

**AUTOMATIC BEHAVIOUR IN INDIVIDUALS WITH NARCOLEPSY: A  
QUALITATIVE APPROACH.**

By

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## **DECLARATION**

I certify that this thesis contains no material which has been accepted for the award of any other higher degree or graduate diploma in any university, and that to the best of my knowledge and belief the thesis contains no copy or paraphrase of material previously published or written by another person, except where due reference is made in the text of the thesis.

Michelle Morandin

## ABSTRACT

Narcolepsy is a debilitating sleep disorder, characterized by excessive daytime sleepiness, cataplexy, hypnagogic hallucinations, sleep paralysis and automatic behaviour. Automatic behaviour can be defined as “stereotyped and repetitive sequences of actions that are performed without awareness”, which usually occur during monotonous tasks (Zorick, Salis, Roth, & Kramer, 1979, p. 194). A classic example is reaching a destination without realizing how one got there. At present little is known about this complex phenomenon, and research in the area is minimal. The aim of the current study was to document the phenomenon of automatic behaviour in ten individuals with narcolepsy (selected on the basis of self-report of moderate to severe automatic behaviour), via phenomenological analysis and a series of case studies. Data was obtained through two structured interviews with each participant, an interview with a spouse or family member, a weekly journal and a daily journal (completed on minimal medication). Using qualitative methodology, a number of important features of automatic behaviour were identified. The current study provided an in depth analysis of the loss of recall associated with episodes of automatic behaviour and was able to define the types of errors associated with this state (sequencing errors, item/ environment intrusions, perseverative action leading to nonsense, context inappropriate behaviours). Different types of automatic behaviour were identified. Type 1 (sleepiness with low cognitive load) and Type 2 (sleepiness with high cognitive load) have been previously reported in the literature (but not so labeled). Type 3 (high cognitive load without sleepiness) however has not previously been identified. The vigilance levels associated with these types (from microsleeps to fluctuating vigilance levels) were discussed, making comparisons with

previous research in the area (Guilleminault et al, 1975; Valley, & Broughton, 1981; 1983). Subsequently, a hypothesised formula for automatic behaviour was developed, including the various factors in its manifestation (that is, excessive daytime sleepiness, cognitive load, and individually determined threshold for automatic behaviour). A descriptive model of automatic behaviour was also developed and compared to previous research. An explanation from a cognitive perspective was considered, linking the automatic behaviour experienced in narcolepsy to automatic behaviour in normals. Finally, a questionnaire to measure automatic behaviour was developed, for further research to pilot.

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## **CHAPTER ONE**

### **INTRODUCTION**

Most individuals will at some time in their life experience feelings of daytime sleepiness. While these feelings can usually be overcome by a good night's sleep, relief from extreme sleepiness can not be as easily found for individuals with narcolepsy. Narcolepsy is a neurological disorder, characterized by excessive daytime sleepiness. Associated features include cataplexy, hypnagogic hallucinations and sleep paralysis (Mahowald, 2000). Despite the large amount of research devoted to the prominent symptoms of narcolepsy, there are many aspects that are still not fully understood. One of these is the symptom of automatic behavior. Automatic behavior involves performing a series of actions without conscious awareness, which usually occurs during repetitive or monotonous tasks (Zorick, Salis, Roth, & Kramer, 1979). With little research in the area, the mechanisms by which automatic behaviour occurs are not fully understood. The current review will examine the literature documenting this phenomenon as well as literature on cognitive functioning and sleepiness (which has been linked to the automatic behaviour literature), in both normal and narcolepsy groups.

