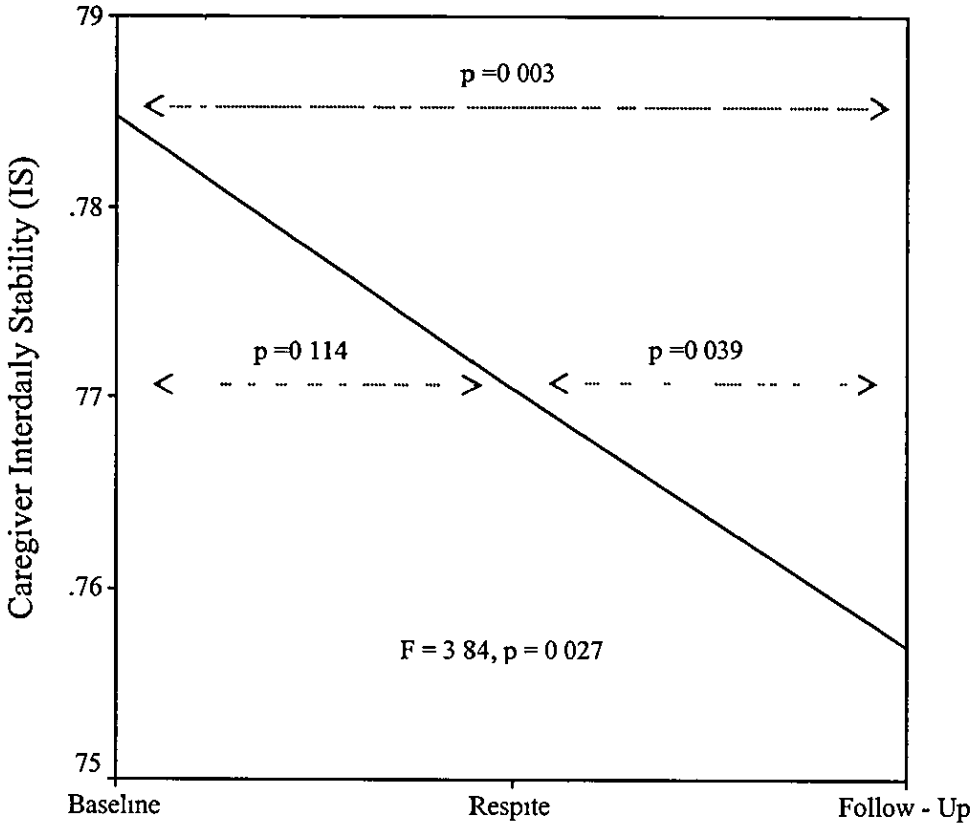
Figure 6.3 Caregiver nocturnal activity levels across the three study periods



Arrows <- > on graphs with accompanying p values show contrast ANOVAs between conditions i e baseline and respite, respite and follow- up, and baseline and follow - up

Caregiver interdaily stability was significantly reduced in follow – up compared to baseline and respite levels (F (2, 60) =3.84, p =0.027). These data are presented graphically in Figure 6.4

Figure 6.4 Caregiver interdaily stability across the three study periods

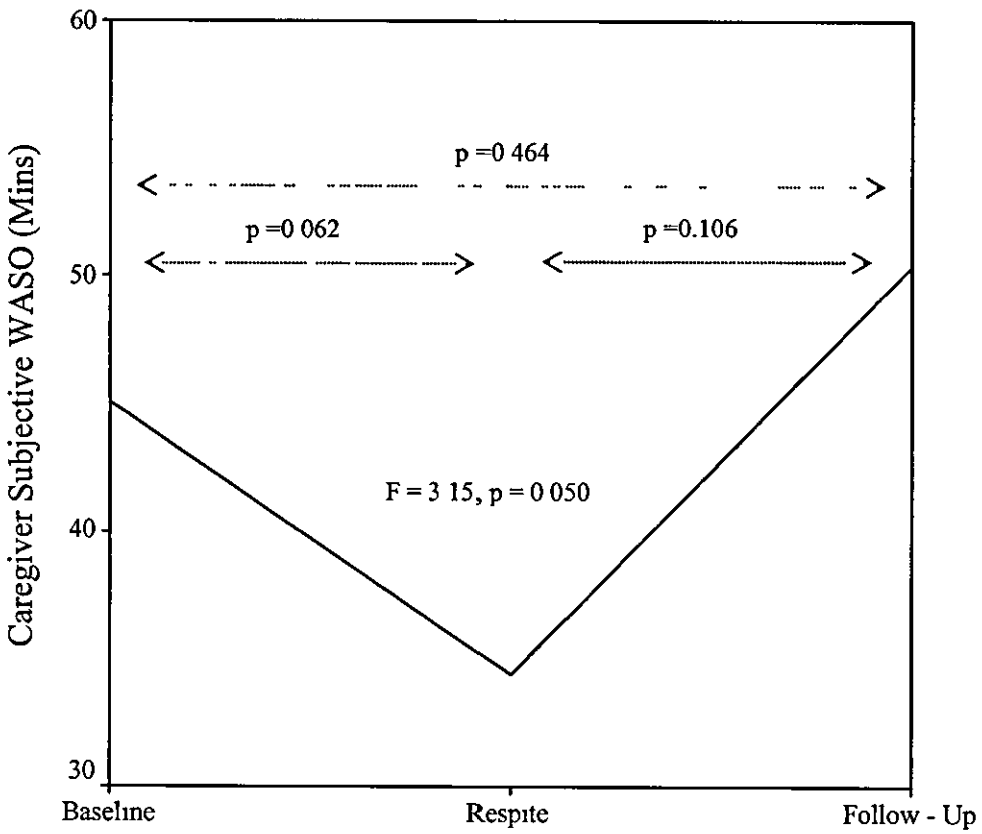


Arrows < > on graphs with accompanying p values show contrast ANOVAs between conditions i e baseline and respite; respite and follow- up, and baseline and follow - up

6.2.2 Speculative findings for caregivers from the respite care intervention

Caregiver subjectively rated wake-time after sleep onset (WASO) was reduced during respite care compared to baseline and follow – up levels (F (2, 60) =3.15; p =0 050) These data are presented graphically in Figure 6 5.

Figure 6.5 Caregiver subjectively rated wake time after sleep onset across the three study periods.



Arrows <----------> on graphs with accompanying p values show contrast ANOVAs between conditions i e baseline and respite, respite and follow- up, and baseline and follow - up

There were no other significant main effects on caregiver sleep, circadian rhythm or subjective outcome measurements between the baseline and respite periods of the study.

6.3 TESTING FOR INTERACTIONS WITH CAREGIVER SLEEPING ARRANGEMENTS

Caregiver data from analyses split by those sharing bedrooms with and those sleeping separately from their care recipients are presented in Table 6.2 (actigraphic) and Table 6 3 (subjective)

Table 6.2 Caregiver multivariate ANOVAs actigraphic outcomes controlling for bedroom partnership, tests for interactions between outcomes and sharing and non-sharing caregivers (n=15, 41.7%, n = 17, 47 2%; n = 18, 50% of the sample)

Outcome measurement	Units	N	Baseline mean (SD)	Respite mean (SD)	Follow-Up mean (SD)	* bed partner F (df)	p
TST (sharers)	Mins	18	421 2 (45 4)	421 6 (46 0)	404 0 (55 7)		
TST (separate sleepers)	Mins	15	381 1 (44 9)	402 6 (56 2)	377 9 (50 9)	1 84 (2,62)	0.168
WASO (sharers)	Mins	17	85 6 (39 0)	80 7 (26 5)	88 0 (32 3)		
WASO (separate)	Mins	15	81 0 (39 9)	79 0 (39.3)	78 1 (42 3)	0 90 (2,60)	0 414
SE (sharers)	%	18	79 6 (7 1)	79 2 (5 8)	76 4 (8 0)		
SE (separate sleepers)	%	15	77 1 (9 7)	77 0 (9.7)	74 9 (10 3)	0 14 (2,62)	0 870
SOL (sharers)	Mins	15	22 4 (11 9)	22.5 (14 3)	23 2 (13 2)		
SOL (separate sleepers)	Mins	13	24 1 (18 0)	23 0 (19 8)	28 3 (27 7)	0 41 (2,52)	0 667
L5 (sharers)	Index	17	773 7 (404 2)	670 1 (351 6)	820 0 (428 8)		
L5 (separate sleepers)	Index	15	891 1 (653 8)	611 1 (322 8)	833 6 (544 4)	1.33 (2,60)	0 272
24 hour TST (sharers)	Mins	17	489 3 (49 5)	483 6 (49 1)	474 8 (54 0)		
24 hour TST (separates)	Mins	15	450 7 (88 2)	463.7 (83 6)	444 9 (86 6)	0 98 (2,60)	0 380
TNT (sharers)	Mins	18	74 9 (31 1)	70 2 (23 1)	78 0 (22 1)		
TNT (separate sleepers)	Mins	15	69 6 (52 5)	61 1 (35 3)	67 0 (44 8)	0 22 (2,62)	0 801
IS (sharers)	Index	17	0 80 (0 04)	0 79 (0 05)	0 76 (0 07)		
IS (separate sleepers)	Index	15	0 77 (0 08)	0 75 (0 07)	0 75 (0 09)	0 55 (2,60)	0 578
IV (sharers)	Index	17	0 96 (0 22)	0 95 (0 18)	1 00 (0 19)		
IV (separate sleepers)	Index	15	0 93 (0 27)	0 90 (0 31)	0 88 (0 26)	1 41 (2,60)	0 252
RA (sharers)	Index	17	0 90 (0 07)	0 91 (0 07)	0 90 (0 08)		
RA (separate sleepers)	Index	15	0.90 (0 07)	0 92 (0 07)	0 90 (0 08)	0 39 (2,60)	0 682

* Denotes "interaction with", TST= Total Sleep Time, WASO = Wake time After Sleep Onset, SE = Sleep Efficiency, SOL = Sleep Onset Latency, L5 = Lowest five hours of activity score, IS = Interdaily Stability, IV = Intradaily Variability, RA = Relative Amplitude

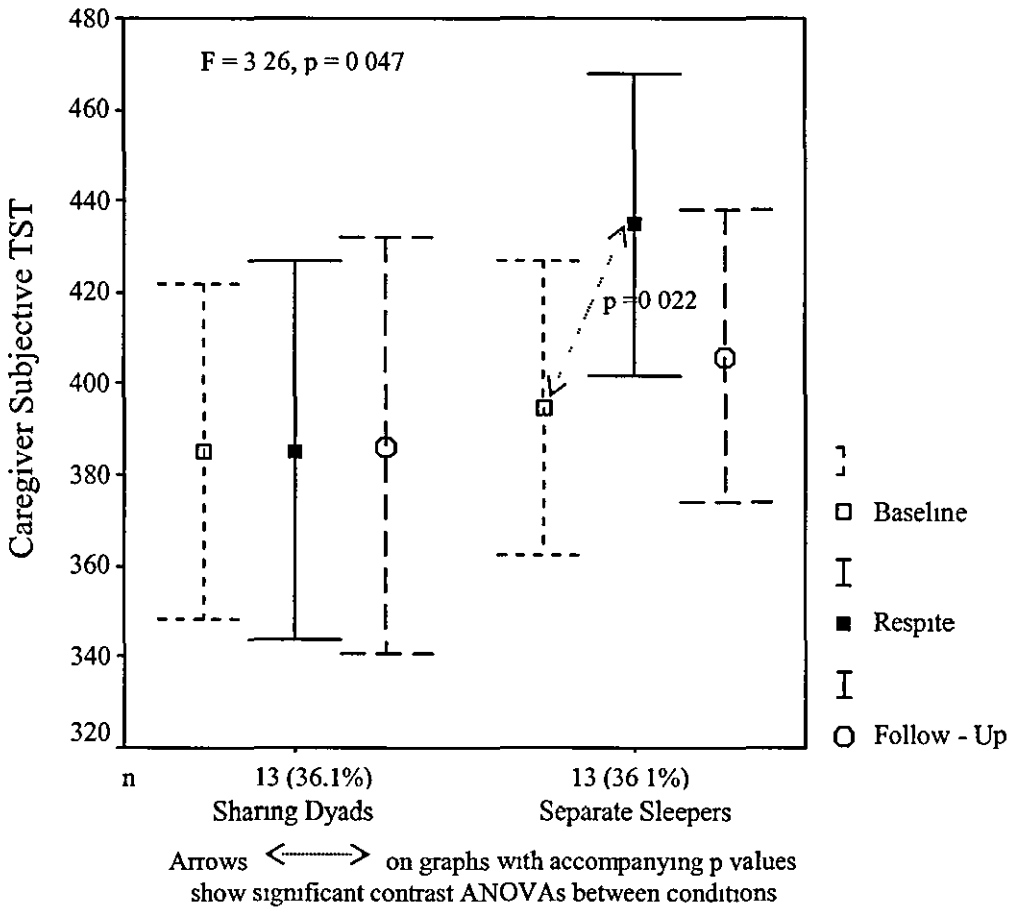
Table 6.3 Caregiver Multivariate ANOVAs of subjective outcomes controlling for bedroom partnership, tests for interactions between outcomes and sharing and non-sharing caregivers (n=12, 33 3%; n=13, 36.1%, n=14, 38 9%, n=15, 41.7%, n=17, 47 2%; n=18, 50% of the sample)

Outcome measurement	Units	N	Baseline mean (SD)	Respite mean (SD)	Follow-Up mean (SD)	* bed partner F (df)	p
TST (sharers)	Mins	13	404 2 (59.7)	394 1 (78 5)	394 1 (67 7)		
TST (separate sleepers)	Mins	13	390 3 (55 4)	432 9 (59 0)	404 9 (57 5)	3 26 (2,48)	**0.047**
TIB (sharers)	Mins	18	529 8 (54 8)	528 8 (41 6)	528 1 (45 0)		
TIB (separate sleepers)	Mins	14	498 2 (64 3)	520 4 (61 0)	506 4 (56 1)	1 73 (2,60)	0 186
WASO (sharers)	Mins	17	53 1 (50 9)	45 2 (41 7)	64 6 (58 9)		
WASO (separate sleepers)	Mins	15	35 8 (29 7)	22 1 (21 6)	34 1 (35 8)	0 53 (2,60)	0 590
SE (sharers)	%	13	76 9 (8 8)	74 9 (14 2)	75 5 (79 5)		
SE (separate sleepers)	%	12	77 7 (10.0)	82 6 (7 4)	79 5 (10 8)	2 37 (2,46)	0 105
SOL (sharers)	Mins	18	35 87 (36 2)	29 8 (27 1)	31 6 (27 4)		
SOL (separate sleepers)	Mins	15	43 7 (31 4)	39 3 (23.9)	34 9 (20 7)	0 31 (2,62)	0 738

* Denotes "interaction with", TST= Total Sleep Time, TIB = Time in Bed, WASO = Wake time After Sleep Onset, SE = Sleep efficiency, SOL = Sleep Onset Latency

There were no significant actigraphic interactions between caregivers sharing and those who slept separately from their care recipients. However, there was a significant interaction between caregivers sharing the same bedroom and those sleeping separately from their care recipients for caregiver subjective TST. Separately sleeping caregivers felt that they slept for significantly longer during respite care than caregivers who were sharers who described sleeping for less time during the respite and follow – up periods than they did at baseline ($F(2, 48) = 3.26$; $p = 0.047$). These data are presented graphically in Figure 6.6.

Figure 6.6 Interactions between caregiver subjective TST for caregivers sharing bedrooms with and those sleeping separately from their care recipients.



There were no other significant interactions between sleeping arrangements and any other actigraphic or subjective outcome measurements for these caregivers

6.4 CAREGIVER WELLBEING SCORES

Caregiver wellbeing scores across the study protocol were examined using the non-parametric Friedman test for three related samples of ordinal data. The caregiver wellbeing scores and this Friedman comparison are presented in Tables 6.4 and 6.5 respectively.

Table 6.4 Caregiver morning wellbeing mean scores across the study protocol

	n (%)	Baseline Mean (SD)	Respite Mean (SD)	Follow – up Mean (SD)
Wellbeing	31 (86.1%)	2.24 (0.69)	2 62 (0.69)	2.40 (0.69)

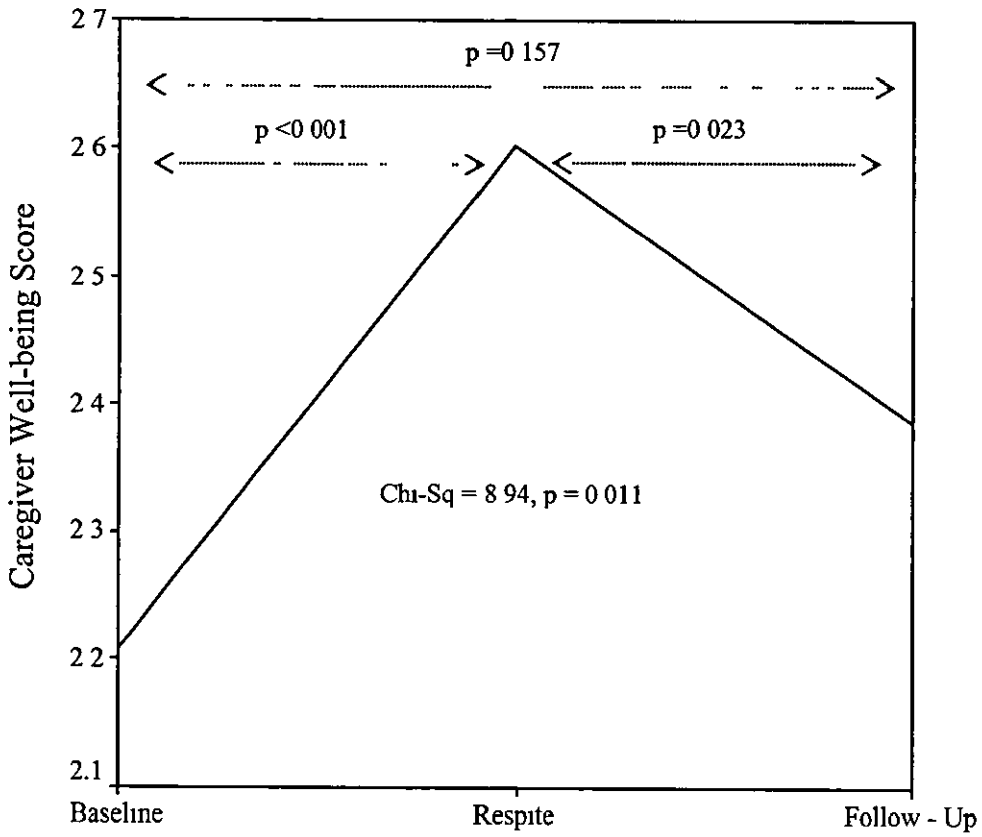
Higher scores indicate increased wellbeing

Table 6.5 Friedman's Chi-Square test on these wellbeing data

	n (%)	Baseline Rank	Respite Rank	Follow – up Rank	Chi-Square (df)	p
Wellbeing	31 (86.1%)	1.68	2.39	1.94	8.94 (2)	**0.011**

Caregiver subjectively rated feelings of morning wellbeing were significantly improved during respite compared to baseline and follow – up period levels. Of the 31 (86 1% of the number of caregivers at baseline) caregivers who provided wellbeing data for both the baseline, respite and follow – up periods Friedman ranks test for repeated measures on ordinal data for these data resulted in a significant increase in feelings of morning wellbeing in these caregivers during respite compared to the baseline and follow - up periods of the study (Chi-Square =8 94; p =0.011). These data are presented graphically in Figure 6.7.

Figure 6.7 Caregiver wellbeing scores across the three study periods n=31 (81.6%)



Arrows <-- --> on graphs with accompanying p values show Friedman's Chi-Square tests between conditions i e baseline and respite, respite and follow- up; and baseline and follow - up
Higher scores indicate increased feelings of wellbeing

6.5 QUALITATIVE DATA FROM CAREGIVERS

The following section will describe two single-case studies with qualitative responses from two of the caregivers who participated in this study.