#### **1.1 Symptoms and pathophysiology of narcolepsy**

Narcolepsy is a life long central nervous system disorder characterized by a tetrad of symptoms. The most prominent and often suggested to be the most incapacitating symptom is excessive daytime sleepiness (Aldrich, 1992). The daytime sleepiness experienced in narcolepsy is similar to that experienced by normal persons however, in narcolepsy no amount of daytime or nighttime sleep results in ongoing full alertness across the day. These periods of extreme daytime drowsiness can result in decreased

awareness of sleepiness level, ending in complete sleep. A second cardinal and often defining symptom is cataplexy. Cataplexy is associated with a loss of skeletal muscle, producing brief episodes of weakness, which may cause the individual to collapse. No loss of consciousness is evident during these attacks, which are frequently prompted by excitement or emotion, the most common precipitant being laughter. Additional extraordinary features include sleep paralysis; an inability to move when falling asleep or awakening, and hypnogogic hallucinations; vivid mental imagery present at the moment of sleep onset which are mistaken for actual visual, auditory or kinesthetic events (Aldrich, 1992; 1996). Individuals with narcolepsy have also reported symptoms of disturbed nocturnal sleep, cognitive difficulties and automatic behavior.

Many of the symptoms experienced by individuals with narcolepsy can be explained by an impairment in the boundaries between sleep and wakefulness (Broughton et al, 1986). Sleep is composed of two distinct states; non- rapid eye movement (NREM) sleep and rapid eye movement (REM) sleep. These two states alternate in cycles during sleep and represent differing levels of brain activity. For example, during REM sleep the brain is in a state of high cortical activation with accompanying skeletal muscle atonia, rapid eye movements and dreaming (Aldrich, 1993). Mental activity in NREM sleep on the other hand is low, with very little dreaming and the absence of rapid eye movements. In individuals without narcolepsy, sleep begins with NREM sleep, followed by REM sleep approximately 90 minutes after sleep onset. Studies have found that, in contrast individuals with narcolepsy tend to have REM periods at the commencement of sleep (SOREMPS) (Vogel, 1960). The increased propensity to enter REM sleep after a few minutes of falling asleep provides a useful tool for diagnosing narcolepsy, and

demonstrates that the abnormal manifestation of REM periods are key to its pathophysiology.

The identification that narcolepsy has a high susceptibility to the rapid onset of REM periods at the beginning of sleep led to the proposal that inappropriate intrusions of REM sleep into the waking state are responsible for many narcoleptic symptoms (Rechtschaffen et al, 1963). For example, the muscle weakness associated with cataplexy and sleep paralysis have been suggested to be associated with the intrusion of REM sleep and the accompanying skeletal muscle atonia that occurs during normal periods of REM sleep (Hobson, 1995). In addition, most dreaming occurs during REM sleep. Therefore, when REM intrudes into waking, dream imagery occurring in this state appear as hypnogogic hallucinations (Dement, Rechtschaffen, & Gulevich, 1966). However, disordered REM sleep is not the only pathophysiological feature of narcolepsy. In fact some symptoms may be associated with an impairment in the boundaries between NREM sleep and wake states, suggesting that there is a “broader problem of impaired sleep wake regulation” (Aldrich, 1993, p. 535). For example, disturbed nocturnal sleep, characterised by multiple awakenings during the night is frequently reported in individuals with narcolepsy, and this may represent an intrusion of waking states into REM periods and NREM sleep.

Early research into the abnormal control and regulation of the REM sleep system in narcolepsy was based around several different areas of research. The earliest hypothesis was presented by Dement and Rechtschaffen (1968) and could be termed the REM/NREM dysfunction theory. Kripke (1976) argued that narcolepsy may be caused by disorders of circadian regulation, while Broughton et al (1986) hypothesized that

narcolepsy may involve a more generalized dysfunction of “state boundary control”. A considerable amount of research in the 1980s focused on possible neurochemical abnormalities in human and canine narcolepsy, with a hypothesis of a dynamic imbalance between dopamine and acetylcholine in the central nervous system being proposed (Smith & Cohen 1988). In 1983 narcolepsy was found to be tightly associated with human leukocyte antigen (HLA) DR2 in the Japanese population and was later also found in Caucasian populations (Billiard, Seignalet, Besset, & Cadilhac, 1986; Honda, Asaka, Tanaka, & Juji, 1983). However, further research in HLA and narcolepsy found that despite the tight association, this genetic marker was not sufficient, nor necessary to induce narcolepsy. Furthermore, the exact same alleles were found in 12 – 38 % of the general population and thus factors other than HLA must be involved in inducing narcolepsy (Mignot et al, 1991).

In recent years the focus of research has shifted toward examining the dysfunction of the hypocretin system (Chemelli et al, 1999; Lin et al, 1999; Peyron et al, 2000). Hypocretins consist of two peptides, hypocretin 1 (Orexin – A) and hypocretin 2 (Orexin – B). They are localized to the lateral hypothalamus and perifornical area and have dense projections to the locus coeruleus, raphe nucleus, basal forebrain and a number of other brainstem and forebrain regions. The link between hypocretins and narcolepsy was first discovered in 1999, when Lin et al demonstrated that narcoleptic dogs had mutations in one of the hypocretin receptors, the hypocretin receptor 2. Further research in humans has found that individuals with narcolepsy have depleted levels of hypocretin neurons. For example a study by Thannickal et al (2000) showed that human narcoleptics have 85% to 95% reduction in the number of hypocretin neurons. In addition, studies that have

examined the cerebrospinal fluid of individuals with narcolepsy have found that out of nine participants, seven had hypocretin concentrations below detection limit (Nishino, Ripley, Overeem, Lammers, Mignot, 2000). It has been suggested that the reductions in hypocretin activation of monoaminergic nuclei of the brainstem and in the cholinergic brainstem and basal forebrain areas (areas considered central to the generation of REM sleep) cause the abnormal manifestations of REM sleep and subsequently the symptoms of cataplexy and excessive daytime sleepiness, respectively (Thannickal et al, 2000).

In order to alter the balance between REM and non- REM oscillation, pharmacological treatments have been useful to some extent in controlling a number of narcolepsy symptoms. Traditional techniques in Australia include the use of amphetamine stimulants and tricyclic antidepressants. In particular, amphetamine stimulants, such as methylphenidate, have been found to be most effective in providing some relief from the symptoms of excessive sleepiness. Amphetamine stimulants inhibit REM sleep by increasing the drive of the aminergic system (Aldrich, 1993). As a result, individuals experience an increase in mood, wakefulness and alertness. Although successful in controlling sleepiness, stimulant medications have been shown to be less successful in controlling other symptoms of narcolepsy, such as cataplexy, hypnagogic hallucinations and sleep paralysis. As an alternative treatment, tricyclic antidepressants have been used. Tricyclic antidepressants have been shown to be able to produce almost complete control of cataplexy in 80% of patients (Hobson, 1995). Similar to amphetamine stimulants, tricyclic antidepressants suppress REM – on neurons by acting on both aminergic and cholinergic neurotransmitter system (Aldrich, 1993). More recently, Modafinil, 2-[(diphenylmethyl)sulfinyl] acetamide, has been used to treat

excessive daytime sleepiness. New to Australia, Modafinil is now often used as the first line of drug for new cases, given its excellent safety profile and the ease with which it is tolerated (Moldofsky, Broughton, & Hill, 2000). If these two pharmacological treatments are chosen appropriately and taken at certain times of the day, they can work together to promote wakefulness, decrease the occurrence of cataplexy and assist with night time sleep (Mitler & Hayduk, 2002).

## **1.2 Psychosocial impact of narcolepsy**

Despite the availability of these medications, the symptoms of narcolepsy are usually not fully controlled. That is, although stimulant medications can result in an increase in subjective arousal they are not able to eliminate somnolence (Parkes, 1994). Non pharmacological approaches, such as regular naps, can assist in increasing the individual's ability to function during the day, however even these techniques have their limitations (Billiard, 1976; Mullington & Broughton, 1993). As a result, narcolepsy can have a formidable impact on psychological and social functioning (Broughton & Broughton, 1994). Initial research by Broughton et al (1981) in 180 aged matched controls from North America, Asia and Europe demonstrated that the symptoms of narcolepsy have a significant negative impact on occupation (over 75%), driving, work and home accidents, education, recreation and personality.