6.5.1 Two single case studies from caregivers

Case 1

Case number 2, Mrs. F. (aged 52) was caring for her mother Mrs. B. (aged 73) who had dementia of the Alzheimer type. They slept in separate rooms and Mrs. F had been looking after her mother for 4.5 years since her mother's diagnosis. Mrs. F. had been receiving respite care for 3 years, having had respite care provided on 18 separate occasions. Mrs. F. had a PSQI score of 7 and energy/vitality scores on the SF 36 of 60% (12% less than average for her age). In the baseline period of the study Mrs. F slept for an average of 5 hours and 41 minutes per night, had a sleep efficiency (SE) of 79%, a sleep onset latency (SOL) of 20 minutes and a wake-time after sleep onset (WASO) of 66 minutes. She complained that her mother, Mrs. B. woke her 0.21 times per night during this baseline period. Mrs. F had a nocturnal activity level (L5) of 540 activity counts during her least active five hour period.

During respite Mrs. F. experienced an increase of 35.1 minutes total sleep time (TST), a reduction of 6 minutes WASO, an increase of 8 minutes SOL and a decrease of 3.3% in her sleep efficiency. Mrs F experienced a 312 point drop in her L5 levels during respite care.

After respite Mrs. F experienced decreased TST, by 17 minutes, increased SOL and WASO by 32 and 5 minutes respectively and an increased SE by 1%. Mrs F experienced an increase in her L5 of 379 activity counts after respite care.

Mrs. F described feelings of fatigue associated with providing care for her mother. She complained of feeling anxious about her mother's condition and about service provision that led to her sleep disturbances (a problem with getting to sleep) and physical disturbances to her sleep as a result of her mother's nighttime behaviours. Mrs. F described feeling much better during the respite care intervention, stating that she felt rested and that she had experienced longer sleep periods than when she was providing care at home. Post-discharge, Mrs. F again complained about sleep disturbances and feeling more active again

at night (similar to her baseline sleep profile). She voiced concerns about her mother going into respite care as she often described her mother as returning home more agitated than she normally was. Mrs. F also stated that she felt that, if it were not for the respite care intervention that she and her mother were receiving then she would have ceased providing care to her mother some years prior to the study.

Case 2

Case number 35, Mrs. T. (aged 78) was caring for her husband Mr. T. (aged 87) who had dementia of the Alzheimer type. They slept in separate bedrooms and Mrs. T had been looking after her husband for 2 years since his diagnosis. Mrs T. had been receiving respite care for 1 year, having had respite care provided on 4 separate occasions Mrs. T. had a PSQI score of 14 and energy/vitality scores on the SF 36 of 20%. In the baseline period of the study Mrs. T slept for an average of 7 hours and 29 minutes per-night, had a sleep efficiency (SE) of 76.9%, a sleep onset latency (SOL) of 37 minutes and a wake-time after sleep onset (WASO) of 63 minutes. She complained that her Husband, Mr. T. woke her 0.93 times per night during this baseline period Mrs. T had a nocturnal activity level (L5) of 459 activity counts during her least active five hour period. During respite care Mrs. T. experienced an increase of 22.6 minutes total sleep time (TST), a reduction of 6 minutes WASO, a reduction of 20 3 minutes SOL and an increase of 2.1% in her sleep efficiency. Mrs. T. experienced a drop of 102 activity counts in her L5 score during respite care. After respite care Mrs T experienced decreased TST, by 25.6 minutes, decreased SOL by 1 minute, increased WASO by 1 minute and a reduced SE by 0.3%. Mrs. T experienced an increase in her L5 score of 223 activity counts after respite care.

Mrs. T described feelings of guilt about accepting a respite care placement for her dependent husband with dementia. She stated that she felt that she had failed her husband about accepting respite care provision and that she felt that she should be able to look after him without resorting to temporary institutional care placements for her husband. However, Mrs. T also stated that her district nurse had explained to her that the service was provided for her to get a rest so

as to enable her to continue providing care for her husband for longer. The district nurse is purported to have emphasized the importance of preserving Mrs. T's health, by providing her with a rest, so that she could indeed provide care for longer for her husband. Mrs. T. stated that she was aware of the reasoning behind this argument and was slowly beginning to accept respite care and to treat it as a service for her to get the chance to rest. Mrs. T also complained that she was unsure of the benefits of this service for her husband, as she felt that he returned home more confused and sleep disturbed than when he entered the hospital. This resulted in large increases in her own nighttime activity levels at follow-up, which she described as problematic.

6.6 SUMMARY OF CAREGIVER DATA PRESENTATION

This chapter has presented the results from the baseline, respite care intervention and follow – up periods of the study protocol previously described. The following chapter will present the results for the dementia care recipients who participated in this study in a similar fashion to those caregiver data just described. Chapter 8 with then discuss the results from Chapters 5, 6 and 7, before drawing together the conclusions from this study.

CHAPTER SEVEN

Intervention Results

The impact of respite care on dementia care recipients

7.1 INTRODUCTION

The previous chapter presented dementia caregiver data, examining the principal effects of the respite care intervention on the actigraphic sleep and circadian rhythm outcomes of a group of dementia caregivers and their subjective reports of their sleep during this study Analyses conducted were multivariate analyses of variance (MANOVAs) which controlled for sleeping arrangements (sharing or not sharing a bedroom with a care recipient) as a between-subjects factor. Data were presented in grouped, two-weekly bins.

This chapter will present data from the care recipients who participated in this study. Similarly to the previous chapter, care recipient data will be presented in grouped, two-weekly bins. Interactions between care recipient outcome measurements and their sleeping arrangements (sharing or not sharing a bedroom with a caregiver) will also be presented.

7.2 PRINCIPAL EFFECTS OF RESPITE CARE ON THE SLEEP OF DEMENTIA CARE RECIPIENTS.

This section will present data analyses from care recipients in the same format as just presented for the caregivers in this study. The impact of the respite care intervention on the sleep and circadian rhythms of care recipients are presented in Table 7.1.

Table 7.1 The principal effects from Multivariate ANOVAs of care recipient actigraphic sleep and circadian rhythm outcomes resulting from the respite care intervention*(n=26, 76 5%, n=27, 79 4%, n=28, 82 4%, n=31,91 2%; n=32, 94 1% of sample)

Outcome measurement	Units	n	Baseline mean (SD)	Respite mean (SD)	Follow-Up mean (SD)	F (df)	p
Actigraphic TST	Mins	28	423 9 (137 8)	401 9 (106 8)	440 6 (133 4)	4 46 (2,52)	**0 016**
Actigraphic WASO	Min	28	80 6 (50.7)	86 5 (62 8)	79 2 (57 4)	0 95 (2,52)	0 394
Actigraphic SE	%	28	75 9 (19 1)	74 3 (18 0)	78 2 (17 2)	2 32 (2,52)	0 108
Actigraphic SOL	Mins	27	26 6 (32 6)	36 4 (30 3)	30 6 (36 3)	0 92 (2,50)	0 407
Actigraphic L5	Index	28	813 8 (1186 8)	1150 2 (1555 9)	886 9 (1917 5)	2 18 (2,52)	0 123
Actigraphic 24-hr TST	Mins	32	587 8 (186 2)	554 4 (192 3)	596 2 (181 8)	3 90 (2,52)	**0.027**
Actigraphic TNT	Mins	26	171 3 (101 6)	152 9 (117.7)	178 7 (110 8)	2 70 (2,48)	0 077
Actigraphic IS	Index	31	0 69 (0 09)	0 69 (0 09)	0.71 (0 08)	0 27 (2,52)	0 768
Actigraphic IV	Index	31	1 27 (0 39)	1 31 (0 34)	1 22 (0 43)	1 23 (2,52)	0 325
Actigraphic RA	Index	31	0 80 (0 16)	0 76 (0 17)	0 83 (0 14)	9 14 (2,52)	**0.001**

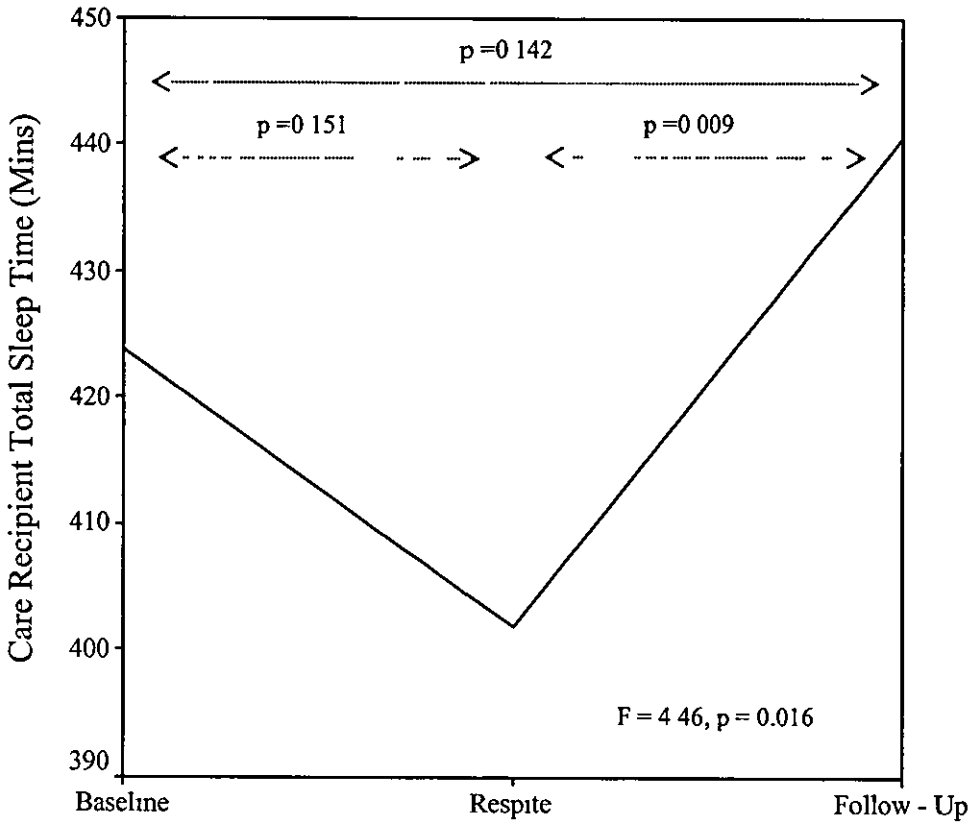
*Analyses comprised 10 MANOVAs for each outcome measurement controlling for sleeping arrangements (care recipients sharing and those not sharing bedrooms with their caregivers) Group means, standard deviations, F ratios and significance estimates are presented here Interactions between outcomes and sleeping arrangements are presented in Table 7 2

TST= Total Sleep Time; WASO = Wake time After Sleep Onset, SE = Sleep Efficiency, SOL = Sleep Onset Latency, L5 = Lowest five hours of activity score, IS = Interdaily Stability, IV = Intradaily Variability, RA = Relative Amplitude

7.2.1 Significant findings for care recipients from the respite care intervention

The care recipients who participated in the baseline, respite and follow – up periods of the study experienced significantly reduced total nocturnal sleep times during respite compared with follow – up levels. Total nocturnal sleep times in these dementia care recipients reduced by approximately 24 minutes in respite (against baseline, although non-significantly) compared with around a 40 minute increase in TST post-discharge (F (2, 52) =4.46; p =0.016). These data are presented graphically in Figure 7 1.

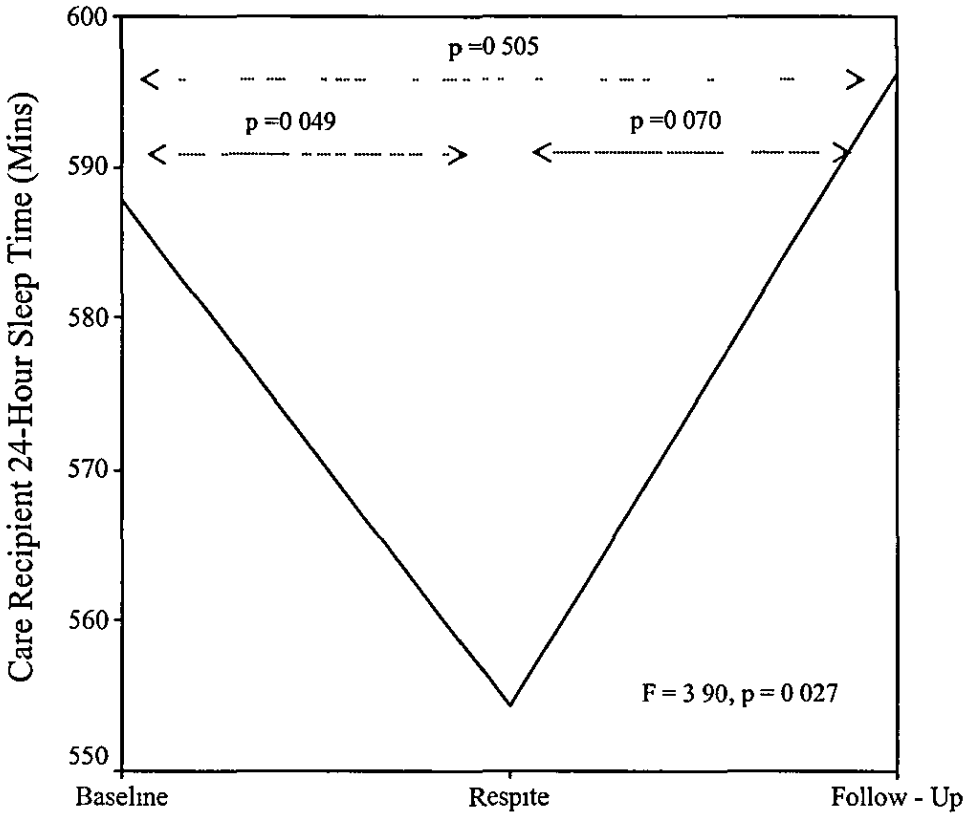
Figure 7.1 Care recipient total sleep time across the three study periods



Arrows < -- > on graphs with accompanying p values show contrast ANOVAs between conditions i e. baseline and respite, respite and follow- up, and baseline and follow - up

The 24-hour sleep times of these 31 care recipients' were also significantly reduced during respite care provision (F (2, 52) =3.90; p =0.027) by approximately 30 minutes. Baseline mean 24-hour sleep time was 588 minutes and this fell to 554 minutes during respite and increased at follow – up to 596 minutes. These data are presented graphically in Figure 7 2.

Figure 7.2 Care recipient 24-hour sleep times across the three study periods

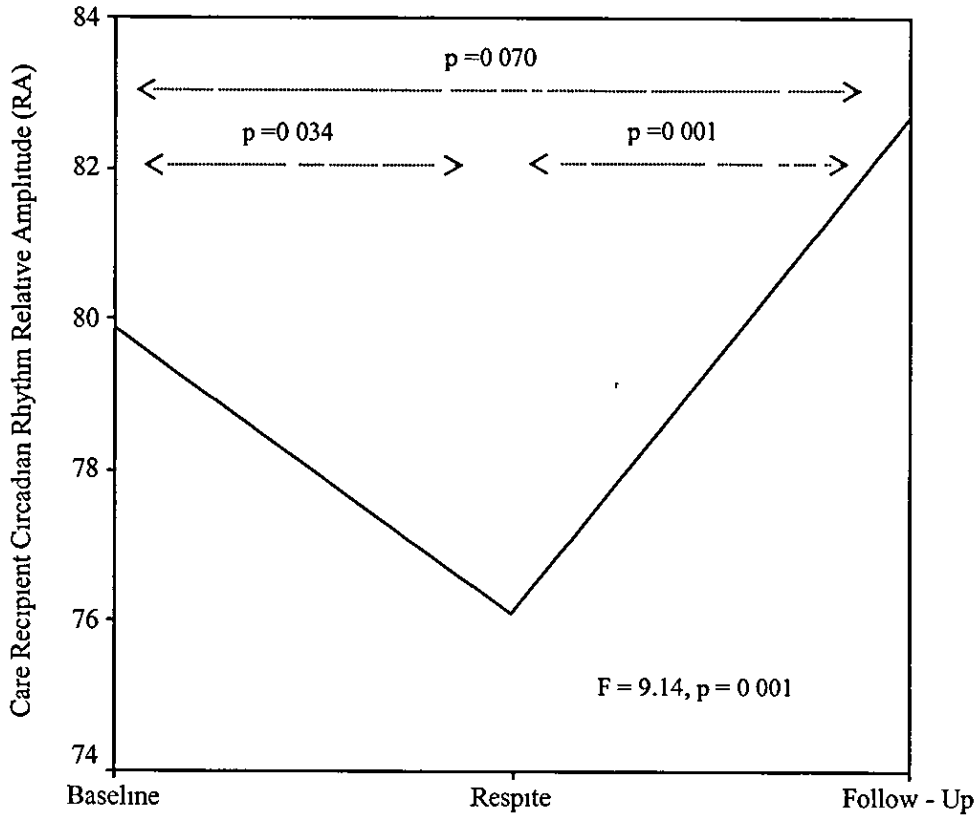


Arrows <--- ----> on graphs with accompanying p values show contrast ANOVAs between conditions i e baseline and respite; respite and follow- up, and baseline and follow - up

The greater difference between respite and follow up was not reflected in the significance value as a result of greater variance in these care recipients sleep times during follow – up. Significance was greater between baseline and respite as there was less variance in the data during these two conditions

The relative amplitudes (RA) of these 31 care recipients' circadian rhythms was also significantly reduced during respite care provision (F (2, 52) =9.14, p =0.001). Baseline mean RA was 0.80 and this ratio fell to 0.76 during respite and increased in follow – up to 0.83. These data are presented graphically in Figure 7.3.

Figure 7.3 Care recipient relative amplitudes across the three study periods

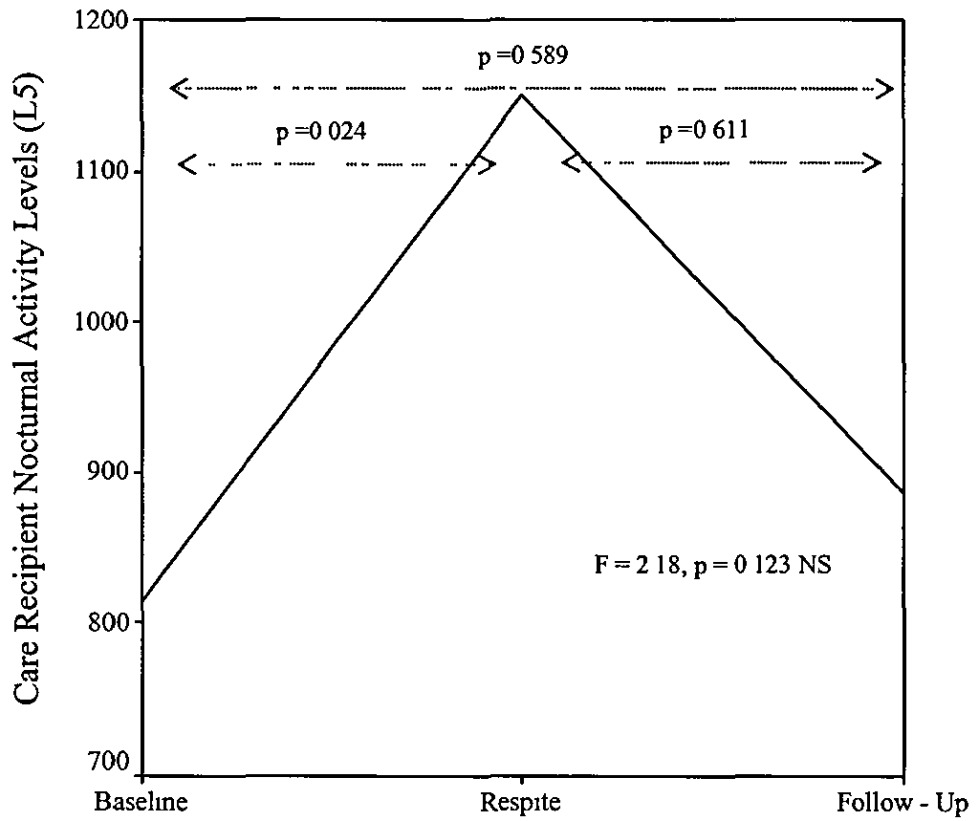


Arrows < ---> on graphs with accompanying p values show contrast ANOVAs between conditions i e baseline and respite, respite and follow- up, and baseline and follow - up

7.2.2 Speculative findings for care recipients from the respite care intervention

There were no other significant differences in care recipient actigraphic sleep or circadian rhythm outcome measurements between the baseline, respite and follow – up periods of the study. However, care recipient nocturnal activity levels were found to be higher during respite care in the 28 (82.4% of baseline sample of care recipients) care recipients who completed the baseline, respite and follow – up periods of the study although this findings fails to reach significance at the 5% level. Mean baseline (at-home) nocturnal activity levels (L5) averaged 814 activity counts during these care recipients' least active five consecutive hours. These levels rose to 1150 activity counts during respite care and reduced to 887 activity counts at follow – up ($F(2, 52) = 2.18$; $p = 0.123$). These data are presented graphically in Figure 7.4.