Further research conducted by Daniels, King, Smith and Shneerson (2001) demonstrated that narcolepsy had a detrimental effect on many psychosocial aspects of life, with the greatest impact on leisure activities (such as holidays, going to the cinema, playing sports). Other areas affected included time spent at work, school (such as difficulty concentrating, achieving less than capable), relationships and everyday duties

in the home (such as domestic activities, supervising children). In addition to these findings, it was reported that over half the sample were depressed (Daniels et al, 2001). Similarly, Bruck (2001) reported that the symptoms of narcolepsy had a clear disruption in individuals' lives and was highly significantly correlated with psychosocial adjustment across a number of domains. Symptom severity was also associated with psychological distress, such as depression.

### **1.3 Cognitive performance and sleepiness**

The negative impact on quality of life can be associated with a number of factors. One factor thought to be associated with these psychosocial difficulties, particularly those at work and school, are subjective reports of impairments in cognitive functioning, such as concentration, memory and attention (Hood & Bruck, 1996). Reported deficits with cognition by individuals with narcolepsy has led to much research examining cognitive functioning using neuropsychological methods in this group. Overall, it has been suggested that cognitive disturbances in narcolepsy can be understood as a consequence of sleepiness on cognition, rather than a deficit of the underlying system (Schulz & Wilde- Frenz, 1995). Similar findings have been documented in studies examining cognitive functioning in normal individuals following periods of sleep deprivation. The following section will present literature examining the relationship between sleepiness and performance, in both clinical (narcolepsy) and non clinical (sleep deprived) groups.

#### **1.3.1 Cognitive performance in sleep deprived individuals**

Over the years, a number of studies have demonstrated that sleep deprivation can have a significant impact on human functioning (Pilcher & Huffcut, 1996). In particular, research has shown that both complete and partial sleep deprivation can impair

performance on a number of measures. In 1959, Williams, Lubin and Goodnow hypothesised that sleep deprivation resulted in a gradual impairment in performance, and attributed this decrement in performance to lapses. Lapses were defined as periods in which individuals were less responsive to stimuli. To assess this assertion, Williams et al (1959) used paced (pace of tasks outside participant's control) and unpaced (pace determined by participant) reaction time tasks in 40 adult males who had undergone between 72 and 98 hours of sleep deprivation. The results of the study indicated that a progressive increase in participant's reaction times was evident over the days of sleep deprivation. Additionally, the number and duration of lapses increased, producing unevenness in performance. Specifically, poorer performance on the unpaced tasks was reported to be a result of a change in speed and not accuracy, stemming from an increased frequency of lapses. On the paced tasks, poorer performance was related to an increase in errors, particularly those of omission rather than commission, again thought to be associated with lapses. It was concluded that sleep deprivation resulted in a gradual deterioration in performance, due to an increase in lapses. The presence of lapses during performance decrements indicated to the authors that sleep deprivation caused a temporal disturbance in cognition, rather than a functional or structural deficit.

Since this report, further research has supported the 'lapse hypothesis' in sleep deprived individuals. For example, Dinges et al (1997) found that restricting sleep to five hours per night over seven consecutive nights produced a marked deterioration in performance on tasks of psychomotor vigilance, probed memory and serial addition testing. In particular, on the psychomotor vigilance task, the frequency of lapses increased and showed a significant elevation after the second day of sleep restriction.

In order to understand what physiological changes occur during lapses, studies have employed electroencephalographic (EEG) methodology. Studies using EEG recordings have shown that fluctuations in performance run in parallel with specific changes in neurophysiological signs of alertness. For example, Torsvall and Akerstedt (1987) reported that one-quarter of the night time train drivers in their study showed a significant increases in alpha (9 – 12 Hz) and theta (4 – 8Hz) activity, as well as slow eye movements (EOG). This activity was highly correlated with subjective sleepiness. In addition, during these changes in EEG and EOG activity, obvious lapses and errors in performance were evident, such as driving against a red light.

These short periods of electrophysiological changes involving increased theta and decreased alpha are termed microsleeps (brief periods of sleep), and are often present during periods of extreme sleepiness. While some studies have suggested that lapses and microsleeps are associated with performance failure, further research into the area has found a differing pattern of results. McCarthy and Waters (1997) used the electrodermal-orienting response, a measure of attentional shift, and a series of cognitive tasks to examine the effects of 36 hours of sleep deprivation on performance. Participants included 71 male undergraduate students, divided into a sleep deprived and a control group. During testing electrophysiological recording was conducted. It was reported that sleep deprivation had a negative effect on all measures of attention (that is, slowed shift of attention to novel stimuli, decreased attentional allocation to stimuli and more rapid habituation to stimuli) in the sleep deprived group, but not in the control group. Additionally it was reported that the sleep deprived group had increased variability and slowed reaction times in a variety of tasks, indicating a significant decrease in

performance. It was suggested that sleep deprivation resulted in a decrease in attentional capacities, thereby decreasing “efficiency of their cognitive processing” (McCarthy & Waters, 1997, p. 120). Further supporting this assertion, EEG recordings were absent of any microsleeps during decreased task performance. It was suggested that fluctuations in attention and not brief intrusions of sleep into wakefulness (microsleep periods) were associated with a decrease in performance.

### **1.3.2 The effect of task characteristics and motivation to perform in sleep deprived individuals**

Further research has supported the hypothesis that sleep deprivation results in fluctuations in one’s ability to remain alert and to sustain attention on a task (Dinges & Kribbs, 1991). However, research has also shown that other factors can have an impact on the relationship between sleepiness and performance. That is, sleep deprivation is not thought to be de arousing alone. For example, the characteristics of a task can in some ways determine whether sleepiness will manifest itself in performance, thus having a role in arousal states. This has not only been demonstrated under sleep restriction conditions, but also in individuals who have not been sleep deprived. For example, Daniel (1967) examined EEG recordings during a vigilance task in 19 participants who had not been sleep deprived. In a one hour session, participants were required to identify a specified digit (by pressing a response key) in a series of digits presented in a random uninterrupted series. Results were examined in terms of errors (omitted responses) and response time. It was reported that a progressive loss of alertness was evident over the one-hour session. Electroencephalographic indicators of alertness also showed a similar pattern of vigilance decay. It was believed that these results indicated that the repetitive

and monotonous nature of the task resulted in decreasing arousal and subsequently performance deterioration. In line with this finding, other research has shown that monotonous tasks requiring sustained attention can increase ones pressure to sleep, particularly in sleep deprived individuals (Dinges & Kribbs, 1991).

The effects of sleep deprivation on motivation to perform have also been examined. In particular, research has been interested in examining how much compensatory effort sleep deprived individuals are able to apply to increase performance (Dinges and Kribbs, 1991). Horne and Pettitt (1985) examined performance on a thirty minute vigilance task (Wilkinson Auditory Vigilance Test), in a sleep deprived with incentive group (I), a sleep deprived without incentive group (NI) and a no sleep deprived, no incentive control group (C). Incentives included money and were increased systematically for each day of deprivation. Participants in group I were also fined for misses and false alarms. It was reported that incentives were able to maintain performance up to baseline levels for one day following a night of sleep deprivation. After this time, performance fell, despite the increasing reward presented. Therefore, despite best efforts, performance was adversely affected in the second night of sleep deprivation.

Examination of individual's perception of their performance and motivation to perform has revealed similar findings. Dinges, Kribbs, Steinberg and Powell (1992) examined performance on a reaction time vigilance task after 64 hours of sleep deprivation. Participants were also asked to rate their performance, the energy they felt they had to expend to achieve this level of performance and whether they could have done better. Results indicated that with sleep deprivation the number of errors increased.

In addition, although participants reported that their effort increased, performance actually worsened. It was also reported that participants believed that they were unable to do any better on the task. It was concluded that although individuals attempted to increase effort on a task following sleep deprivation, this did not improve performance.

Overall, the literature suggests that sleep deprivation can have a negative impact on performance, indicated by fluctuations in attention abilities and an increase in lapses. In addition to the effects of sleepiness, research has demonstrated that the tasks that are most sensitive to performance decrements are those which are unstimulating, repetitive, simple and of long duration (usually given for at least 30 minutes). Individuals are able to place greater compensatory effort on tasks. However, an increase in effort does not necessarily produce improved performance (Dinges et al, 1992; Horne and Pettitt, 1985).