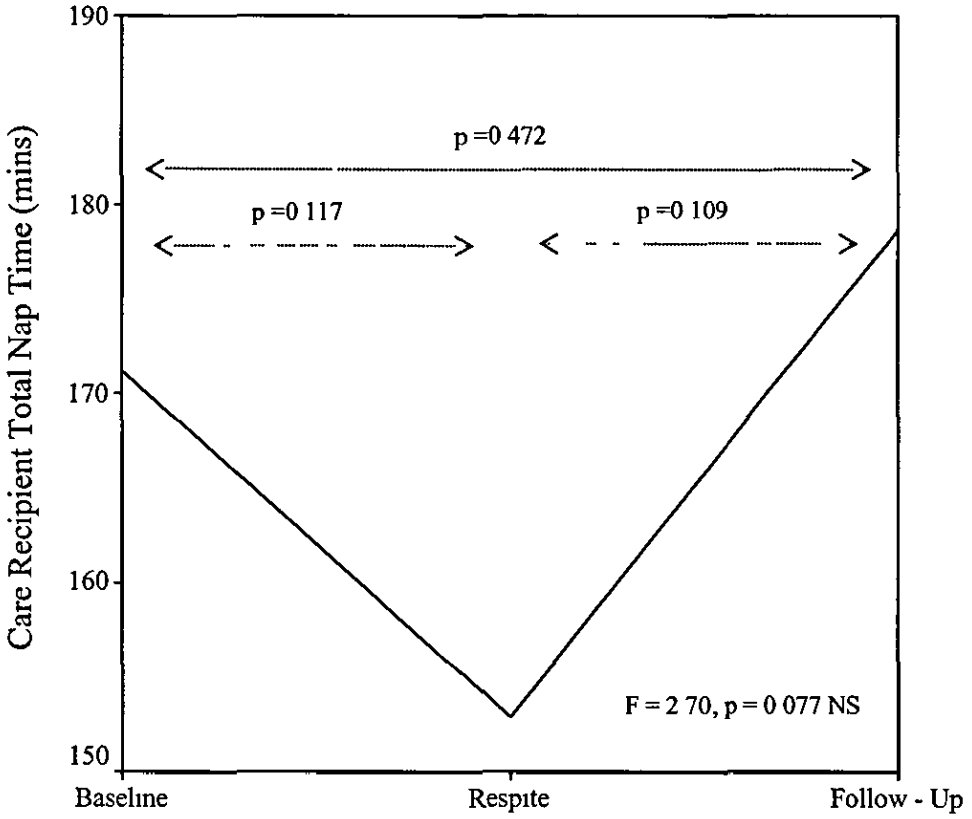
Figure 7.4 Care recipient nocturnal activity levels across the three study periods



Arrows < -> on graphs with accompanying p values show contrast ANOVAs between conditions i e baseline and respite, respite and follow- up, and baseline and follow - up

Furthermore, care recipients total nap times were also impacted by the intervention, although again these findings failed to reach significance at the 5% level. Care recipient total nap times were reduced (although not significantly) by approximately 20 minutes during the intervention compared to baseline and follow – up total nap times ($F(2, 48) = 2.70$; $p = 0.077$). These data are presented graphically in Figure 7.5.

Figure 7.5 Care recipient total nap times across the three study periods



Arrows < - - > on graphs with accompanying p values show contrast ANOVAs between conditions i e. baseline and respite, respite and follow- up, and baseline and follow - up

These speculative results are presented as there is a possibility that they may have reached significance if there were not such wide variation in the outcome measurements of these dementia care recipients or if the sample size of the study were increased Although non-significant results, these outcomes (L5 and TNT) are approaching significant changes as a result of the respite intervention, indicating that respite care had an impact on these outcomes in these older people with dementia although these findings failed to reach significance at the 5% level. These results will be discussed more fully in Chapter 8

7.3 Testing for interactions between care recipient sleeping arrangements between the baseline, respite and follow – up periods of the study.

As with the caregiver data presented in the previous chapter, care recipient data from analyses split by care recipients who were sharing with and those sleeping separately from their caregivers are presented in Table 7.2.

Table 7.2 Care recipient Multivariate ANOVAs actigraphic outcomes controlling for bedroom partnership, tests for interactions between outcomes and sharing and non sharing care recipients (n=12, 35.3%; n=13, 38 2%, n=14, 41.2%, n=15, 44 1%, n=16, 47 1% of the sample)

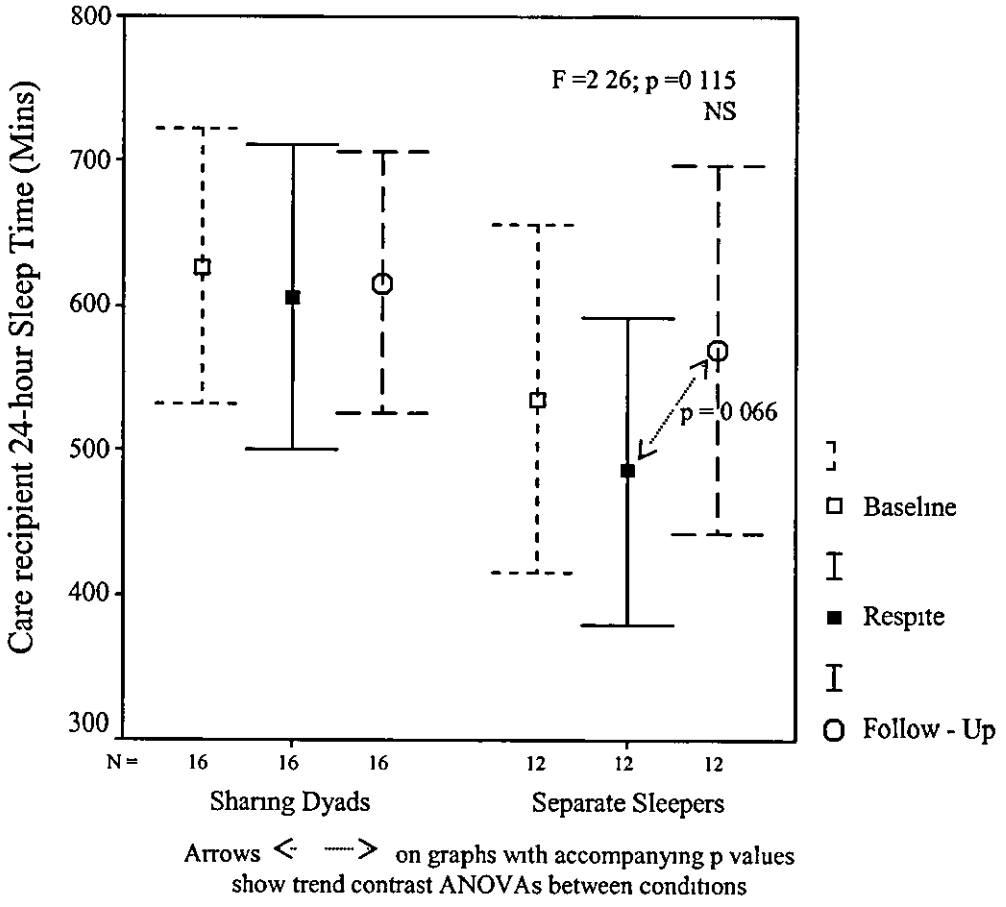
Outcome measurement	Units	N	Baseline mean (SD)	Respite mean (SD)	Follow-Up mean (SD)	* bed partner F (df)	p
TST (sharers)	Mins	16	456 0 (94 1)	436.1 (85 2)	462 5 (123 9)		
TST (separate sleepers)	Mins	12	381 2 (176 2)	356 2 (118 9)	411 5 (145 5)	0 63 (2,52)	0 536
WASO (sharers)	Mins	16	66 7 (30 6)	71 9 (45 2)	62 9 (39 0)		
WASO (separates)	Mins	12	99 1 (66 1)	105 9 (78 6)	101 0 (71 4)	0 14 (2,52)	0 871
SE (sharers)	%	16	82 4 (8 3)	79.8 (12 1)	82 2 (13 4)		
SE (separate sleepers)	%	12	67.2 (25 6)	67 0 (22 2)	72 9 (20.7)	1.17 (2,52)	0 320
SOL (sharers)	Mins	15	21 8 (22 4)	28 4 (21 9)	35 3 (39 0)		
SOL (separate sleepers)	Mins	12	32 5 (42 4)	46 4 (36 9)	24 7 (33 4)	1 80 (2,50)	0 176
L5 (sharers)	Index	15	563 2 (513 6)	772 9 (1161 3)	476 3 (430 7)		
L5 (separate sleepers)	Index	13	1103 0 (1640 9)	1585.4 (1868 2)	1360 8 (2757 2)	0 55 (2,52)	0 578
24 hour TST (sharers)	Mins	16	627 0 (178 6)	605 8 (198 2)	615 9 (170 1)		
24 hour TST (separates)	Mins	12	535 6 (190 8)	485 9 (168 0)	570 1 (201 0)	2 26 (2,52)	0 115
TNT (sharers)	Mins	14	174 2 (123 1)	168 4 (140 6)	185 0 (122 6)		
TNT (separate sleepers)	Mins	12	167 9 (74 4)	134 8 (86 2)	171 4 (100 3)	0 72 (2,48)	0 493
IS (sharers)	Index	15	0 73 (0 08)	0 71 (0 08)	0 73 (0 06)		
IS (separate sleepers)	Index	13	0 68 (0 10)	0 68 (0 10)	0 69 (0 09)	0 064 (2,52)	0 938
IV (sharers)	Index	15	1 17 (0 40)	1 23 (0 36)	1.10 (0 37)		
IV (separate sleepers)	Index	13	1 30 (0 30)	1 37 (0 34)	1 35 (0 46)	0 79 (2,52)	0.459
RA (sharers)	Index	15	0 82 (0 15)	0 80 (0 15)	0 84 (0 12)		
RA (separate sleepers)	Index	13	0 78 (0 18)	0 71 (0 18)	0 82 (0 16)	2.38 (2,52)	0 103

*Denotes " interaction with", TST= Total Sleep Time, WASO = Wake time After Sleep Onset, SE = Sleep Efficiency, SOL = Sleep Onset Latency, L5 = Lowest five hours of activity score, IS = Interdaily Stability, IV = Intradaily Variability, RA = Relative Amplitude

7.3.1 Speculative findings for care recipients from the respite care intervention by bedroom partnership

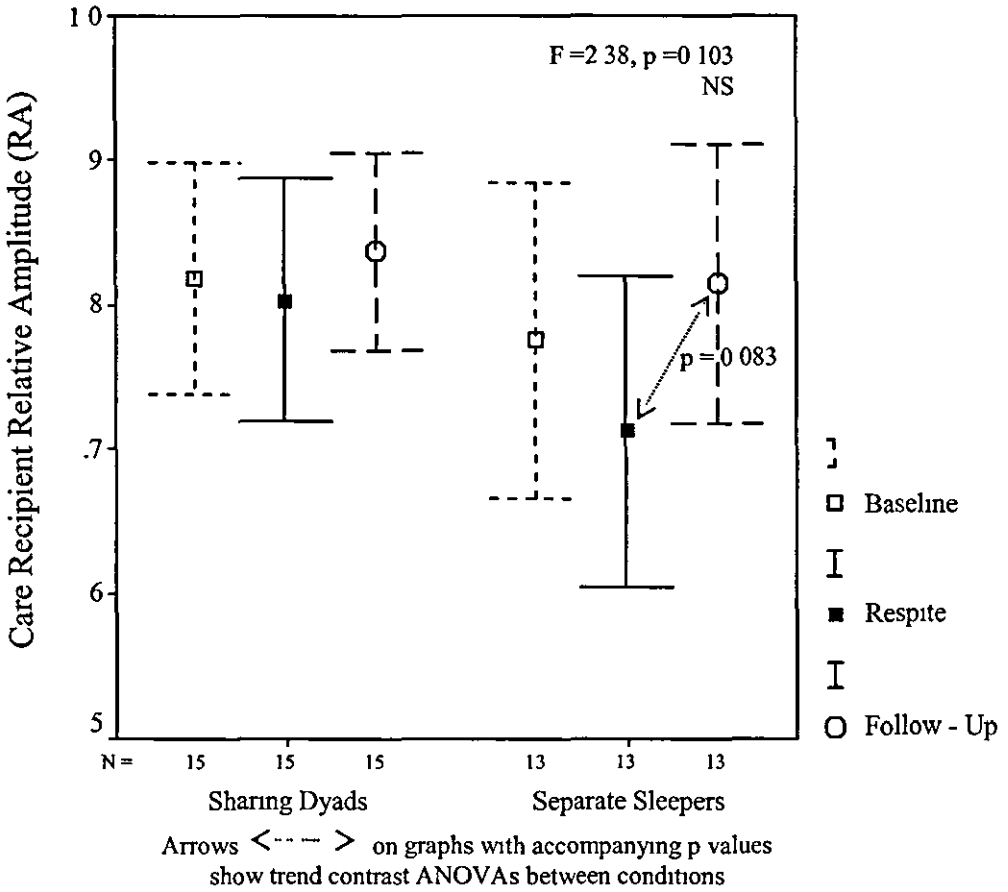
There were no significant interactions between these care recipients' outcome measurements and their sleeping arrangements (sharing bedrooms with their caregivers, or sleeping in a separate room). Although 24-hour sleep times and the relative amplitudes of these care recipients almost reach a significant interaction with bedroom partnership. Twenty-four hour sleep times were increased in care recipients who shared bedrooms with their caregivers than those who slept separately (by approximately 100 minutes at baseline and respite and 45 minutes post-discharge) indicating a possible impact of sleeping arrangements on 24-hour sleep times ($F(2, 52) = 2.26$, $p = 0.115$). These data are presented in Figure 7.6.

Figure 7.6 Interactions between care recipient sleeping arrangements and their 24-hour sleep times.



Sharing dementia care recipients relative amplitudes were also enhanced over those who slept separately, although again this increase failed to reach significance ($F(2, 52) = 2.38$, $p = 0.103$). These data are presented graphically in Figure 7.7.

Figure 7.7 Interactions between care recipient sleeping arrangements and the relative amplitudes of their circadian rhythms.



7.4 QUALITATIVE DATA FROM CAREGIVERS OF OLDER PEOPLE WITH DEMENTIA

The following section will describe two single-case studies from two of the care recipients who participated in this study, including qualitative information provided by caregivers of these older people with dementia

7.4.1 Two single case studies from care recipients

Case 1

Case number 4: Mr. B. was 88 years old when he joined the study and had been diagnosed with dementia of the Alzheimer type some 4 years prior to this date He had been receiving respite care for 2 years and had been into his local hospital on some 15 occasions. Mr. B. was prescribed with and was a regular consumer of hypnotic, antipsychotic and antidepressant medications. During the baseline period of this study Mr. B. slept for an average of 385 minutes per night. His mean nighttime activity level during his least active five hours (L5) was 543 activity counts. During respite care his TST decreased by 14 minutes to 371 minutes per night. In follow-up his TST increased to 447 minutes. Mr. B's L5 increased to 2974 activity counts during respite and reduced to 369 activity counts at follow-up.

Mr. B was being cared for by his son, who voiced serious concerns about the impact of the respite care intervention on the state of mind of his father. He reported that his father would return from respite care extremely tired, very confused and that it would take several days for these symptoms to subside to what he referred to as 'currently normal' levels. Mr. B's son was aware that his father's condition was deteriorating in cognitive and physical terms, but was unhappy with the impact that the intervention was having on his father. He did however, state that he found the respite care intervention invaluable for himself as it allowed him time to get on with chores, visits and excursions that he would otherwise be unable to perform.

Case 2

Case number 6: Mr. C. was 70 years old when he joined the study protocol and had been diagnosed with dementia associated with advanced Parkinson's disease

some 2.5 years prior to his entry into the study. Mr. C. had been in receipt of respite care services for 6 months and had been into his local hospital on 2 separate occasions during this time. He was prescribed with and was a regular consumer of hypnotic and antipsychotic medications. During the baseline period of this study Mr. C. slept for an average of 360 minutes per night. His mean nighttime activity level (L5) during this period was 1702 activity counts. During respite care Mr. C. experienced a reduction in his TST from 360 minutes to 236 minutes per night In follow-up his TST increased to a mean of 270 minutes. During respite care Mr. C's L5 increased to 4747 activity counts, his L5 reduced again in follow-up to 1647 activity counts.

Mr. C was cared for at home by his wife who was 68 years old at the time of participating in the study. Mrs. C was receiving treatment for depression and was very anxious about her husband's condition and the respite care intervention. She felt that she was capable of looking after her husband at home as she had been doing so for a number of years. She did describe feeling tired and at some times 'exhausted' with her caregiving responsibilities, and had reluctantly agreed to try out respite care to see how she would feel after some extended rest. Post-discharge Mrs. C was very dissatisfied with the way in which her husband returned home to her. She described short sleep times and high levels of agitation that were not as noticeable to her prior to his moving into hospital for 2 weeks Mrs. C was highly critical of the respite care intervention as a result of this negative impact on her husband and subsequently withdrew from subsequent respite care placements.

7.5 SUMMARY OF CARE RECIPIENT DATA PRESENTATION

The data presented in this chapter concludes the results chapters of this thesis. Data described here have been from the dementia care recipients who successfully completed the entire study protocol. These data have been presented in a similar fashion as those described for dementia caregivers in Chapter 6 i.e. the principal

effects of the intervention, followed by the possible interactions with sleeping arrangements across the study protocol

The following chapter will discuss these results in the order in which they have been presented (caregivers and then care recipients) and will attempt to answer the research aims posed at the end of Chapter 3

CHAPTER EIGHT

Discussion of Results

8.1 INTRODUCTION

This chapter will discuss the results presented in the previous three chapters of this thesis and will discuss these results in terms of. caregiver and care recipient sleep profiles; interrelationships between caregiver and care recipient sleep organisation; the impact of the respite care intervention; and the impact of the sleeping arrangements of these groups. These analyses will be discussed in terms of the descriptive and actigraphic baseline data presented in Chapter 5 and the baseline, respite and follow – up periods of the study described in Chapters 6 and 7 providing detailed sleep and circadian rhythm profiles of dementia caregivers and their dementia care recipients. The qualitative data collected from caregivers will also be discussed, both from the perspective of the caregivers who participated in this study and also from their dependent care recipients. Following the discussion of the results from this study. design limitations; possible directions for further research; recommendations for policy makers; and conclusions from this study will be presented at the end of this chapter and conclude this thesis on the sleep of older people with dementia, their caregivers and the impact of the respite care intervention on these groups.

8.2 CAREGIVER SLEEP AND CIRCADIAN RHYTHM PROFILES

The caregivers who participated in this study described sleep outcome measurements that were in agreement with those studies of sleep in the older adults presented in Chapter 1, Table 1.1 (Speigel *et al* 1990; Reynolds *et al* 1985; Hoch *et al* 1994; Dijk *et al* 2001; Prinz 1977). Caregivers described mean sleep times,

sleep onset latencies, wake-times after sleep onset and sleep efficiencies that were congruent with the findings of these five studies These findings reinforce the suggestion made by Van Someren *et al* (2003) that actigraphic sensitivity thresholds should be set at higher sensitivity levels for the generation of reliable outcomes in the assessment of sleep in older adults with dementia. Caregiver sleep was frequently disturbed by their care recipients (1.08 times per-night at baseline) and they described lengthy periods of nocturnal wakefulness (42.5 minutes at baseline), 46% of this time these caregivers directly attributed to care recipient disturbance factors and this amounted to a mean of 19.5 minutes per-night at baseline. Caregiver actigraphic and subjective sleep efficiencies were less than 85% indicating that these caregivers experienced poor quality sleep (Spielman *et al* 1987, Morin *et al* 1990) This finding was corroborated by caregiver subjectively reported PSQI scores averaging in excess of 5, again placing this group in the clinical range for disturbed sleep (Buysee *et al* 1989). The examination of sleep and circadian rhythm outcomes from good and poorly sleeping caregivers (defined by a median split of caregiver PSQI scores) indicates that those caregivers who described their sleep as poor on the PSQI experienced significantly increased actigraphically defined nocturnal wake times and significantly increased nocturnal activity levels than those who rated their sleep as good. They also described reduced actigraphically defined sleep efficiencies and subjectively rated energy / vitality scores from the SF-36 Health-Related Quality of Life Questionnaire than those caregivers who rated their sleep as good. These findings suggest that objectively recorded sleep disturbances (WASO and SE) are the best predictors of subjectively reported sleep disturbances. These findings support the work of Monroe (1967) and Adams *et al* (1986) who described subjectively rated poor sleepers as experiencing increased nocturnal wake-times compared to those who rate their sleep as good Although instrumentally assessed nocturnal wake-times may be less than poor sleepers report subjectively, there is a reduction in actigraphic WASO in those who rated their sleep as good compared to those who rated their sleep as poor (a significant reduction in this study by around 35 minutes). This objectively examined reduction is magnified by subjective

reporting, i.e. the more disturbed the sleep the more likely that subjective descriptions of this disturbance will be made Adams *et al* (1986) described this phenomenon and the present study has examined similar trends between subjective and instrumentally assessed sleep disturbances. The examination of the actigraphically derived nocturnal wake-times and activity levels of care recipients of good and poorly sleeping caregivers indicate that (although non-significant results) the care recipients of poorly sleeping caregivers are substantially more active at night and more wakeful than the care recipients of those caregivers who rated their sleep as good. These findings suggest that care recipients impact significantly on the sleep described by their caregivers both in terms of instrumentally and subjectively described sleep outcomes. The good sleepers in this study were sharing their lives with care recipients who were also sleeping well; had low nocturnal activity levels (50% of those described by care recipients of poorly sleeping caregivers); and in terms of reduced nocturnal wake-times (16 minutes less than care recipients of poorly sleeping caregivers). These findings suggest that caregivers' preconceptions about their sleep impacts on their subjective and objective experiences of sleep and that the behaviour of their dementia care recipients also impacts on their sleep. This identifies dementia caregiving as a significant risk factor for disturbed, unsatisfactory nighttime sleep.

With regard to daytime sleepiness, these caregivers reported napping for 73 minutes per-day at baseline and reported high Epworth Sleepiness Scale scores (6.1) indicative of excessive daytime sleepiness (Johns 1991) These feelings of daytime sleepiness were also examined using the SF-36 energy / vitality domain score. These caregivers reported energy / vitality scores that were reduced compared to normative population scores (Brazier *et al* 1993) again indicating increased sleepiness in caregivers of older people with dementia. Collectively these findings identify dementia caregiving as a risk factor for increased levels of daytime sleepiness and substantial sleep difficulties at night It should be noted that these caregivers did nap for over an hour each day *whilst* providing care (mean baseline nap times of approximately 1¼ hours) indicating that sleepiness in

dementia caregivers was sufficient enough for them to sleep during the day despite their caregiving responsibilities.

These caregivers experienced reduced nighttime sleep quality and increased feelings of daytime sleepiness as a result of providing care. These findings support the work of Sanford (1975), Gilleard (1984); Gilhooly (1984); Pollak and Perlick (1991); and Kesselring *et al* (2001) in describing high levels of sleep disruption in dementia caregivers and increased dissatisfaction with their sleep as a direct result of caregiving. These five studies all describe caregiver sleep disturbances by care recipients as occurring frequently and being poorly tolerated This work can confirm those conclusions, although the studies mentioned above all examined caregiver sleep in subjective terms, this is the first time that dementia caregiver sleep has been assessed instrumentally. Indeed, this is the first time that high levels of insomnia in dementia caregivers have been examined in a systematic empirical study. This study therefore adds objective weight to the findings of the subjective studies previously described.

The results from these caregivers presents a profile of dementia caregiving that characterises the sleep of this group in terms of bed and wake times that accommodate caregiving; caregiving leading to poor subjective sleep quality; low levels of sleep satisfaction, high levels of daytime sleepiness; chronic fatigue; and reduced Health-Related Quality of Life, particularly in terms of social inclusion and mental health characteristics. The reduced sleep times, sleep efficiencies, subjective WASO and increased nocturnal activity levels of caregivers when their care recipients returned home post-discharge from hospital indicates the difficulty with which these caregivers re-adapt to their caregiving roles after periods of respite care. This latter point will be discussed further in Section 8.5.

8.3 CARE RECIPIENT SLEEP AND CIRCADIAN RHYTHM PROFILES

The care recipients who participated in this study described sleep outcome measurements that were congruent with those described in Chapter 1, Table 1.3 from other studies conducted on the sleep of older adults with dementia Care recipients again described similar sleep times; sleep latencies, and nocturnal wake-times as those studies presented in Chapter 1, Table 1.3 (Prinz *et al* 1982; Allen *et al* 1997; Aharon-Peretz *et al* 1991; Moe *et al* 1995; Ancoli-Israel *et al* 1997). The two notable differences between the sleep of older adults with dementia and their caregivers were daytime sleep times (i e. Total Nap Times; TNTs) and their circadian rhythm outcome measurements, particularly nighttime activity levels (L5). Care recipient TNTs were significantly greater than caregiver TNTs averaging nearly 3 hours of daytime sleep per-day at baseline compared to the 1¼ hours examined in their caregivers. This finding indicates the increased sleep propensity of older people with dementia during the day; this had the effect of raising dementia care recipient 24-hour sleep times. These outcomes corroborate those described by Ancoli-Israel *et al* (1997) and Van Someren *et al* (1996) who have both reported lengthy periods of daytime napping in institutionalised older adults with dementia Although these findings support the work of the above mentioned hospital studies, this is the first time that the sleep of community-residing older adults with dementia and their sleep whilst within a respite care environment have been examined systematically and in an instrumental and empirical way. These findings suggest that increased daily nap times in dementia are not exclusive to the hospital environment and that significantly increased daily nap times in older people with dementia (compared to people without dementia – the caregivers in this study) also occurs in the community. Increased nocturnal activity levels in older people with dementia have yet to be described in the literature. This study identifies high nocturnal activity levels as common in older people with dementia and that these high nocturnal activity levels in dementia has negative consequences for caregiver sleep. Furthermore, this study has identified nocturnal activity levels in older people with dementia which increase whilst within

an institutional setting compared to home-based levels Although there is circumstantial evidence for this phenomenon in the literature (Schnelle *et al* 1998), this is again the first time that this feature of dementia care recipient sleep has been described in a quantitative sense and the first time that this has been described across community and institutional settings. Moreover, this is the first time that comparative increases in nocturnal activity levels as a function of hospital admission have been described empirically.

Care recipient circadian rhythmicity of sleep and wakefulness was much reduced compared to their caregivers. Care recipients had significantly reduced interdaily stabilities, significantly increased intradaily variabilities and significantly reduced relative amplitudes of their circadian rhythms of sleep and wakefulness compared to their caregivers Collectively, these findings indicate that these dementia care recipients experienced increased difficulties with their diurnal activity patterning, with less activity and more sleep occurring during the daytime, which impacted on their caregivers' and their own sleep during the nighttime; particularly in care recipients of poorly sleeping caregivers. Again, these findings are congruent with those described by Ancoli-Israel *et al* (1989); Witting *et al* (1990) and Van Someren *et al* (1996) who all describe reduced circadian rhythmicity in institutionalised older people with dementia. There is a suggestion here that a policy of reducing daytime nap times might enhance this diurnal separation of activity into a more active daytime period and a less active nighttime period, with enhanced sleep outcomes for dementia care recipients. This suggestion is discussed further in Section 8.11.5.

The findings from these older adults with dementia who participated in this study corroborate previous, hospital based studies, but in community-residing dementia care recipients as opposed to those in institutions. These studies suggest that environmental placement (be it the home or the hospital) may not be as influential as other factors (such as deteriorating neurology, stimulus control and sleep hygiene practices) are at disturbing dementia care recipient sleep and circadian

rhythmicity. These results present a profile of dementia care recipient sleep that is more disturbed than their caregivers in terms of increased nocturnal wake-times and increased nocturnal activity levels; more prevalent during daylight hours than their caregivers; further disturbed by admission to an institutional setting; and rebounding post-discharge resulting in increased sleep outcomes (TST, TNT, 24-hour TST) and increased nocturnal activity levels. Furthermore, the return of a sleepier dementia care recipient to their caregivers post-discharge, and the increased nocturnal activity levels of these older people with dementia at follow – up, leads to diminished sleep outcomes for caregivers after their respite period. This latter point, from the perspective of caregivers is discussed further in Section 8.5.

8.4 INTERREALTIONSHIPS BETWEEN CAREGIVER AND CARE RECIPIENT SLEEP AND CIRCADIAN RHYTHM OUTCOMES

The caregivers who completed the baseline period of the study went to bed after they assisted their care recipients into bed (Section 5.7.1, page 111) These caregivers reported waking before their care recipients and getting up shortly after their care recipients awoke. These findings suggest that caregiver / care recipient sleep timings are synchronised, with caregivers going to bed after their care recipients and awaking before them, but not arising until their care recipients had awakened. Some caregivers reported that they considered the period in-between their and their care recipients' bedtimes (a mean of 40 minutes) as 'their time' for a rest in the evening before bed without having to provide care. Furthermore, increased caregiver time in bed during periods of respite care provision compared to the baseline and follow – up periods clearly shows how caregiver lifestyles and sleep patterns are driven by their care recipients

There were no significant correlations between care recipient and caregiver sleep or circadian rhythm outcome measurements with the exception of total sleep time (TST) and intradaily variability (IV). There is a possibility that TST correlated

between these dyads as their bed and wake times were synchronised. Indeed, previous research on older people with dementia and their caregivers indicated that (in caregivers and dementia care recipients who live together) nighttime sleep schedules are synchronised, as are daytime naps (Pollak and Stokes 1997) Dyadic intradaily variabilities also correlated significantly indicating either that fluctuations in care recipient activity levels precipitated a similarly disturbed circadian rhythm in their caregivers; or that the rate of change of caregiver daily activity levels caused a disruption in care recipient circadian rhythmicity. This latter explanation is less likely as the literature has described reduced circadian rhythmicity in dementia care recipients compared with older people without dementia (Witting *et al* 1990; Pollak and Stokes 1997). This finding suggests that circadian rhythm disturbances in caregivers are negatively influenced by the presence of a care recipient. This study can reinforce this hypothesis as the care recipients in this study had mean baseline IV scores of 1.25 (SD = 0 44) and their caregivers experienced reduced mean baseline IV scores of 0.98 (SD = 0 21). This finding indicates that these dementia care recipients had more compromised circadian rhythmicity than their caregivers and that there was more variation in their sample These findings again suggest that dementia care recipients experience reduced circadian rhythmicity of their diurnal activity patterning than their caregivers.

As mentioned previously, there was an impact of care recipient nighttime sleep disturbance factors on caregivers, and this was particularly the case in those caregivers who rated their sleep as poor. These data suggest that caregivers who rated their sleep as poor did so as a result of looking after a more sleep disturbed care recipient. This finding implies that the more sleep disturbed a dementia care recipient is, the more likely that their caregivers will: a) report more disturbed sleep; and b) describe increased objectively measured sleep disturbances including raised nighttime activity levels.

Examining the impact of respite care on these groups can also test the hypothesis that dementia care-recipients impact negatively on the circadian rhythmicity of their caregivers. Should caregiver IV become less variable and care recipient IV remain stable or become more variable during the respite care intervention then the conclusion that dementia care recipients impose negatively on the circadian rhythmicity of their caregivers will be corroborated. Indeed, although non-significant changes, caregiver IV reduced during respite from 0 94 at baseline to 0.91 at respite and care recipient IV increased from 1.27 at baseline to 1.31 at respite This finding supports the hypothesis that the reduced circadian rhythmicity of dementia care recipients' activity patterns impacts negatively on their caregivers' circadian rhythmicity. Further, that the respite care intervention had the effect of reducing caregiver and increasing dementia care recipient intradaily variability, suggesting that the mechanisms which control the circadian rhythm are vulnerable to the impact of environmental change. This suggestion implies that caregivers and older people with dementia maintain some plasticity in these regulatory mechanisms, indicating that sleep and wake rhythmicity in these groups are open to intervention, i e. sleep / wake rhythms in older people with dementia and their caregivers can be impacted by environmental interventions. This certainly is the case for caregivers, whose circadian rhythm outcomes improved during the intervention compared to the baseline and follow-up periods of the investigation. However, the circadian rhythmicity of care recipients was reduced during respite and returned toward baseline levels at follow-up. The implications of this are that circadian rhythm outcomes in dementia are impacted negatively by the respite care intervention (and these are mirrored in negative changes to their sleep outcomes during periods of respite care). The return toward baseline levels at follow-up implies that care recipient circadian rhythmicity can be impacted by environmental interventions, but do not suggest that these outcomes can be improved by such an intervention The question, therefore, as to whether environmental interventions can improve circadian rhythmicity of activity patterning in older people with dementia remains. This finding is unsurprising, as the novelty of an environmental shift in older adults with dementia would intuitively lead to a reduction in sleep and

circadian rhythm outcomes, as might be expected in any person, in health or disease.

Interrelating outcomes from the dyads who participated in this study show that: dyadic sleep organisation is synchronised across the 24-hour day; care recipient circadian rhythmicity impacts negatively on the sleep / wake schedules of caregivers, dyadic sleep / wake patterns are susceptible to behavioural / environmental modifications; and, post-discharge, both caregivers and their dementia care recipients experience decrements to their sleep / wake profiles, beyond those recorded during the baseline period of the study. The following sections will discuss the impact of the respite care intervention on dementia caregivers and dementia care recipients respectively.

8.5 THE IMPACT OF THE RESPITE CARE INTERVENTION ON THE SLEEP AND CIRCADIAN RHYTHM PROFILES OF CAREGIVERS

Actigraphically derived sleep outcome measurements from the present study indicate that these caregivers slept for significantly longer during the respite period compared to the baseline period of the investigation. Caregiver nighttime activity levels were also significantly reduced during the respite care intervention compared to the baseline period, as was caregiver sleep efficiency at follow – up compared to the baseline and respite periods. In terms of circadian rhythmicity of their diurnal activity patterning, these caregivers interdaily stability of circadian rhythmicity was reduced at respite and follow – up compared with baseline period levels.

In terms of subjectively reported sleep outcome measurements: these caregivers reported reductions in their subjective WASO and increased time in bed at respite compared to the baseline and follow – up periods of the investigation. These findings indicate the extent to which these caregivers felt that they had benefited from the respite care intervention, both in the objective and subjective measures of their sleep. Significant increases in TST indicate that these dementia caregivers

had an enhanced opportunity to rest during respite. They also described feeling better about nighttime sleep disturbances as their self reported WASO was reduced in the absence of their care recipients during periods of respite care. This statistically significant increase in caregiver total sleep time as a result of the respite care intervention may, in terms of actual time (i.e. an increase of 10 minutes), be regarded as modest in real terms. However modest these increases in total sleep time at respite, the literature shows clearly that small changes in objectively examined sleep outcomes (when good and poor sleepers are compared) equate to large differences in the subjective reporting of sleep experiences and quality of life (Monroe 1967; Adams *et al* 1986). These findings explain the reason for caregivers describing large improvements in their subjective sleep experiences, as a result of relatively modest increases in their objectively examined sleep outcomes.

The significant reduction in caregiver interdaily stability during periods of respite care is possibly explained by the fact that these caregivers stepped out of their normal caregiving routines during respite, their lifestyle changed, thus impacting on their circadian rhythmicity. The possibility of these changes in the normal routines of caregivers during respite care may explain the reductions observed in the interdaily stability of their circadian rhythms during the respite period compared to the baseline and follow – up periods of the study. These increased sleep outcomes shows clearly how a looking after a dementia care recipient impacts on caregiver lifestyles and sleep patterns, indicating the extent to which caregivers experience improvements in subjectively felt and objectively observed sleep outcomes in the absence of their care recipients.

At follow – up these caregivers experienced reduced total sleep times, reduced sleep efficiencies, reduced interdaily stabilities and increased subjectively reported wake-time after sleep onset compared to baseline levels. These findings suggest that the re-entrainment to the caregiving role post-discharge is problematic for caregivers Times in bed were similar between conditions, but TST was reduced, this had the effect of significantly reducing caregiver sleep efficiencies at follow –

up. The reduced interdaily stabilities of these caregivers at follow – up compared to the baseline period of the study indicates that the 'usual' daily patterning of caregiver activity at baseline did not return in these caregivers at follow – up again suggesting difficulties with readapting to the caregiving role post-discharge. Dementia caregivers also reported increased levels of subjective nighttime wakefulness post-discharge compared to baseline values, although this result was not significant. There is an implication from these findings that the respite care intervention, although providing a tangible opportunity for caregivers to rest, may induce difficulties for these caregivers post-discharge. This is important as the respite care intervention may have left these caregivers in a position where they were unprepared and / or unsupported to a sufficient degree at follow – up and this resulted in reduced caregiver sleep and circadian rhythm outcomes after their care recipients were discharged from hospital. There is a suggestion therefore, that respite care may have induced increased sleepiness and reduced circadian rhythmicity of activity patterning in these caregivers over the long-term, which may be generating the requirement for more respite care provision for these caregivers

Subjective reporting by caregivers of their feelings of wellbeing indicates that the respite care intervention caused significant increases in caregiver wellbeing compared to the baseline and follow-up periods of the study. These findings suggest that the dementia caregivers who participated in this study felt better during periods of rest than they did during periods of care provision, and that these were significant improvements in wellbeing induced, in isolation, by respite service provision These findings support the work of Pearson (1988), Melzer (1990); and Watkins and Redfern (1997) in indicating positive caregiver feelings towards the respite care intervention. Although this is the first time that sleep in, and respite care for, community-residing dementia caregivers has been measured instrumentally; for such a long time period (a 6-week study protocol); and as part of a systematic empirical evaluation.

Two key policy documents relating to caregiving in the UK have been produced in recent years; the Office for National Statistics (ONS) Carers 2000 report (ONS 2002) cited high levels of subjectively reported sleep disturbance in caregivers; and The NHS Service Delivery and Organisation (SDO) review of respite care and short-term breaks for carers for people with dementia (Arskey *et al* 2004) described substantial subjectively reported evidence of improved sleep in dementia caregivers as a result of overnight respite care in hospital environments These documents, produced by government and NHS agencies highlight the importance of sleep disturbances in dementia caregiving in the way in which dementia care is provided and managed in the UK at the present time. However, these influential documents cite only subjectively reported evidence from caregivers. This study reinforces those subjectively reported findings with systematically evaluated instrumental measures of caregiver sleep experiences of respite care and does so for the first time The findings presented in this thesis therefore form the only available empirical evidence of the effectiveness of respite care service delivery for caregivers.

The increased time in bed described by caregivers during the respite care intervention indicates that the intervention served to increase opportunities for dementia caregivers to rest. As this is the main purpose of the respite care service, this study can confirm that the service is meeting this requirement from the perspective of caregivers. However, the reduced caregiver sleep times, sleep efficiencies, nocturnal wake times and interdaily stabilities at follow – up compared with the baseline period of the study indicates that the intervention may have caused increased difficulties with sleep for these caregivers at follow – up. With regard to sleep and circadian rhythm outcomes these caregivers were impacted negatively by the intervention at follow – up, suggesting that the intervention, although greatly received and appreciated by these caregivers in subjective terms, did not serve them well over the longer term and may be precipitating a requirement for more respite care, i e. respite care may inadvertently be self-generating a requirement for more respite care over the longer term.

This section has discussed the principal effects of the respite care intervention from the perspective of caregivers identified in Chapter 6. The following section will discuss the principal effects of the respite care intervention from the perspective of those dementia care recipients who participated in the three periods of this study from data presented in Chapter 7.

8.6 THE IMPACT OF RESPITE CARE ON THE SLEEP AND CIRCADIAN RHYTHM PROFILES OF DEMENTIA CARE RECIPIENTS

The dementia care recipients who participated in the baseline, respite and follow – up periods of this study experienced a significant decrease in their nocturnal total sleep times during the respite care intervention and significant reductions in the relative amplitudes of their circadian rhythmicity of sleep / wake distribution. They also described significantly increased nocturnal activity levels at respite compared with the baseline period of the study. These findings indicate the effectiveness of the respite care intervention at impacting on both dementia care recipient sleep outcomes *and* their circadian rhythmicity of diurnal activity patterning Unfortunately, the intervention served to impact negatively on these outcomes in these dementia care recipients, with this group experiencing reductions in total sleep time at night and in the distribution of their activity levels across the 24-hour day. Indeed, dementia care recipient 24-hour sleep times were significantly reduced during periods of respite care compared to the baseline and follow-up period sleep times by around 30 minutes.