### **1.3.3 Cognitive performance in individuals with narcolepsy**

Similar findings have been reported in the research into cognitive difficulties experienced by individuals with narcolepsy. Studies have shown that performance deficits in this group are related to decreased ability to maintain wakefulness and sustain attention, rather than to specific cognitive deficits (Aguirre, Broughton, & Stuss, 1985; Godbout & Montplaisir, 1986). These studies will now be examined.

To evaluate the relationship between sleepiness and performance in narcolepsy, Godbout and Montplaisir (1986) administered a four choice reaction time task in ten untreated narcoleptics and eight matched controls. Performance on this task was examined both when participants had been permitted to nap (five naps throughout the day at two hour intervals) and on days when they had not napped. It was observed that on the days in which individuals with narcolepsy did not nap, performance was significantly

poorer than for the control group. When individuals with narcolepsy were given the opportunity to nap, both speed and accuracy improved, but the percentage of lapses remained significantly higher compared to controls. This finding indicated to the authors that poorer performance in individuals with narcolepsy was not associated with a cognitive deficit, but rather an inability to sustain alertness.

This difficulty with maintaining alertness has also been useful in explaining self-reports of poor functioning in other areas of cognitive functioning, such as memory. Research has shown that individuals with narcolepsy have lower self-efficacy for memory performance than individuals experiencing excessive daytime sleepiness alone and controls. That is, they express anxiety, decreased evaluation of memory capacity and increased perception of memory decline (Hood & Bruck, 1997). To evaluate this discrepancy, Rogers and Rosenberg (1990) compared subjective memory deterioration with objective measures of memory function in 30 individuals with narcolepsy and 30 controls. Participants were compared on tests of immediate and delayed memory, as well as tests of verbal and visual memory. The results indicated that while participants with narcolepsy had more difficulty maintaining attention, there were no significant differences between narcoleptics and controls on tests of memory or concentration. It was suggested that subjective memory impairments in individuals with narcolepsy were associated with “sustained periods of decreased alertness”(p.49). That is, excessive daytime sleepiness reduced periods of sustained and full alertness in individuals with narcolepsy, which are necessary for adequate attention to stimuli and subsequent memory performance. Similar findings were demonstrated by Ollo et al (1987) who reported that a “memory deficit in most narcoleptics is not due to cortical dysfunction as in dementia,

but rather is secondary to decreased concentration in tasks that require effortful processing” (Ollo et al, 1987, p. 402).

To evaluate other areas of functioning, Hood and Bruck (1996) examined automatic, attentional and complex cognitive functioning in eight individuals with narcolepsy and eight matched controls. In addition to investigating various areas of functioning, Hood and Bruck examined performance under two test conditions; a high arousal condition and a low arousal condition. Creating an environment with low stimulation produced the low arousal condition and giving participants a period of 30 minutes to nap, facilitated the high arousal condition. It was reported that individuals with narcolepsy in the high arousal condition performed as well as the control group on automatic tasks. However, in the low arousal condition narcolepsy participants had decreased performance on tasks of complex cognitive functioning. Similar to other research, it was concluded that cognitive performance decrements in narcolepsy were secondary to the effects of sleepiness.

#### **1.3.4 The effect of task characteristics on performance in individuals with narcolepsy**

As was reported from the sleep deprivation literature, simple reaction time tasks have been shown to be most sensitive to sleepiness, while complex or interesting tasks are thought to counteract the effect of sleepiness (Dinges & Kribbs, 1991). Similar findings have been found in the narcolepsy literature. For example, Valley and Broughton (1981) performed one of the first systematic and controlled studies of performance deficits in narcolepsy utilizing EEG methods. Ten patients with narcolepsy – cataplexy and a group of controls matched for sex, age, education and occupation were assessed on

four tests; The Wilkinson- Auditory Vigilance Task (WAVT), the 4 – choice reaction time task, the paced auditory serial addition task (PASAT) and digit span. It was reported that performance by individuals with narcolepsy was significantly lower than that of normals in tasks of low stimulation and was characterised by “lapses of intermittent response omissions” (p. 137). However, no significant difference was observed between the narcolepsy and control groups on the PASAT or digit span, tasks thought to be short and stimulating.