There was one other speculative feature of the sleep of older people with dementia at respite that is worthy of note: this was total daytime nap times. These results indicate a trend towards reduced daytime sleep (20 minutes during the daytime) at respite compared with the baseline period of the study. These findings are of interest as previous research has suggested that the attenuation of what has been termed 'inappropriate amounts' of daytime sleep (Ancoli – Israel *et al* 1996) may

enhance sleep outcomes in older people with dementia at night. The rationale behind this hypothesis is that reducing sleep in the daytime may lead to increased sleep propensity at night and to an enhanced division between higher daytime, and lower nighttime, activity levels – a concept linked to good sleep practice or sleep hygiene (Bootzin 1972; Morin *et al* 1990). The theoretical base behind this thinking is well established (Bootzin 1972; Spielman *et al* 1987; Lichstein and Morin 1992), but in this group of older people with dementia, this reduced 24-hour sleep time (as a result of both reduced nap times *and* nighttime sleep times) has not impacted positively on the nighttime sleep outcomes of these older people with dementia. The implication of this equivocal finding is complex. There is a distinct possibility that reductions in daytime napping in older people with dementia may enhance their nighttime sleep outcomes, but, in the hospital environment, the chance of this occurring is reduced, possibly as a result of extra-patient disturbance factors within the hospital environment identified by Schnelle *et al* (1998).

Post-discharge these older adults with dementia experienced increased total sleep times and enhanced circadian rhythmicity (in terms of RA) suggesting that the respite intervention had a rebounding effect at follow – up The intervention may have had the effect of inducing increased sleepiness in these older people with dementia to such an extent that, post – discharge they experienced improved sleep and circadian rhythmicity of their 24-hour activity patterning Again, these findings lend credence to the possibility of maintained plasticity of those mechanisms that drive and control sleep in dementia (Regestein and Morris 1989, Vitiello *et al* 1990, Meguro *et al* 1995). These findings suggest that the respite care intervention should be adjusted such that the intervention better serves these dementia care recipients in terms of their sleep experiences whilst in the hospital. The question of whether a more efficacious intervention, than the respite care intervention described, may improve circadian rhythmicity in older people with dementia therefore remains Mechanisms by which respite care could achieve improvements in dementia care recipient sleep are discussed in more depth in Section 8.11.4.

8.7 THE IMPACT OF SHARING A BEDROOM WITH AN OLDER ADULT WITH DEMENTIA ON CAREGIVER SLEEP

There were no significant interactions between bedroom partnership and any sleep / circadian rhythm outcome measurements, with the exception of subjective total sleep time in the caregivers who participated in the complete study protocol. Caregivers who were sleeping separately from their care recipients reported significant increases in subjective total sleep time (sTST) at respite against baseline levels compared with those caregivers who shared a bedroom with their care recipients.

This study cannot reject the null hypothesis that sleep in dementia caregiving is not affected by sleeping arrangements. As there were no actigraphic sleep or circadian rhythm outcomes which interacted with dyadic sleeping arrangements and only one subjective outcome measurement (sTST); the present study can confirm that any significant changes in caregiver sleep and circadian rhythm outcomes as a result of the respite care intervention occurred independently of dyads sharing bedrooms or sleeping separately. Indeed, the absence of any interactions between actigraphic outcome measurements and bedroom partnership strongly suggests that respite care has a generalised impact on the sleep of caregivers regardless of pre-respite sleeping arrangements.

The finding that sharing caregivers felt that their sleep did not improve, but that non-sharers felt that they did experience better sleep during periods of respite care may be due to relationship factors There is a possibility that non-sharing caregivers experienced relief during periods of respite care provision, whereas those caregivers who shared bedrooms with their caregivers may have experienced feelings of loss that possibly offset subjective positive feelings about the respite care period There is a possibility that these differential responses by sharing and non-sharing caregivers may influence subjective sleep outcomes in opposing directions; with sharing caregivers missing their partners and non-sharing

caregivers, having habituated to separate sleeping arrangements, experiencing feelings of relief during the respite period.

This section concludes discussion on the findings from the caregivers who took part in this study. The following section will discuss the impact of bedroom partnership (or sleeping in a separate bedroom) on the sleep and circadian rhythmicity of the dementia care recipients who participated in the study.

8.8 THE IMPACT OF SHARING A BEDROOM WITH A CAREGIVER ON CARE RECPIENT SLEEP

There were no significant interactions between care recipient outcome measurements and their sleeping arrangements, indicating that the respite care intervention impacted on these older adults with dementia independently from their sleeping arrangements (be they sharers or sleeping separately from their caregivers). These findings imply that any impact of the respite care intervention on dementia care recipient sleep and circadian rhythm outcomes occurred independently from community-based sleeping arrangements. However, at baseline dementia care recipient WASO was significantly greater (by around 36 minutes) in those sleeping separately from their caregivers compared to those sharing bedrooms with their caregivers. Separately sleeping dementia care recipients also experienced increased nocturnal activity levels and reduced sleep efficiencies than those sharing bedrooms with their caregivers at baseline. These findings indicate that those care recipients who shared bedrooms with their caregivers experienced nocturnal sleep outcomes and activity levels that were better than those sleeping separately.

These findings are supported by two non-significant, speculative results across the whole study protocol, which are worthy of note here and these are care recipient 24-hour sleep times and the relative amplitude of these care recipients' circadian rhythms. Those care recipients who shared bedrooms with their caregivers

experienced around 100 minutes more sleep than those who slept in separate bedrooms at baseline and at respite (this reduced to an increase of around 45 minutes at follow – up). This finding is mirrored in the relative amplitudes of the circadian rhythms of those sharing and those separately sleeping care recipients. Separately sleeping care recipients experienced reduced relative amplitudes of their circadian rhythms compared to those sharing bedrooms with their caregivers.

These latter results are presented as they show a marked difference between these two sub-groups of dementia care recipients. Further research is required to explore more fully the impact of bedroom sharing on the sleep and circadian rhythm outcomes of dementia care recipients as these findings are presented as potential trends, as the power of the study was not sufficient to examine significant changes in these outcome measurements from these dementia care recipients. This, and further limitations to this study are discussed in Section 8.9 and 8.10.

The closeness of bedroom sharing could be indicative of the closeness of the relationship between dyads, which may explain the increased sleep times and patterning of activity levels around the 24-hour day in those who maintained closeness in their relationships in terms of still sharing a bedroom. Kesselring *et al* (2001) described the closeness of spouses as a significant predictor of nursing home placement, with partners who had and maintained a close relationship, providing care for longer time periods in the community. There is a possibility that these factors, closeness and sleep disturbances, interact and impact on the delivery of care in the community over time. This latter suggestion has not been addressed in the present study and requires further investigation

The sleeping arrangements of older people with dementia and their caregivers show that: in objectively examined terms, the respite care intervention impacts on the sleep of these groups independently from bedroom sharing status; care recipients who shared a bedroom with their caregivers experienced reduced WASO during the baseline period of the study than those sleeping separately but, caregivers who

shared bedrooms with their charges were less satisfied, in subjectively reported terms, with sleep improvements during the respite care intervention than those who slept in separate bedrooms. This latter finding may be influenced by differential feelings toward the respite care intervention, i.e. separately sleeping caregivers experiencing relief, whereas bedroom sharers maybe experiencing feelings of loss as a result of the removal of their habitual sleeping partner from the bedroom This latter suggestion requires further analysis as the remit of this study did not include examination of the qualitative experiences of dementia caregivers outside of feelings about their sleep.

This section concludes the discussion on the findings from the care recipients who participated in this study.

8.9 STUDY LIMITATIONS

The diagnostic heterogeneity of the dementia care recipients who participated in this study may have led to the wide variations seen in the outcomes they described. As such, the study would have benefited from recruiting older people with one type of dementia, either AD or MID. However, being selective in this way would have reduced the sample size and increased the time required for data collection which was already substantial (2.5 years) Furthermore, diagnoses were mostly conducted on the basis of GP interviews only, as definitive diagnoses are only available post-mortem. As a result, conclusive diagnoses are impossible to obtain *in vivo*, so the separation of dementia cases into sub-groups for analyses of this type would be difficult to perform. Similarly to this initial criticism, the study may also have benefited from not collecting data from bedroom sharers and from non-sharers, so examining these groups in isolation – either sharers or non-sharers. However, the findings from this split analyses are useful as similarities and differences between these groups have been shown that have not been previously reported.

The power calculations in Chapter 4 were designed to examine the number of participants required for the main effects of the respite care intervention to reach significance at the 5% level. It should be noted that these calculations did not take into consideration interactive cofactors or sub-group analyses that have been conducted. These interaction and sub-group analyses may be underpowered as no adjustments were made for multiple testing (therefore a higher level of Type I error rate has been accepted) and so these may require further examination by reproducing this study with a larger sample size in order to more effectively test for any such interactions No checks were made to test for multivariate normality, by inspecting residuals or by checking Mahalanobis distances, as the main effects of the respite care intervention were significantly demonstrable without performing these additional tests. The reader should be cautious in interpreting the findings from this study; as no adjustments were made for multiple testing, there is a possibility of an increased Type I error rate. Furthermore, with regard to the interaction effects and sub-group analyses, the low statistical power will have potentially increased the Type II error rate, suggesting that some effects may have been substantial despite them failing to reach a level of statistical significance.

A further possible limitation of this study was that the level of dementia in the care recipients who participated (i.e the extent to which the disease had progressed) was not formally controlled for at the selection or analytical phases of the study However, in defense of this consideration, in order for an older adult with dementia to be eligible for institutional respite care admission then they would be in the moderate to severe stages of dementia. This admission eligibility criterion therefore acted as a proxy measure for moderate to severe dementia.

Ideally the application of the SF-36 Health-Related Quality of Life Questionnaire and the Pittsburgh Sleep Quality Index would have been applied twice, at the beginning and end of the study. However, only one application of these questionnaires was made so as to reduce time demands on the caregivers who took part in the study. Despite the limitations and potential weaknesses of this study, as

described in this section, this thesis does report for the first time empirical evidence of the impact of respite care on the sleep and activity patterning of older people with dementia and their caregivers. Conducting research in an applied setting is notorious from the perspective of project management: access to participants; access to medical files; access to hospital wards; attrition resulting from withdrawal; drop-outs and deaths; a long study protocol in and out of community settings; etc... All combine to increase the difficulty with which participants can be recruited and maintained within an applied research study such as the one described herein. Data collection spanned 2.5 years in the present study and these findings reported do so for the first time, thus contributing to the knowledge-base surrounding respite care, dementia care and caregivers despite the limitations of the study described above.

8.10 DIRECTIONS FOR FUTURE RESEARCH

The recruitment of a similarly sized group of control subjects matched for age but not caregivers and not experiencing the effects of dementia could contextualise sleep and circadian rhythm outcomes in caregivers and care recipients with respect to a 'normative' sample. This approach would indicate the level of sleep disturbances in normal ageing, caregiving and in dementia, providing a more complete examination of the sleep of older people.

The present study was of prospective design and has revealed findings that may be useful in improving the management of dementia and for more effectively supporting caregivers in their caregiving responsibilities. However, following – up these participants in a more longitudinal design may be useful in identifying which caregivers are still providing care and how many have decided to institutionalise their care recipients, possibly providing information on the reasons for and the rate at which care breaks-down in the community Such a longitudinal approach could also detail the survival rates of care recipients and the examination of changes in sleep and circadian rhythm outcomes between Time 1 (the present study) and Time

2 (the proposed follow – up). This design could report on any changes in sleep and circadian rhythm outcomes over time, a question which has been examined in terms of dementia care recipients, but not in terms of caregivers or dyads (Prinz 1982; McCurry *et al* 2000).

The wide variation in dementia care recipient outcomes discussed in the previous sections may have influenced some of the non-significant findings generated by this study. Future examination of the sleep of older people with dementia and their caregivers could usefully recruit a larger sample within which sub-grouping interactions (e.g. bedroom partnership, diagnosis, gender and drug consumption) could be examined in order to establish a clearer understanding of the impact of respite care on the sleep of older people with dementia and their caregivers.

8.11 CONCLUSIONS

This section will conclude the findings from this study and will begin by pulling together the findings from the caregivers who participated in this study and their experiences of respite care. The sections following this will conclude those findings from the dementia care recipients who participated in the study; respite care services and policy recommendations. This section will conclude this thesis on the sleep of older people with dementia, their caregivers and the impact of respite care on these groups.

8.11.1 Caregiver sleep, circadian rhythmicity and respite care

The caregivers who participated in this study reported clinically disturbed sleep, as measured using the PSQI, in 78% of cases. Their sleep was disturbed very frequently (46% of the time at baseline) by their dependent older adults with dementia and these disturbances caused chronic daytime fatigue. Respite care service provision was the only opportunity that these caregivers had to gain some consolidated rest from their caregiving roles. For the first time, respite care service

provision has been linked to significant improvements in both objectively measured sleep / wake and circadian rhythm outcomes as well as subjective ratings of sleep outcomes and wellbeing for caregivers.

McCurry *et al* (2000) reported that, as caregiver sleep can be improved, then, by definition, their sleep must be suboptimal. This study can confirm that caregiver sleep outcomes can be improved, that caregivers describe their sleep experiences as sub-optimal (i.e. reduced SE, high WASO, high L5 and subjective reports) and that their sleep can be improved by an environmental / behavioural intervention in agreement with McCurry's *et al* (2000) conjecture. This study identifies dementia caregiving as a risk factor for developing chronic insomnia, high levels daytime sleepiness and reduced Health-Related Quality of Life.

8.11.2 Qualitative reports by caregivers on their experiences of respite care

The qualitative reports by the caregivers who participated in this study indicated significant improvements in caregiver self-rated feelings of wellbeing during periods of respite care. Approximately 90% of the caregivers sampled in this study stated that, if it had not been for respite care service provision for themselves and their care recipients, then they considered that they would no longer be providing care in the community. Caregivers who had only recently begun providing care often expressed feelings of guilt. They described feelings of inadequacy and, in some cases, feelings of failing their partner or parent in their decision to seek or accept a respite placement. However, of the caregivers who had received respite care services on a number of previous occasions these feelings of guilt were often superceded by a positive anticipation of the next respite period. Indeed, Watkins and Redfern (1997) described positive feelings toward the respite care intervention in most caregivers as they felt that the service allowed them to continue caring. However, they described some users as feeling unhappy or guilty about the use of respite for several reasons: some felt that they could not cope any more and so were being given respite care services; some felt their care recipient had not wanted to

leave the family home; and some that they had failed their care recipient by accepting a respite placement. Pearson also described feelings of guilt in 20% of his sample of caregivers as a result of accepting a respite placement. These feelings of guilt were also described by one caregiver in the qualitative data presented in Chapter 6.

Caregivers commonly described 'looking forward' to their next two-week break and would often have planned activities or extended periods of rest whilst away from their caregiving responsibilities. Most caregivers described using the respite care period to do things that they would otherwise be unable to do, for example, visiting the doctor, the dentist, socialising, extended shopping trips or other excursions (other than normal day-to-day grocery shopping). These caregivers described the respite care intervention as invaluable and many of them stated that if respite care provision had not been made available to them then they would have ceased caregiving and previously sought out a permanent placement in an institution for their partner or parent with dementia. Again these findings have been echoed by the qualitative responses of these caregivers (presented in Chapter 6) and in previous research into the effectiveness of respite care on improving caregiver wellbeing and extending extra-institutional care (Pearson 1988; Arksey *et al* 2004).

Many of these caregivers described an almost complete inability to get out of their homes to go shopping, make and meet appointments or pursue any other activity whilst providing care in the community. They described frustration and impotence at their inability to perform these usual Activities of Daily Living as a result of their dependent care recipients. Social inclusion and mental health status, as examined on the SF-36 Health-Related Quality of Life Questionnaire, were both substantially reduced compared to a 'normative' non-caregiving cohort and this identifies dementia caregiving as a risk factor for reduced mental health and social mobility. These caregivers described a lack of service provision whilst providing care in the community; a few caregivers had made contact with privately managed 'sitting'

services, but reported that these services were expensive, inflexible, sporadic, and required advanced booking. The inflexibility of these 'sitting services' meant that many of those caregivers who had engaged with this type of service found that they could not take full advantage of it and often remained isolated in their homes The reductions in caregiver mental health and social inclusion highlight this group as particularly 'at-risk' in the community. Further examination of the requirements for support services for caregivers in the community and the initiation of useable and inclusive support services are therefore required in order to support this vulnerable group more fully. Supporting community caregivers in their caregiving roles will enhance their quality of life, enhance the quality of lives of their charges, potentially extending care in the community and so result in reducing the substantial costs of state-borne institutional care.

8.11.3 Care recipient sleep, circadian rhythmicity and respite care

The care recipients who participated in this study displayed highly disturbed sleep / wake and circadian rhythm schedules, far more than was seen in the comparison group of non-dementing caregivers. Sleep times were highly variable, daytime napping was significantly more prevalent in these care recipients than their caregivers and nighttime activity levels were also significantly increased over those of their caregivers during periods of respite care These findings are congruent with the reported instrumental sleep outcomes of dementia care recipients by Ancoli-Israel *et al* (1997) and Van Someren *et al* (1996) who described high levels of variation in sleep and circadian rhythmicity outcomes in institutionalised older adults with dementia. However, these findings are described here in community-residing older adults with dementia for the first time. The impact of the respite care intervention on the sleep and circadian rhythmicity of sleep and wakefulness in these care recipients was pronounced, care recipients slept for significantly less time during the night during periods of respite care than at baseline or at follow - up. Similarly, the relative amplitudes of their circadian rhythms of activity were significantly reduced at respite than at baseline or follow – up. This study can

confirm the caregiver citations of disturbed sleep routines in dementia care recipients during respite care reported by Pearson (1988), indicating that most caregivers are aware of sleep disruption in dementia care recipients as a result of the respite care intervention and that respite care has a negative impact on dementia care recipient sleep routines. It should be noted that many caregivers still use respite care services despite this negative impact on their dementia care recipients, but would undoubtedly feel better about the service if this were not the case. Furthermore, should respite care services be improved for community-residing older adults with dementia. more caregivers may engage with these services than do so at present; those caregivers that do engage with these services but become disillusioned with them and withdraw may be encouraged to remain engaged with them, a commonly reported phenomenon (Melzer *et al* 1990; Levin *et al* 1994), and, these factors will extend community-based care, keeping families together for longer and relieving the state-borne burden of full-time institutional care. A burden that is pertinent not just in financial terms, but in terms of the availability of beds on wards, the numbers of available nursing / consultant and ancillary staff required to provide such care, and in terms of projected increases in demand resulting from the demographic age-shift that is being experienced throughout the developed world at the present time.

The relationship between dementing illnesses and sleep remains complex; this study has identified the sleep and activity characteristics of a group of older adults with dementia across community and hospital environments for the first time. Some of these older people with dementia slept very poorly, whereas others still maintained good quality sleep, the reasons for this remain unclear, but what emerges is that sleep in dementia is not impacted solely by neurological changes to the brain, but by multiple factors. These considerations have implications for the improved management of older people with dementia and in the quality of life of those with dementia and those providing care for them

8.11.4 Respite care services

The recent Cochrane review (Lee and Cameron 2004) on respite care services for older people with dementia and their caregivers highlighted a lack of knowledge on the usefulness or otherwise of the respite care intervention and called for well designed trials in this area. Indeed, Schultz *et al* (2002) described a lack of empirical evidence at the clinical level of significance for any caregiver interventions. This study is the first empirical trial of the respite care intervention and the findings from these dementia care recipients and their caregivers identify the respite care intervention as an important service in the lives of caregivers. The caregivers sampled in this study, as a whole, experienced benefits during respite care that were measurable, both in terms of actigraphically assessed sleep / wake and circadian rhythm schedules and in terms of the self-reporting of their sleep experiences. Caregivers described the service as invaluable and essential in their ability to maintain caregiving at home. Although these benefits of the respite care intervention are offset by reduced caregiver sleep outcomes at follow – up compared to the baseline period of the investigation. There is a clear indication here that caregivers have difficulties re-adapting to the caregiving role post-discharge.

The dementia care recipients who participated in this study experienced increased nighttime activity levels, reduced sleep times and increased fragmentation of their activity patterning during periods of respite care compared to the baseline and follow – up periods of the study. Respite care service providers should therefore examine opportunities to reduce nighttime disturbance factors in the hospital in order to have a positive impact on care recipient sleep and on nighttime activity levels on the ward. Schnelle *et al* (1998) identified increased noise and light factors in the hospital and hypothesised that the reduction of these nighttime noise and light levels would improve the sleep of hospital in-patients. The present study, although not measuring noise or light *per se*, does lend credence to the work of Schnelle *et al* (1998) in that nighttime sleep in the hospital is impacted negatively

by the novelty of sleeping in the hospital and other factors that are possibly not present at-home. For example: other patients, nighttime cleaning staff and other extra-patient noise sources, such as opening and closing doors, alarms and other hospital technology / equipment Indeed, Alessi *et* al (1999) showed improvements to the sleep of a group of institutionalised older adults with dementia as a result of reducing noise and light sources within the hospital environment suggesting that this approach is beneficial to the sleep of older adults with dementia.

The findings of the present study cannot generalise beyond the sleep and circadian rhythmicity of dementia care recipients, as older adults with other conditions have not been examined by the present study. However, the present study has identified respite care as instrumental in providing caregivers with necessary breaks from caregiving (Travers 1996; Royal Commission for the Long Term Care of the Elderly 1999) and shown that these periods of rest are indeed tangible for caregivers both in objectively and subjectively reported sleep outcomes. Intervention at times of entry to and exit from respite for caregivers may facilitate the move in and out of the hospital environment and assist caregivers at these times, possibly augmenting reductions in caregiver sleep quantity and quality at follow - up.

8.11.5 Policy recommendations

Despite the potential usefulness to respite care staff, no information on care recipient sleep patterns follows them into the hospital, resulting in all dementia care recipients receiving similar approaches to treatment. Furthermore, respite care, as it is currently organised offers no therapeutic interventions for disturbed sleep patterns in dementia care recipients (or indeed any other therapeutic interventions other than pharmacological approaches or the very basic daycare), this is a lost opportunity for care staff to intervene with these older people with dementia and to possibly enhance their lives From the perspective of community caregivers, no advice is provided on sleep management or sleep hygiene practices by any health or

social care service providers, again providing another lost opportunity to intervene with and potentially enhance the lives of older people with dementia and their caregivers.

Respite care services, as they are presently organised, act as a source of sleep disruption for dementia care recipients during the intervention and for caregivers post-discharge. This latter point is of most concern, as the intervention, which is designed to alleviate caregiver stress, does not appear to serve them well in the long-term. By returning their care recipients into the community with more corrupted sleep and disorganised activity patterns than when they entered the hospital and no useful advice on how to effectively manage dementia care recipient sleep disturbances, caregivers are unsurprisingly experiencing reduced sleep outcomes and potentially reduced quality of life at follow – up.

In light of the findings from this research, healthcare providers and service managers should investigate the following areas in order to enhance and develop services for older adults with dementia and their caregivers:

- Examine opportunities to reduce nighttime disturbance factors in the hospital
- Develop support services and advisory strategies for caregivers to assist them in managing sleep disturbances in dementia (for themselves and their charges) and in readapting to their caregiving role post-respite
- Conduct further research into reducing nighttime and increasing daytime activity levels in older people with dementia and so enhance their nighttime sleep outcomes e g. reducing daytime napping
- Identify and develop services for caregivers to give them the opportunity to take short periods of time for day-to-day appointments etc...
  (e.g. an inclusive, affordable and flexible sitting service)

In conclusion, the respite care intervention, so enjoyed by caregivers must be regarded as a valued and important service for caregivers. The benefits of this intervention for caregivers in improving their sleep outcomes and providing an opportunity for them to rest can only: facilitate their ability to provide suitable levels of care in the community; enhance their ability to do so for longer time periods, keep families together for longer; and so alleviate some of the state-borne financial and strategic burdens of permanent institutional care. Although the reduced sleep quantity measured at follow – up suggests a potentially self-generating requirement for respite care. Caregivers remain unaware of this 'cost' of respite care, but were they to become aware, they would certainly be willing to pay this cost, as these caregivers described respite as beneficial and as vital for it was their only chance for a rest.

Both the Audit commission (2000) and the Carers 2000 (ONS 2002) report that caregivers have a right to at least two-weeks of respite care per-year. At the present time the respite care service has received very little attention in terms of the definition, effectiveness and evaluation of its purpose. The recent SDO report on respite care (Arksey *et al* 2004) identified a requirement for other support services to back-up respite care in order to provide time for caregivers to manage their own emotional and physical health. This SDO report (2004) also confirms a lack of evidence in the literature and a paucity of information on key outcomes with which to measure the effectiveness of respite care services. The present study therefore, details for the first time, a systematic, empirical evaluation, using suitable outcome measurements (sleep outcomes and quality of life measures) of respite care services from the perspective of both dementia caregivers and their dependent older adults with dementia. It is the hope of the author that the information contained herein can be used effectively to make respite care services more beneficial for older adults with dementia and their caregivers

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Appendix 1 Caregiver consent form.

Declaration

Sleep, Dementia and 24 hour Activity

Principal Investigator: Professor Kevin Morgan

I agree to take part in the above study as described in the Information Sheets.

I have read the patient information sheets on the above study and have had the opportunity to discuss the details with _____and ask any questions. The nature and the purpose of the assessments to be undertaken have been explained to me and I understand what will be required if I take part in the study. I understand that I may withdraw from the study at any time without justifying my decision and without affecting the care and services I usually receive.

I understand that members of the research team may wish to view relevant medical records, but that all the information will be treated as confidential.

I understand medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

Signature _____ Name _____

Date _____

I confirm I have explained the nature of the study, as detailed in the Patient Information Sheet, in terms which in my judgement are suited to the understanding of the patient.

Signature of Investigator _____ Name _____

Date_____

Appendix 2 Care recipient consent form.

Sleep, Dementia and 24 hour Activity
Principal Investigator: Professor Kevin Morgan

CARE RECIPIENT CONSENT FORM

This form should be read in conjunction with the Patient Information Sheets

I agree to take part in the above study as described in the Patient Information Sheets. I understand that I may withdraw from the study at any time without justifying my decision and without affecting my normal care and medical management.

I understand that members of the research team may wish to view relevant sections of my medical records, but that all the information will be treated as confidential. I understand medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

I have read the patient information sheets on the above study and have had the opportunity to discuss the details with .....and ask any questions. The nature and the purpose of the assessments to be undertaken have been explained to me and I understand what will be required if I take part in the study.

Signature of patient_____
Date_____

Name in BLOCK LETTERS_____

I confirm I have explained the nature of the study, as detailed in the Patient Information Sheet, in terms which in my judgement are suited to the understanding of the patient.

Signature of Investigator _____
Date_____

Name in BLOCK LETTERS _____

Appendix 3. Pittsburgh Sleep Quality Index (PSQI)

The Pittsburgh Sleep Quality Index

Name_____ Date_____

Instructions:

The following questions relate to your usual sleep habits during the past month *only*. Your answers should indicate the most accurate reply for the *majority* of days and nights in the past month. Please answer all the questions

1. During the past month, when have you usually gone to bed at night?

   usual bed time_____

2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?

   number of minutes_____

3. During the past month, when have you usually got up in the morning?

   usual getting up time_____

4. During the past month, how many hours of *actual* sleep did you get at night? (This may be different than the number of hours you spend in bed).

   hours of sleep per night_____

For each of the remaining questions, check the one best response. Please answer *all* questions.

5 During the past month, how often have you had trouble sleeping because you.....

(a) Cannot get to sleep within 30 minutes

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(b) Wake up in the middle of the night or early morning

Not during the past month____	Less than once a week_____	Once or twice a week_____	Three or more times a week_____

(c) Have to get up to use the bathroom

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(d) Cannot breathe comfortably

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(e) Cough or snore loudly

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(f) Feel too cold

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(g) Feel too hot

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(h) Had bad dreams

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(i) Have pain

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

(j) Other reason(s), please describe_____

_____

_____

How often during the past month have you had trouble sleeping because of this?

Not during the	Less than	Once or	three or more

past month____ once a week_____ twice a week_____ times a week_____

6. During the past month, how would you rate your sleep quality overall?

Very good_____
Fairly good_____
Fairly bad_____
Very bad_____

7. During the past month, how often have you taken medicine (prescribed or " over the counter") to help you sleep?

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?

Not during the past month____	Less than once a week_____	Once or twice a week_____	three or more times a week_____

9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

No problem at all_____
Only a very slight problem__
Somewhat of a problem_____
A very big problem_____

10 Do you have a bed partner or roommate?

No bed partner or roommate _____
Partner/roommate in other room _____
Partner in same room, but not same bed____
Partner in same bed _____

11. How often do you feel tired during the following times during the day?

Morning:

0	1	2	3
most days	often	occasionally	never

Afternoon:

0	1	2	3
most days	often	occasionally	never

Evening:

0	1	2	3
most days	often	occasionally	never

Appendix 4. The Epworth Sleepiness Scale.

The Epworth Sleepiness Scale

Initials: _____
Date: _____
Date of Birth: _____
Gender: Male/ Female (delete as appropriate)

How likely are you to doze off or fall asleep in the following situations, in contrast to just feeling tired? This refers to your usual way of life in recent times. Even if you have not done some of these things recently, try to work out how they would have affected you.

Use the following Scale to choose the most appropriate number for each situation

0 - would never doze
1 - slight chance of dozing
2 - moderate chance of dozing
3 - high chance of dozing

Situation Chance of Dozing

Sitting and reading _____
Watching TV _____
Sitting, inactive in a public place (e g. Cinema)_____
As a passenger in a car for an hour with out a break _____
Lying down to rest in the afternoon when given a chance _____
Sitting and talking to someone _____
Sitting quietly after lunch with out alcohol _____
In a car, while stopped for a few minutes in traffic _____

Office Use Only: **Score** _____

Appendix 5. The SF-36 Health-Related Quality of Life Questionnaire

The SF-36v2 Health Survey

Instructions for Completing the Questionnaire

Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

EXAMPLE

This is for your review. Do not answer this question. The questionnaire begins with the section ***Your Health in General*** below.
For each question you will be asked to fill in a bubble in each line:

1. How strongly do you agree or disagree with each of the following statements?
Strongly agree Agree Uncertain Disagree Stronglydisagree
a) I enjoy listening to music.
b) I enjoy reading magazines.

Please begin answering the questions now.

Your Health in General

1. In general, would you say your health is:

Excellent
Very good
Good
Fair
Poor

2. **Compared to one year ago,** how would you rate your health in general now?

Much better now than one year ago
Somewhat better now than one year ago
About the same as one year ago
Somewhat worse now than one year ago
Much worse now than one year ago

Please turn the page and continue.

3. The following questions are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

Yes, limited a lot
Yes, limited a little
No, not limited at all

a) **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports

b) **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

c) Lifting or carrying groceries

d) Climbing **several** flights of stairs

e) Climbing **one** flight of stairs

f) Bending, kneeling, or stooping

g) Walking **more than a mile**

h) Walking **several hundred yards**

i) Walking **one hundred yards**

j) Bathing or dressing yourself

4. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

All of the time
Most of the time
Some of the time
A little of the time
None of the time

a) Cut down on the **amount of time** you spent on work or other activities

b) **Accomplished less** than you would like

c) Were limited in the **kind** of work or other activities

d) Had **difficulty** performing the work or other activities (for example, it took extra effort)

Please turn the page and continue.

5. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

All of the time
Most of the time
Some of the time
A little of the time
None of the time

a) Cut down on the **amount of time** you spent on work or other activities

b) **Accomplished less** than you would like

c) Did work or other activities **less carefully than usual**

6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all
Slightly
Moderately
Quite a bit
Extremely

7. How much bodily pain have you had during the **past 4 weeks**?

None
Very mild
Mild
Moderate
Severe

8 During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all
A little bit
Moderately
Quite a bit
Extremely

Please turn the page and continue.

9. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the **past 4 weeks**.

All of the time
Most of the time
Some of the time
A little of the time
None of the time

a) did you feel full of life?
b) have you been very nervous?
c) have you felt so down in the dumps nothing could cheer you up?
d) have you felt calm and peaceful?
e) did you have a lot of energy?
f) have you felt downhearted and depressed?
g) did you feel worn out?
h) have you been happy?
i) did you feel tired?

10. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)?

All of the time
Most of the time
Some of the time
A little of the time
None of the time

11. How TRUE or FALSE is each of the following statements for you?
Definitely true
Mostly true
Don't know
Mostly false
Definitely false

a) I seem to get sick a little easier than other people
b) I am as healthy as anybody I know
c) I expect my health to get worse
d) My health is excellent

***THANK YOU* FOR COMPLETING THIS QUESTIONNAIRE!**

Appendix 6. Loughborough University Sleep Diary

Loughborough University

Daily Sleep Diary

Initials:		Date of Birth:			Date of Day 1:			
		Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
1	At what time did you go to bed last night?							
2	After settling down, how long did it take you to fall asleep?							
3	After falling asleep, for how long were you awake during the night in total?							
4	At what time did you finally wake up?							
5	At what time did you get up?							
6	Did you take a sleeping tablet last night?							
7	At what time did you put your friend or relative to bed?							
8	At what time did they awake in the morning?							
9	Did they disturb you in the night? How many times?							
	And for how long (minutes)?							

1	How well do you feel this morning? **0 1 2 3 4** not at all moderately very							
2	How enjoyable was your sleep last night? **0 1 2 3 4** not at all moderately very							
3	How active was your mind in bed last night? **0 1 2 3 4** not at all moderately very							
4	How physically tense were you in bed last night? **0 1 2 3 4** not at all moderately very							
5	How anxious were you in bed last night? **0 1 2 3 4** not at all moderately very							

Appendix 7. Post Study Questionnaire.

Post-Study Questionnaire

Caregiver

Name.

Sex:

Date of Birth:

Age:

Relationship to Patient:

Sleep Problems (None,

Onset, Maintenance, EMA)

Does Patient Snore?
If so, how severely (Mild, Moderate, Severe)?

Does dependants snoring disturb caregiver?
If so, how much disturbance (Mild, Moderate, Severe)?

Medications:

Drug Name	Dose	Frequency

Care recipient

Name:

Sex:

Date of Birth:

Age:

Sleep Problems (None, Onset,

Maintenance, EMA):

Medications:

Drug Name	Dose	Frequency

Diagnosis.

Date of Diagnosis:

Date of First Respite Admission:

Number of Respite Admissions:

GLOSSARY OF TERMS

Acronym	Definition (units where applicable)
AD	Alzheimer's Disease
ASDA	American sleep disorders association
EEG	Electroencephalography (see also PSG)
FTD	Fronto-temporal dementia
IS	Interdaily stability
IV	Intradaily variability
L5	Lowest five consecutive hours of activity (activity score)
MID	Multi-infarct dementia (also Vascular dementia (VaD))
OAWD	Older adults with dementia
OAWI	Older adults with insomnia
OPWD	Older people with dementia
PSG	Polysomnography (the same as EEG)
RA	Relative amplitude of the circadian rhythm (index)
SDAT	Senile dementia of the Alzheimer type
SE	Sleep efficiency (%)
SOL	Sleep onset latency (minutes)
sSE	Subjectively rated sleep efficiency (%)
sSOL	Subjectively rated sleep onset latency (minutes)
sTST	Subjectively rated total sleep time (minutes)
sWASO	Subjectively rated wake-time after sleep onset (minutes)
SWS	Slow wave sleep
TIB	Time in bed (minutes)
TNT	Total nap time (minutes)
TST	Total sleep time (minutes)
VaD	Vascular dementia (also Multi-infarct dementia (MID)
WASO	Wake-time after sleep onset (minutes)
24ST	24-hour sleep time (minutes)

Appendix 9
Caregiver ANOVA tables

Caregiver TST 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	7332 331	2	3666 165	7 112	002
	Greenhouse-Geisser	7332 331	1 442	5084 670	7 112	005
	Huynh-Feldt	7332 331	1 542	4754 122	7 112	004
	Lower-bound	7332 331	1 000	7332 331	7 112	012
FACTOR1 * BPARTNER	Sphericity Assumed	1892 703	2	946 351	1 836	168
	Greenhouse-Geisser	1892 703	1 442	1312 512	1 836	179
	Huynh-Feldt	1892 703	1 542	1227 187	1 836	178
	Lower-bound	1892 703	1 000	1892 703	1 836	185
Error(FACTOR1)	Sphericity Assumed	31958 463	62	515 459		
	Greenhouse-Geisser	31958 463	44 703	714 899		
	Huynh-Feldt	31958 463	47 812	668 425		
	Lower-bound	31958 463	31 000	1030 918		

Caregiver WASO 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	232 227	2	116 113	770	468
	Greenhouse-Geisser	232 227	1 588	146 218	770	441
	Huynh-Feldt	232 227	1 718	135 140	770	450
	Lower-bound	232 227	1 000	232 227	770	387
FACTOR1 * BPARTNER	Sphericity Assumed	270 298	2	135 149	896	414
	Greenhouse-Geisser	270 298	1 588	170 188	896	394
	Huynh-Feldt	270 298	1 718	157 295	896	401
	Lower-bound	270 298	1 000	270 298	896	351
Error(FACTOR1)	Sphericity Assumed	9048 249	60	150 804		
	Greenhouse-Geisser	9048 249	47 647	189 903		
	Huynh-Feldt	9048 249	51 552	175 515		
	Lower-bound	9048 249	30 000	301 608		

Caregiver SE 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	147 033	2	73 517	4 728	012
	Greenhouse-Geisser	147 033	1 685	87 244	4 728	017
	Huynh-Feldt	147 033	1 829	80 392	4 728	015
	Lower-bound	147 033	1 000	147 033	4 728	037
FACTOR1 * BPARTNER	Sphericity Assumed	4 350	2	2 175	140	870
	Greenhouse-Geisser	4 350	1 685	2 581	140	835
	Huynh-Feldt	4 350	1 829	2 378	140	852
	Lower-bound	4 350	1 000	4 350	140	711
Error(FACTOR1)	Sphericity Assumed	963 954	62	15 548		
	Greenhouse-Geisser	963 954	52 245	18 451		
	Huynh-Feldt	963 954	56 698	17 002		
	Lower-bound	963 954	31 000	31 095		

Appendix 9
Caregiver ANOVA tables

Caregiver SOL 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	143 678	2	71 839	727	488
	Greenhouse-Geisser	143 678	1 574	91 276	727	459
	Huynh-Feldt	143 678	1 723	83 409	727	470
	Lower-bound	143 678	1 000	143 678	727	402
FACTOR1 * BPARTNER	Sphericity Assumed	80 725	2	40 363	408	667
	Greenhouse-Geisser	80 725	1 574	51 283	408	619
	Huynh-Feldt	80 725	1 723	46 864	408	637
	Lower-bound	80 725	1 000	80 725	408	528
Error(FACTOR1)	Sphericity Assumed	5141 822	52	98 881		
	Greenhouse-Geisser	5141 822	40 927	125 634		
	Huynh-Feldt	5141 822	44 787	114 807		
	Lower-bound	5141 822	26 000	197 762		

Caregiver 24 hour sleep time 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	3274 319	2	1637 159	2 297	109
	Greenhouse-Geisser	3274 319	1 638	1998 888	2 297	120
	Huynh-Feldt	3274 319	1 778	1841 913	2 297	116
	Lower-bound	3274 319	1 000	3274 319	2 297	140
FACTOR1 * BPARTNER	Sphericity Assumed	1401 708	2	700 854	983	380
	Greenhouse-Geisser	1401 708	1 638	855 707	983	367
	Huynh-Feldt	1401 708	1 778	788 507	983	372
	Lower-bound	1401 708	1 000	1401 708	983	329
Error(FACTOR1)	Sphericity Assumed	42765 902	60	712 765		
	Greenhouse-Geisser	42765 902	49 142	870 250		
	Huynh-Feldt	42765 902	53 330	801 908		
	Lower-bound	42765 902	30 000	1425 530		