Further research in the area has demonstrated poorer performance with tasks of low stimulation. Specifically examining the impact of excessive sleepiness on vigilance levels in individuals with narcolepsy and sleep apnea, Findley et al (1995), designed a simulated driving computer program called Steer Clear. The program included simulating a drive on a long and monotonous highway, where participants were instructed to avoid hitting 780 obstacles appearing in the participant’s automobile lane at two second to two minute intervals, for 30 minutes. It was reported that compared to controls, participants with sleep apnea and narcolepsy performed poorer by hitting a higher percentage of obstacles than controls. Poorer performance in these groups was attributed to their greater difficulty remaining alert and attentive. Consistent with the sleep deprivation literature (Daniel,1967; Horne & Wilkinson, 1985), it was speculated that poorer performance was related to the rather boring and monotonous nature of the task, which increased the effects of sleepiness on performance.

### **1.3.5 Electroencephalographic patterns during performance decrements in narcolepsy**

Similar to the sleep deprivation literature, the neurophysiological underpinnings of performance errors in narcolepsy have interested researchers. Early research reported that performance decrements in narcolepsy were associated with microsleep episodes. For example, in a group of individuals with hypersomnia (individuals not meeting the criteria for a diagnosis of narcolepsy, but presenting with chronic excessive nocturnal sleep or daytime sleep and sleepiness), Guilleminault, Phillips and Dement (1975) reported significant performance decrements on two vigilance tasks, compared to controls. Of interest, during testing and non - testing periods, a number of microsleep episodes were noted on EEG recording. In particular, decrements in performance were observed to correspond to the presence of brief bursts of microsleep episodes occurring in close clusters. It was reported that in between these microsleep episodes participants performed as well as controls. When questioned at the end of testing, participants denied being asleep during these microsleep episodes, even though there were obvious impairments in their performance and they were unable to recall the period. The authors speculated that the performance difficulties often reported at home and at work by this group was associated with the occurrence of microsleep episodes.

Extending on from the previous study, to specifically examine individuals with narcolepsy, Guilleminault, Billiard, Montplaisir and Dement (1975) investigated performance on vigilance tasks, again using EEG recording. While conducting a series of tests, individuals with narcolepsy were found to suddenly perform inadequately, “sometimes doing the same addition again and again” (p.383), or increasing the number

of errors. During this time the participants would also stare blankly and make inappropriate statements that bore no relevance to the preceding conversation. The authors reported that associated with these periods, EEG recordings showed repetitive bursts of microsleep episodes (defined as a sudden, short lasting burst of stage one, slow wave sleep and/ or a short burst of synchronous theta activity recorded in central monopolar derivations, i.e., C3/A2, C4/A1, O2/A1). These conclusions have been criticised by some researchers (Valley & Broughton, 1983). That is, although the study had a good design, the authors failed to provide statistical comparison of controls and individuals with narcolepsy, and their design was developed to enhance drowsiness. For example, participants completed multiple testing sessions during the day and tasks consisted of repetitive and monotonous tasks, all potentially exacerbating sleepiness in these participants.

In a more recent replication of their previous study, Guilleminault, Heinzer, Mignot and Black (1998) examined performance and EEG patterns in 34 individuals with narcolepsy. Utilising a simple finger tapping task, a Wilkinson Addition Test and a symptom questionnaire, they again showed that performance failures were associated with episodes of microsleeps and these errors in performance were not evident before or after periods of repetitive microsleeps. Additionally, at the end of the testing session participants greatly underestimated the duration of their drowsiness and the number of errors they had made. Therefore, it was concluded that this study had supported previous findings that repetitive bursts of microsleep episodes were associated with increased drowsiness and decreased performance ability.