Caregiver IS

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	1 197E-02	2	5 986E-03	3 840	027
	Greenhouse-Geisser	1 197E-02	1 644	7 284E-03	3 840	036
	Huynh-Feldt	1 197E-02	1 784	6 710E-03	3 840	032
	Lower-bound	1 197E-02	1 000	1 197E-02	3 840	059
FACTOR1 * BPARTNER	Sphericity Assumed	1 727E-03	2	8 635E-04	554	578
	Greenhouse-Geisser	1 727E-03	1 644	1 051E-03	554	545
	Huynh-Feldt	1 727E-03	1 784	9 679E-04	554	558
	Lower-bound	1 727E-03	1 000	1 727E-03	554	462
Error(FACTOR1)	Sphericity Assumed	9 352E-02	60	1 559E-03		
	Greenhouse-Geisser	9 352E-02	49 308	1 897E-03		
	Huynh-Feldt	9 352E-02	53 528	1 747E-03		
	Lower-bound	9 352E-02	30 000	3 117E-03		

Appendix 9
Caregiver ANOVA tables

Caregiver IV

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	6 828E-03	2	3 414E-03	320	728
	Greenhouse-Geisser	6 828E-03	1 876	3 641E-03	320	714
	Huynh-Feldt	6 828E-03	2 000	3 414E-03	320	728
	Lower-bound	6 828E-03	1 000	6 828E-03	320	576
FACTOR1 * BPARTNER	Sphericity Assumed	3 017E-02	2	1 509E-02	1 412	252
	Greenhouse-Geisser	3 017E-02	1 876	1 609E-02	1 412	252
	Huynh-Feldt	3 017E-02	2 000	1 509E-02	1 412	252
	Lower-bound	3 017E-02	1 000	3 017E-02	1 412	244
Error(FACTOR1)	Sphericity Assumed	641	60	1 068E-02		
	Greenhouse-Geisser	641	56 265	1 139E-02		
	Huynh-Feldt	641	60 000	1 068E-02		
	Lower-bound	641	30 000	2 136E-02		

Caregiver TNT 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	989 125	2	494 562	1 599	210
	Greenhouse-Geisser	989 125	1 885	524 685	1 599	212
	Huynh-Feldt	989 125	2 000	494 562	1 599	210
	Lower-bound	989 125	1 000	989 125	1 599	215
FACTOR1 * BPARTNER	Sphericity Assumed	138 095	2	69 048	223	801
	Greenhouse-Geisser	138 095	1 885	73 253	223	788
	Huynh-Feldt	138 095	2 000	69 048	223	801
	Lower-bound	138 095	1 000	138 095	223	640
Error(FACTOR1)	Sphericity Assumed	19175 680	62	309 285		
	Greenhouse-Geisser	19175 680	58 441	328 123		
	Huynh-Feldt	19175 680	62 000	309 285		
	Lower-bound	19175 680	31 000	618 570		

Caregiver RA

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	5 545E-03	2	2 772E-03	2 243	115
	Greenhouse-Geisser	5 545E-03	1 919	2 890E-03	2 243	117
	Huynh-Feldt	5 545E-03	2 000	2 772E-03	2 243	115
	Lower-bound	5 545E-03	1 000	5 545E-03	2 243	145
FACTOR1 * BPARTNER	Sphericity Assumed	9 524E-04	2	4 762E-04	385	682
	Greenhouse-Geisser	9 524E-04	1 919	4 964E-04	385	673
	Huynh-Feldt	9 524E-04	2 000	4 762E-04	385	682
	Lower-bound	9 524E-04	1 000	9 524E-04	385	539
Error(FACTOR1)	Sphericity Assumed	7 415E-02	60	1 236E-03		
	Greenhouse-Geisser	7 415E-02	57 560	1 288E-03		
	Huynh-Feldt	7 415E-02	60 000	1 236E-03		
	Lower-bound	7 415E-02	30 000	2 472E-03		

Appendix 9
Caregiver ANOVA tables

Caregiver L5

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	759847 790	2	379923 895	8 058	001
	Greenhouse-Geisser	759847 790	1 774	428292 175	8 058	001
	Huynh-Feldt	759847 790	1 941	391573 188	8 058	001
	Lower-bound	759847 790	1 000	759847 790	8 058	008
FACTOR1 * BPARTNER	Sphericity Assumed	125367 960	2	62683 980	1 329	272
	Greenhouse-Geisser	125367 960	1 774	70664 305	1 329	271
	Huynh-Feldt	125367 960	1 941	64606 007	1 329	272
	Lower-bound	125367 960	1 000	125367 960	1 329	258
Error(FACTOR1)	Sphericity Assumed	2829051 612	60	47150 860		
	Greenhouse-Geisser	2829051 612	53 224	53153 657		
	Huynh-Feldt	2829051 612	58 215	48596 608		
	Lower-bound	2829051 612	30 000	94301 720		

Caregiver TIB 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	1847 908	2	923 954	1 498	232
	Greenhouse-Geisser	1847 908	1 997	925 337	1 498	232
	Huynh-Feldt	1847 908	2 000	923 954	1 498	232
	Lower-bound	1847 908	1 000	1847 908	1 498	231
FACTOR1 * BPARTNER	Sphericity Assumed	2132 851	2	1066 426	1 728	186
	Greenhouse-Geisser	2132 851	1 997	1068 023	1 728	186
	Huynh-Feldt	2132 851	2 000	1066 426	1 728	186
	Lower-bound	2132 851	1 000	2132 851	1 728	199
Error(FACTOR1)	Sphericity Assumed	37018 711	60	616 979		
	Greenhouse-Geisser	37018 711	59 910	617 902		
	Huynh-Feldt	37018 711	60 000	616 979		
	Lower-bound	37018 711	30 000	1233 957		

Caregiver subjective sleep time 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	4009 551	2	2004 775	1 443	246
	Greenhouse-Geisser	4009 551	1 739	2305 236	1 443	247
	Huynh-Feldt	4009 551	1 942	2065 024	1 443	247
	Lower-bound	4009 551	1 000	4009 551	1 443	241
FACTOR1 * BPARTNER	Sphericity Assumed	9045 983	2	4522 991	3 255	047
	Greenhouse-Geisser	9045 983	1 739	5200 863	3 255	055
	Huynh-Feldt	9045 983	1 942	4658 918	3 255	049
	Lower-bound	9045 983	1 000	9045 983	3 255	084
Error(FACTOR1)	Sphericity Assumed	66701 758	48	1389 620		
	Greenhouse-Geisser	66701 758	41 744	1597 885		
	Huynh-Feldt	66701 758	46 600	1431 381		
	Lower-bound	66701 758	24 000	2779 240		

Appendix 9
Caregiver ANOVA tables

Caregiver subjective sleep efficiency 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	31 571	2	15 785	503	608
	Greenhouse-Geisser	31 571	1 518	20 799	503	558
	Huynh-Feldt	31 571	1 673	18 867	503	576
	Lower-bound	31 571	1 000	31 571	503	485
FACTOR1 * BPARTNER	Sphericity Assumed	148 523	2	74 261	2 368	105
	Greenhouse-Geisser	148 523	1 518	97 848	2 368	120
	Huynh-Feldt	148 523	1 673	88 757	2 368	115
	Lower-bound	148 523	1 000	148 523	2 368	137
Error(FACTOR1)	Sphericity Assumed	1442 462	46	31 358		
	Greenhouse-Geisser	1442 462	34 912	41 318		
	Huynh-Feldt	1442 462	38 487	37 479		
	Lower-bound	1442 462	23 000	62 716		

Caregiver subjective sleep onset latency 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	773 249	2	386 625	1 406	253
	Greenhouse-Geisser	773 249	1 959	394 758	1 406	253
	Huynh-Feldt	773 249	2 000	386 625	1 406	253
	Lower-bound	773 249	1 000	773 249	1 406	245
FACTOR1 * BPARTNER	Sphericity Assumed	167 874	2	83 937	305	738
	Greenhouse-Geisser	167 874	1 959	85 703	305	734
	Huynh-Feldt	167 874	2 000	83 937	305	738
	Lower-bound	167 874	1 000	167 874	305	585
Error(FACTOR1)	Sphericity Assumed	17053 891	62	275 063		
	Greenhouse-Geisser	17053 891	60 723	280 849		
	Huynh-Feldt	17053 891	62 000	275 063		
	Lower-bound	17053 891	31 000	550 126		

Caregiver subjective WASO 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	4119 030	2	2059 515	3 145	050
	Greenhouse-Geisser	4119 030	1 881	2189 745	3 145	054
	Huynh-Feldt	4119 030	2 000	2059 515	3 145	050
	Lower-bound	4119 030	1 000	4119 030	3 145	086
FACTOR1 * BPARTNER	Sphericity Assumed	696 353	2	348 177	532	590
	Greenhouse-Geisser	696 353	1 881	370 193	532	580
	Huynh-Feldt	696 353	2 000	348 177	532	590
	Lower-bound	696 353	1 000	696 353	532	472
Error(FACTOR1)	Sphericity Assumed	39294 091	60	654 902		
	Greenhouse-Geisser	39294 091	56 432	696 313		
	Huynh-Feldt	39294 091	60 000	654 902		
	Lower-bound	39294 091	30 000	1309 803		

Appendix 10
Care recipient ANOVA tables

Care recipient TST 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	22939 493	2	11469 746	4 457	016
	Greenhouse-Geisser	22939 493	1 877	12220 756	4 457	018
	Huynh-Feldt	22939 493	2 000	11469 746	4 457	016
	Lower-bound	22939 493	1 000	22939 493	4 457	045
FACTOR1 * BPARTNER	Sphericity Assumed	3247 109	2	1623 555	631	536
	Greenhouse-Geisser	3247 109	1 877	1729 861	631	527
	Huynh-Feldt	3247 109	2 000	1623 555	631	536
	Lower-bound	3247 109	1 000	3247 109	631	434
Error(FACTOR1)	Sphericity Assumed	133830 035	52	2573 655		
	Greenhouse-Geisser	133830 035	48 804	2742 171		
	Huynh-Feldt	133830 035	52 000	2573 655		
	Lower-bound	133830 035	26 000	5147 309		

Care recipient WASO 2 weekly bins

Tests of Within-Subjects

Measure

Source		Type III of	df	Mean	F	Sig
FACTOR	Sphericity	786 24	2	393 12	947	394
	Greenhouse-	786 24	1 824	431 15	947	388
	Huynh-	786 24	2 000	393 12	947	394
	Lower-	786 24	1 000	786 24	947	339
FACTOR1 *	Sphericity	115 21	2	57 608	139	871
	Greenhouse-	115 21	1 824	63 181	139	852
	Huynh-	115 21	2 000	57 608	139	871
	Lower-	115 21	1 000	115 21	139	713
Error(FACTOR	Sphericity	21586 50	52	415 12		
	Greenhouse-	21586 50	47 413	455 28		
	Huynh-	21586 50	52 000	415 12		
	Lower-	21586 50	26 000	830 25		

Care recipient sleep efficiency 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	241 366	2	120 683	2 324	108
	Greenhouse-Geisser	241 366	1 946	124 016	2 324	110
	Huynh-Feldt	241 366	2 000	120 683	2 324	108
	Lower-bound	241 366	1 000	241 366	2 324	139
FACTOR1 * BPARTNER	Sphericity Assumed	120 967	2	60 484	1 165	320
	Greenhouse-Geisser	120 967	1 946	62 154	1 165	319
	Huynh-Feldt	120 967	2 000	60 484	1 165	320
	Lower-bound	120 967	1 000	120 967	1 165	290
Error(FACTOR1)	Sphericity Assumed	2699 877	52	51 921		
	Greenhouse-Geisser	2699 877	50 602	53 355		
	Huynh-Feldt	2699 877	52 000	51 921		
	Lower-bound	2699 877	26 000	103 841		

Appendix 10
Care recipient ANOVA tables

Care recipient SOL 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	1497 379	2	748 689	916	407
	Greenhouse-Geisser	1497 379	1 640	912 859	916	391
	Huynh-Feldt	1497 379	1 810	827 133	916	399
	Lower-bound	1497 379	1 000	1497 379	916	348
FACTOR1 * BPARTNER	Sphericity Assumed	2938 040	2	1469 020	1 797	176
	Greenhouse-Geisser	2938 040	1 640	1791 140	1 797	184
	Huynh-Feldt	2938 040	1 810	1622 936	1 797	180
	Lower-bound	2938 040	1 000	2938 040	1 797	192
Error(FACTOR1)	Sphericity Assumed	40874 079	50	817 482		
	Greenhouse-Geisser	40874 079	41 008	996 735		
	Huynh-Feldt	40874 079	45 258	903 133		
	Lower-bound	40874 079	25 000	1634 963		

Care recipient TNT 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	9805 020	2	4902 510	2 704	077
	Greenhouse-Geisser	9805 020	1 773	5529 146	2 704	084
	Huynh-Feldt	9805 020	1 984	4941 042	2 704	078
	Lower-bound	9805 020	1 000	9805 020	2 704	113
FACTOR1 * BPARTNER	Sphericity Assumed	2599 875	2	1299 938	717	493
	Greenhouse-Geisser	2599 875	1 773	1466 095	717	478
	Huynh-Feldt	2599 875	1 984	1310 155	717	492
	Lower-bound	2599 875	1 000	2599 875	717	406
Error(FACTOR1)	Sphericity Assumed	87028 849	48	1813 101		
	Greenhouse-Geisser	87028 849	42 560	2044 851		
	Huynh-Feldt	87028 849	47 626	1827 351		
	Lower-bound	87028 849	24 000	3626 202		

Care recipient 24 TST 2 weekly bins

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	33075 020	2	16537 510	3 895	027
	Greenhouse-Geisser	33075 020	1 986	16653 779	3 895	027
	Huynh-Feldt	33075 020	2 000	16537 510	3 895	027
	Lower-bound	33075 020	1 000	33075 020	3 895	059
FACTOR1 * BPARTNER	Sphericity Assumed	19172 168	2	9586 084	2 258	115
	Greenhouse-Geisser	19172 168	1 986	9653 480	2 258	115
	Huynh-Feldt	19172 168	2 000	9586 084	2 258	115
	Lower-bound	19172 168	1 000	19172 168	2 258	145
Error(FACTOR1)	Sphericity Assumed	220794 194	52	4246 042		
	Greenhouse-Geisser	220794 194	51 637	4275 895		
	Huynh-Feldt	220794 194	52 000	4246 042		
	Lower-bound	220794 194	26 000	8492 084		

Appendix 10
Care recipient ANOVA tables

Care recipient IS

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	2 516E-03	2	1 258E-03	265	768
	Greenhouse-Geisser	2 516E-03	1 844	1 364E-03	265	750
	Huynh-Feldt	2 516E-03	2 000	1 258E-03	265	768
	Lower-bound	2 516E-03	1 000	2 516E-03	265	611
FACTOR1 * BPARTNER	Sphericity Assumed	6 040E-04	2	3 020E-04	064	938
	Greenhouse-Geisser	6 040E-04	1 844	3 275E-04	064	927
	Huynh-Feldt	6 040E-04	2 000	3 020E-04	064	938
	Lower-bound	6 040E-04	1 000	6 040E-04	064	803
Error(FACTOR1)	Sphericity Assumed	247	52	4 742E-03		
	Greenhouse-Geisser	247	47 951	5 143E-03		
	Huynh-Feldt	247	52 000	4 742E-03		
	Lower-bound	247	26 000	9 485E-03		

Care recipient IV

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	9 414E-02	2	4 707E-02	1 148	325
	Greenhouse-Geisser	9 414E-02	1 551	6 071E-02	1 148	316
	Huynh-Feldt	9 414E-02	1 694	5 557E-02	1 148	319
	Lower-bound	9 414E-02	1 000	9 414E-02	1 148	294
FACTOR1 * BPARTNER	Sphericity Assumed	6 484E-02	2	3 242E-02	791	459
	Greenhouse-Geisser	6 484E-02	1 551	4 181E-02	791	431
	Huynh-Feldt	6 484E-02	1 694	3 827E-02	791	441
	Lower-bound	6 484E-02	1 000	6 484E-02	791	382
Error(FACTOR1)	Sphericity Assumed	2 132	52	4 100E-02		
	Greenhouse-Geisser	2 132	40 319	5 288E-02		
	Huynh-Feldt	2 132	44 048	4 840E-02		
	Lower-bound	2 132	26 000	8 200E-02		

Care recipient RA

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	6 515E-02	2	3 258E-02	9 135	000
	Greenhouse-Geisser	6 515E-02	1 915	3 402E-02	9 135	000
	Huynh-Feldt	6 515E-02	2 000	3 258E-02	9 135	000
	Lower-bound	6 515E-02	1 000	6 515E-02	9 135	006
FACTOR1 * BPARTNER	Sphericity Assumed	1 698E-02	2	8 488E-03	2 380	103
	Greenhouse-Geisser	1 698E-02	1 915	8 865E-03	2 380	105
	Huynh-Feldt	1 698E-02	2 000	8 488E-03	2 380	103
	Lower-bound	1 698E-02	1 000	1 698E-02	2 380	135
Error(FACTOR1)	Sphericity Assumed	185	52	3 566E-03		
	Greenhouse-Geisser	185	49 789	3 725E-03		
	Huynh-Feldt	185	52 000	3 566E-03		
	Lower-bound	185	26 000	7 132E-03		

Care recipient L5

Tests of Within-Subjects Effects

Measure MEASURE_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Sphericity Assumed	1811224 536	2	905612 268	2 180	123
	Greenhouse-Geisser	1811224 536	1 620	1118087 596	2 180	134
	Huynh-Feldt	1811224 536	1 778	1018444 483	2 180	130
	Lower-bound	1811224 536	1 000	1811224 536	2 180	152
FACTOR1 * BPARTNER	Sphericity Assumed	460285 014	2	230142 507	554	578
	Greenhouse-Geisser	460285 014	1 620	284138 689	554	543
	Huynh-Feldt	460285 014	1 778	258816 466	554	558
	Lower-bound	460285 014	1 000	460285 014	554	463
Error(FACTOR1)	Sphericity Assumed	21600279 0	52	415389 981		
	Greenhouse-Geisser	21600279 0	42 118	512849 043		
	Huynh-Feldt	21600279 0	46 239	467144 328		
	Lower-bound	21600279 0	26 000	830779 962		

TST caregiver planned contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	3961 331	1	3961 331	9 260	005
	Level 3 vs Previous	8027 498	1	8027 498	6 550	016
FACTOR1 * BPARTNER	Level 2 vs Level 1	3653 515	1	3653 515	8 540	006
	Level 3 vs Previous	98 918	1	98 918	081	778
Error(FACTOR1)	Level 2 vs Level 1	13261 852	31	427 802		
	Level 3 vs Previous	37991 306	31	1225 526		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	3378 719	1	3378 719	2 221	146
	Level 3 vs Previous	8464 456	1	8464 456	20 873	000
FACTOR1 * BPARTNER	Level 2 vs Level 1	1613 459	1	1613 459	1 061	311
	Level 3 vs Previous	1628 960	1	1628 960	4 017	054
Error(FACTOR1)	Level 2 vs Level 1	47155 659	31	1521 150		
	Level 3 vs Previous	12570 951	31	405 515		

Waso caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	370 783	1	370 783	870	358
	Level 3 vs Previous	70 253	1	70 253	530	472
FACTOR1 * BPARTNER	Level 2 vs Level 1	64 264	1	64 264	151	701
	Level 3 vs Previous	357 248	1	357 248	2 693	111
Error(FACTOR1)	Level 2 vs Level 1	12790 647	30	426 355		
	Level 3 vs Previous	3979 388	30	132 646		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1 553	1	1 553	010	923
	Level 3 vs Previous	347 175	1	347 175	1 048	314
FACTOR1 * BPARTNER	Level 2 vs Level 1	221 795	1	221 795	1 372	251
	Level 3 vs Previous	239 100	1	239 100	722	402
Error(FACTOR1)	Level 2 vs Level 1	4849 911	30	161 664		
	Level 3 vs Previous	9934 940	30	331 165		

SE caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	2 592	1	2 592	146	705
	Level 3 vs Previous	218 605	1	218 605	6 564	015
FACTOR1 * BPARTNER	Level 2 vs Level 1	1 211	1	1 211	068	796
	Level 3 vs Previous	5 616	1	5 616	169	684
Error(FACTOR1)	Level 2 vs Level 1	551 399	31	17 787		
	Level 3 vs Previous	1032 382	31	33 303		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	243 059	1	243 059	6 176	019
	Level 3 vs Previous	38 255	1	38 255	2 234	145
FACTOR1 * BPARTNER	Level 2 vs Level 1	8 526	1	8 526	217	645
	Level 3 vs Previous	129	1	129	008	931
Error(FACTOR1)	Level 2 vs Level 1	1220 008	31	39 355		
	Level 3 vs Previous	530 925	31	17 127		

SOL caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	6 201	1	6 201	039	844
	Level 3 vs Previous	210 866	1	210 866	1 181	287
FACTOR1 * BPARTNER	Level 2 vs Level 1	10 201	1	10 201	065	801
	Level 3 vs Previous	113 438	1	113 438	635	433
Error(FACTOR1)	Level 2 vs Level 1	4094 656	26	157 487		
	Level 3 vs Previous	4641 741	26	178 529		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	176 257	1	176 257	588	450
	Level 3 vs Previous	83 324	1	83 324	1 161	291
FACTOR1 * BPARTNER	Level 2 vs Level 1	81 971	1	81 971	273	606
	Level 3 vs Previous	59 610	1	59 610	831	370
Error(FACTOR1)	Level 2 vs Level 1	7796 708	26	299 873		
	Level 3 vs Previous	1865 203	26	71 739		

24 ST caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	433 441	1	433 441	561	460
	Level 3 vs Previous	4586 398	1	4586 398	2 943	097
FACTOR1 * BPARTNER	Level 2 vs Level 1	2800 276	1	2800 276	3 622	067
	Level 3 vs Previous	2 355	1	2 355	002	969
Error(FACTOR1)	Level 2 vs Level 1	23193 989	30	773 133		
	Level 3 vs Previous	46753 362	30	1558 445		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	3284 818	1	3284 818	1 743	197
	Level 3 vs Previous	2447 865	1	2447 865	3 375	076
FACTOR1 * BPARTNER	Level 2 vs Level 1	621 219	1	621 219	330	570
	Level 3 vs Previous	1636 648	1	1636 648	2 257	143
Error(FACTOR1)	Level 2 vs Level 1	56524 141	30	1884 138		
	Level 3 vs Previous	21755 748	30	725 192		

IS caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	6 728E-03	1	6 728E-03	2 654	114
	Level 3 vs Previous	1 291E-02	1	1 291E-02	4 654	039
FACTOR1 * BPARTNER	Level 2 vs Level 1	3 402E-04	1	3 402E-04	134	717
	Level 3 vs Previous	2 335E-03	1	2 335E-03	842	366
Error(FACTOR1)	Level 2 vs Level 1	7 606E-02	30	2 535E-03		
	Level 3 vs Previous	8 323E-02	30	2 774E-03		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	2 391E-02	1	2 391E-02	10 597	003
	Level 3 vs Previous	2 213E-05	1	2 213E-05	007	932
FACTOR1 * BPARTNER	Level 2 vs Level 1	1 529E-03	1	1 529E-03	678	417
	Level 3 vs Previous	1 444E-03	1	1 444E-03	484	492
Error(FACTOR1)	Level 2 vs Level 1	6 770E-02	30	2 257E-03		
	Level 3 vs Previous	8 950E-02	30	2 983E-03		

IV caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1 179E-02	1	1 179E-02	501	485
	Level 3 vs Previous	1 400E-03	1	1 400E-03	097	757
FACTOR1 * BPARTNER	Level 2 vs Level 1	1 594E-04	1	1 594E-04	007	935
	Level 3 vs Previous	4 514E-02	1	4 514E-02	3 139	087
Error(FACTOR1)	Level 2 vs Level 1	707	30	2 355E-02		
	Level 3 vs Previous	431	30	1 438E-02		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	2 849E-04	1	2 849E-04	012	915
	Level 3 vs Previous	1 003E-02	1	1 003E-02	739	397
FACTOR1 * BPARTNER	Level 2 vs Level 1	4 786E-02	1	4 786E-02	1 942	174
	Level 3 vs Previous	9 362E-03	1	9 362E-03	690	413
Error(FACTOR1)	Level 2 vs Level 1	739	30	2 464E-02		
	Level 3 vs Previous	407	30	1 356E-02		

TNT caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1426 619	1	1426 619	1 861	182
	Level 3 vs Previous	413 723	1	413 723	1 172	287
FACTOR1 * BPARTNER	Level 2 vs Level 1	118 737	1	118 737	155	697
	Level 3 vs Previous	118 090	1	118 090	335	567
Error(FACTOR1)	Level 2 vs Level 1	23760 788	31	766 477		
	Level 3 vs Previous	10942 929	31	352 998		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	2 117	1	2 117	004	952
	Level 3 vs Previous	1482 099	1	1482 099	2 995	093
FACTOR1 * BPARTNER	Level 2 vs Level 1	266 187	1	266 187	461	502
	Level 3 vs Previous	7 502	1	7 502	015	903
Error(FACTOR1)	Level 2 vs Level 1	17897 881	31	577 351		
	Level 3 vs Previous	15340 109	31	494 842		

RA caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	4 085E-03	1	4 085E-03	1 594	216
	Level 3 vs Previous	5 253E-03	1	5 253E-03	2 942	097
FACTOR1 * BPARTNER	Level 2 vs Level 1	1 537E-03	1	1 537E-03	600	445
	Level 3 vs Previous	2 758E-04	1	2 758E-04	154	697
Error(FACTOR1)	Level 2 vs Level 1	7 689E-02	30	2 563E-03		
	Level 3 vs Previous	5 356E-02	30	1 785E-03		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1 642E-03	1	1 642E-03	824	371
	Level 3 vs Previous	7 086E-03	1	7 086E-03	3 202	084
FACTOR1 * BPARTNER	Level 2 vs Level 1	8 968E-06	1	8 968E-06	005	947
	Level 3 vs Previous	1 422E-03	1	1 422E-03	642	429
Error(FACTOR1)	Level 2 vs Level 1	5 978E-02	30	1 993E-03		
	Level 3 vs Previous	6 639E-02	30	2 213E-03		

L5 caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1173313 800	1	1173313 800	9 381	005
	Level 3 vs Previous	259786 335	1	259786 335	5 453	026
FACTOR1 * BPARTNER	Level 2 vs Level 1	248141 818	1	248141 818	1 984	169
	Level 3 vs Previous	1945 577	1	1945 577	041	841
Error(FACTOR1)	Level 2 vs Level 1	3752311 386	30	125077 046		
	Level 3 vs Previous	1429343 879	30	47644 796		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1017 971	1	1017 971	011	916
	Level 3 vs Previous	1139008 206	1	1139008 206	15 511	000
FACTOR1 * BPARTNER	Level 2 vs Level 1	85953 261	1	85953 261	948	338
	Level 3 vs Previous	123586 994	1	123586 994	1 683	204
Error(FACTOR1)	Level 2 vs Level 1	2720824 549	30	90694 152		
	Level 3 vs Previous	2202959 007	30	73431 967		

TIB caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	3522 778	1	3522 778	2 961	096
	Level 3 vs Previous	129 778	1	129 778	135	716
FACTOR1 * BPARTNER	Level 2 vs Level 1	4234 415	1	4234 415	3 560	069
	Level 3 vs Previous	23 465	1	23 465	024	877
Error(FACTOR1)	Level 2 vs Level 1	35686 440	30	1189 548		
	Level 3 vs Previous	28763 237	30	958 775		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	334 322	1	334 322	269	608
	Level 3 vs Previous	2521 120	1	2521 120	2 740	108
FACTOR1 * BPARTNER	Level 2 vs Level 1	766 851	1	766 851	618	438
	Level 3 vs Previous	2624 138	1	2624 138	2 852	102
Error(FACTOR1)	Level 2 vs Level 1	37228 804	30	1240 960		
	Level 3 vs Previous	27606 464	30	920 215		

sTST caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	6827 143	1	6827 143	2 254	146
	Level 3 vs Previous	893 968	1	893 968	471	499
FACTOR1 * BPARTNER	Level 2 vs Level 1	18066 692	1	18066 692	5 964	022
	Level 3 vs Previous	18 955	1	18 955	010	921
Error(FACTOR1)	Level 2 vs Level 1	72703 407	24	3029 309		
	Level 3 vs Previous	45525 082	24	1896 878		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	130 278	1	130 278	075	787
	Level 3 vs Previous	5916 617	1	5916 617	2 070	163
FACTOR1 * BPARTNER	Level 2 vs Level 1	3950 427	1	3950 427	2 260	146
	Level 3 vs Previous	10606 154	1	10606 154	3 711	066
Error(FACTOR1)	Level 2 vs Level 1	41950 406	24	1747 934		
	Level 3 vs Previous	68589 833	24	2857 910		

sSE caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	52 731	1	52 731	754	394
	Level 3 vs Previous	7 808	1	7 808	188	669
FACTOR1 * BPARTNER	Level 2 vs Level 1	295 980	1	295 980	4 231	051
	Level 3 vs Previous	799	1	799	019	891
Error(FACTOR1)	Level 2 vs Level 1	1608 838	23	69 949		
	Level 3 vs Previous	957 064	23	41 611		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	700	1	700	024	878
	Level 3 vs Previous	46 832	1	46 832	648	429
FACTOR1 * BPARTNER	Level 2 vs Level 1	59 415	1	59 415	2 039	167
	Level 3 vs Previous	178 223	1	178 223	2 468	130
Error(FACTOR1)	Level 2 vs Level 1	670 155	23	29 137		
	Level 3 vs Previous	1661 077	23	72 221		

sSOL caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	881 168	1	881 168	1 458	236
	Level 3 vs Previous	498 998	1	498 998	1 342	256
FACTOR1 * BPARTNER	Level 2 vs Level 1	19 879	1	19 879	033	857
	Level 3 vs Previous	236 902	1	236 902	637	431
Error(FACTOR1)	Level 2 vs Level 1	18736 017	31	604 388		
	Level 3 vs Previous	11528 823	31	371 898		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1382 390	1	1382 390	2 927	097
	Level 3 vs Previous	123 082	1	123 082	261	613
FACTOR1 * BPARTNER	Level 2 vs Level 1	173 247	1	173 247	367	549
	Level 3 vs Previous	121 876	1	121 876	259	615
Error(FACTOR1)	Level 2 vs Level 1	14642 283	31	472 332		
	Level 3 vs Previous	14599 124	31	470 939		

sWASO caregiver contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	3729 480	1	3729 480	3 752	062
	Level 3 vs Previous	3381 435	1	3381 435	2 773	106
FACTOR1 * BPARTNER	Level 2 vs Level 1	272 906	1	272 906	275	604
	Level 3 vs Previous	839 850	1	839 850	689	413
Error(FACTOR1)	Level 2 vs Level 1	29817 703	30	993 923		
	Level 3 vs Previous	36577 859	30	1219 262		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	762 609	1	762 609	550	464
	Level 3 vs Previous	5606 589	1	5606 589	6 065	020
FACTOR1 * BPARTNER	Level 2 vs Level 1	1386 825	1	1386 825	1 000	325
	Level 3 vs Previous	4 411	1	4 411	005	945
Error(FACTOR1)	Level 2 vs Level 1	41608 634	30	1386 954		
	Level 3 vs Previous	27734 661	30	924 489		

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Patient TST contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	13825 075	1	13825 075	2 187	151
	Level 3 vs Previous	24040 433	1	24040 433	8 069	009
FACTOR1 * BPARTNER	Level 2 vs Level 1	178 036	1	178 036	028	868
	Level 3 vs Previous	4737 137	1	4737 137	1 590	219
Error(FACTOR1)	Level 2 vs Level 1	164370 059	26	6321 925		
	Level 3 vs Previous	77467 508	26	2979 520		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	9265 937	1	9265 937	2 291	142
	Level 3 vs Previous	27459 786	1	27459 786	5 857	023
FACTOR1 * BPARTNER	Level 2 vs Level 1	3863 289	1	3863 289	955	337
	Level 3 vs Previous	1973 197	1	1973 197	421	522
Error(FACTOR1)	Level 2 vs Level 1	105142 499	26	4043 942		
	Level 3 vs Previous	121888 179	26	4688 007		

Patient WASO contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	993 478	1	993 478	1 024	321
	Level 3 vs Previous	434 263	1	434 263	839	368
FACTOR1 * BPARTNER	Level 2 vs Level 1	16 016	1	16 016	017	899
	Level 3 vs Previous	160 813	1	160 813	311	582
Error(FACTOR1)	Level 2 vs Level 1	25232 152	26	970 467		
	Level 3 vs Previous	13455 650	26	517 525		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	25 799	1	25 799	045	834
	Level 3 vs Previous	1160 023	1	1160 023	1 421	244
FACTOR1 * BPARTNER	Level 2 vs Level 1	215 566	1	215 566	377	545
	Level 3 vs Previous	11 150	1	11 150	014	908
Error(FACTOR1)	Level 2 vs Level 1	14881 032	26	572 347		
	Level 3 vs Previous	21218 990	26	816 115		

Patient SE contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	53 468	1	53 468	457	505
	Level 3 vs Previous	321 947	1	321 947	4 727	039
FACTOR1 * BPARTNER	Level 2 vs Level 1	38 313	1	38 313	328	572
	Level 3 vs Previous	152 717	1	152 717	2 242	146
Error(FACTOR1)	Level 2 vs Level 1	3038 650	26	116 871		
	Level 3 vs Previous	1770 828	26	68 109		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	204 112	1	204 112	1 905	179
	Level 3 vs Previous	208 964	1	208 964	2 771	108
FACTOR1 * BPARTNER	Level 2 vs Level 1	238 787	1	238 787	2 229	147
	Level 3 vs Previous	2 361	1	2 361	031	861
Error(FACTOR1)	Level 2 vs Level 1	2785 278	26	107 126		
	Level 3 vs Previous	1960 857	26	75 418		

Patient SOL contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	2808 504	1	2808 504	3 139	089
	Level 3 vs Previous	139 690	1	139 690	078	782
FACTOR1 * BPARTNER	Level 2 vs Level 1	351 223	1	351 223	393	537
	Level 3 vs Previous	4143 643	1	4143 643	2 326	140
Error(FACTOR1)	Level 2 vs Level 1	22369 882	25	894 795		
	Level 3 vs Previous	44533 707	25	1781 348		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	215 462	1	215 462	117	735
	Level 3 vs Previous	2084 472	1	2084 472	1 938	176
FACTOR1 * BPARTNER	Level 2 vs Level 1	3025 073	1	3025 073	1 648	211
	Level 3 vs Previous	2138 255	1	2138 255	1 988	171
Error(FACTOR1)	Level 2 vs Level 1	45889 179	25	1835 567		
	Level 3 vs Previous	26894 235	25	1075 769		

Patient TNT contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	9798 789	1	9798 789	2 641	117
	Level 3 vs Previous	7358 438	1	7358 438	2 770	109
FACTOR1 * BPARTNER	Level 2 vs Level 1	4851 313	1	4851 313	1 308	264
	Level 3 vs Previous	261 328	1	261 328	098	757
Error(FACTOR1)	Level 2 vs Level 1	89044 607	24	3710 192		
	Level 3 vs Previous	63759 818	24	2656 659		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1316 741	1	1316 741	534	472
	Level 3 vs Previous	13719 974	1	13719 974	3 820	062
FACTOR1 * BPARTNER	Level 2 vs Level 1	348 197	1	348 197	141	710
	Level 3 vs Previous	3638 665	1	3638 665	1 013	324
Error(FACTOR1)	Level 2 vs Level 1	59131 700	24	2463 821		
	Level 3 vs Previous	86194 498	24	3591 437		

Patient 24ST contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	34528 221	1	34528 221	4 260	049
	Level 3 vs Previous	23716 364	1	23716 364	3 561	070
FACTOR1 * BPARTNER	Level 2 vs Level 1	5603 312	1	5603 312	691	413
	Level 3 vs Previous	24555 767	1	24555 767	3 687	066
Error(FACTOR1)	Level 2 vs Level 1	210716 702	26	8104 489		
	Level 3 vs Previous	173153 765	26	6659 760		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	3732 273	1	3732 273	457	505
	Level 3 vs Previous	46813 325	1	46813 325	7 080	013
FACTOR1 * BPARTNER	Level 2 vs Level 1	14226 564	1	14226 564	1 742	198
	Level 3 vs Previous	18088 328	1	18088 328	2 736	110
Error(FACTOR1)	Level 2 vs Level 1	212383 377	26	8168 591		
	Level 3 vs Previous	171903 758	26	6611 683		

Patient IS contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1 537E-03	1	1 537E-03	131	721
	Level 3 vs Previous	2 621E-03	1	2 621E-03	485	492
FACTOR1 * BPARTNER	Level 2 vs Level 1	1 181E-03	1	1 181E-03	100	754
	Level 3 vs Previous	2 031E-05	1	2 031E-05	004	952
Error(FACTOR1)	Level 2 vs Level 1	306	26	1 176E-02		
	Level 3 vs Previous	141	26	5 408E-03		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	9 984E-04	1	9 984E-04	103	751
	Level 3 vs Previous	3 025E-03	1	3 025E-03	435	515
FACTOR1 * BPARTNER	Level 2 vs Level 1	1 607E-04	1	1 607E-04	017	899
	Level 3 vs Previous	7 855E-04	1	7 855E-04	113	739
Error(FACTOR1)	Level 2 vs Level 1	252	26	9 697E-03		
	Level 3 vs Previous	181	26	6 954E-03		

Patient IV contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	126	1	126	1 471	236
	Level 3 vs Previous	4 653E-02	1	4 653E-02	794	381
FACTOR1 * BPARTNER	Level 2 vs Level 1	1 971E-03	1	1 971E-03	023	881
	Level 3 vs Previous	9 578E-02	1	9 578E-02	1 634	213
Error(FACTOR1)	Level 2 vs Level 1	2 231	26	8 582E-02		
	Level 3 vs Previous	1 524	26	5 863E-02		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	1 448E-03	1	1 448E-03	034	854
	Level 3 vs Previous	140	1	140	1 532	227
FACTOR1 * BPARTNER	Level 2 vs Level 1	110	1	110	2 619	118
	Level 3 vs Previous	1 475E-02	1	1 475E-02	161	691
Error(FACTOR1)	Level 2 vs Level 1	1 092	26	4 201E-02		
	Level 3 vs Previous	2 379	26	9 149E-02		

Patient RA contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	4 301E-02	1	4 301E-02	4 984	034
	Level 3 vs Previous	6 547E-02	1	6 547E-02	15 494	001
FACTOR1 * BPARTNER	Level 2 vs Level 1	1 560E-02	1	1 560E-02	1 807	190
	Level 3 vs Previous	1 377E-02	1	1 377E-02	3 258	083
Error(FACTOR1)	Level 2 vs Level 1	224	26	8 631E-03		
	Level 3 vs Previous	110	26	4 225E-03		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	2 315E-02	1	2 315E-02	3 574	070
	Level 3 vs Previous	8 036E-02	1	8 036E-02	13 762	001
FACTOR1 * BPARTNER	Level 2 vs Level 1	3 013E-03	1	3 013E-03	465	501
	Level 3 vs Previous	2 321E-02	1	2 321E-02	3 974	057
Error(FACTOR1)	Level 2 vs Level 1	168	26	6 479E-03		
	Level 3 vs Previous	152	26	5 839E-03		

Patient L5 Contrasts

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	3337205 147	1	3337205 147	5 721	024
	Level 3 vs Previous	213932 944	1	213932 944	265	611
FACTOR1 * BPARTNER	Level 2 vs Level 1	517480 966	1	517480 966	887	355
	Level 3 vs Previous	302316 796	1	302316 796	374	546
Error(FACTOR1)	Level 2 vs Level 1	15167698 7	26	583373 026		
	Level 3 vs Previous	21024644 5	26	808640 174		

Tests of Within-Subjects Contrasts

Measure MEASURE_1

Source	FACTOR1	Type III Sum of Squares	df	Mean Square	F	Sig
FACTOR1	Level 2 vs Level 1	203285 639	1	203285 639	299	589
	Level 3 vs Previous	2564372 575	1	2564372 575	3 482	073
FACTOR1 * BPARTNER	Level 2 vs Level 1	827216 035	1	827216 035	1 217	280
	Level 3 vs Previous	70015 495	1	70015 495	095	760
Error(FACTOR1)	Level 2 vs Level 1	17670450 9	26	679632 726		
	Level 3 vs Previous	19147580 4	26	736445 399		