While studies have shown microsleep patterns to be associated with performance decrements in individuals with narcolepsy, further research into the area has found a differing pattern of results. Valley and Broughton (1981; 1983) demonstrated that individuals with narcolepsy showed fairly slow fluctuations in vigilance during performance deficits, rather than the briefer periods of microsleeps as described by Guilleminault et al (1975). Valley and Broughton (1983) suggested that microsleep patterns are only present at extreme low levels of vigilance, and do not parallel vigilance levels experienced by individuals with narcolepsy on a daily basis (Valley & Broughton, 1983). In contrast to Guilleminault et al, Valley and Broughton conducted testing only once in the morning and encouraged alertness and motivation in their participants. This was thought to be a better parallel to the outside world, in which many demands are placed on the individual. During testing it was reported that individuals with narcolepsy continued to fluctuate between wakefulness and sleep. Electroencephalographic recordings of narcolepsy participants showed fluctuations between wakefulness and stage 1A (slowed and diffusing alpha) and stage 1B (theta activity) compared to controls who were continually awake. During these stages, deficits in performance were noted. These errors included omission of responses, lapses, false positives, inappropriate responses and were attributed to participant's inability to sustain wakefulness over time, and therefore, maintain attention. It was concluded that the microsleep hypothesis was inadequate in explaining performance deterioration in these patients and was better accounted for by unstable periods of fluctuating vigilance (Valley & Broughton, 1981).

Therefore, the literature on the relationship between performance and narcolepsy, indicates that individuals with narcolepsy are unlikely to show any performance deficits

when the tests are short, pose a challenge to the individuals and are conducted in a setting which facilitates high arousal levels (Rogers & Rosenberg, 1990; Hood & Bruck, 1996). However, when tasks are monotonous and require a longer period of sustained performance, performance deficits are observed (Valley & Broughton, 1981; 1983). The literature presents mixed findings on the physiological underpinnings of errors in performance. Some research has reported that performance deficits are associated with microsleep episodes (Guilleminault et al, 1975). While others have noted that microsleep patterns occur at very low levels of vigilance and performance deficits in real world settings are associated with fluctuating vigilance levels (Valley & Broughton, 1983).

#### **1.4 Automatic behaviour phenomenon**

As demonstrated, fluctuating periods of vigilance hamper the integrity of cognitive processes such as attention, concentration, learning and memory. Fluctuating vigilance can also cause disturbance in the regulation, implementation and control of motor behaviour, as is demonstrated in the automatic behaviour syndrome (Guilleminault et al, 1975). Automatic behavior involves performing familiar actions without conscious awareness (Utley, 1995). That is, the body continues to function while the mind has partially retreated to sleep. Consequently the individual has no recollection of the events that occurred while in this state and frequent errors in performance are evident.

##### **1.4.1 Automatic behaviour in normal populations**

Automatic behaviour is a phenomenon that is experienced by most people at some time in their lives. Automatic behaviour can occur while completing any task, such as writing, completing household tasks, speaking, etc. A classic example of automatic behaviour, which has been the focus of research in the area, is arriving to a destination

and having no recollection of the drive. Literature examining automatic behaviour associated with driving in normal individuals has developed a number of constructs to describe this phenomenon. According to Wertheim (1991) (who described this state as 'highway hypnosis'), driving automatically occurs as an imbalance between two types of attention: controlled versus automatic. That is, when first learning how to complete a task (such as driving), individuals operate under a controlled mode, investing effort in the task and using feedback to monitor and process their performance. After much practice and experience, the individual becomes skilled at the activity. It is here where the controlled mode is replaced by the automatic mode. As performance is now based on readily available internal motor programs, external feedback is used sporadically. In addition, the fact that individuals are unable to put sufficient effort into the easy task (as not much feedback monitoring is required), the extent to which alertness can be raised is limited. Subsequently, the task or situation leads to a decrease in alertness and arousal.

Kerr (1991), who termed the construct driving without attention mode (DWAM) provided a similar explanation. Again, this hypothesis was based on human's ability to process certain information automatically. In many aspects of life, our perception of familiar settings becomes automatic, in that the perceptual system only takes in relevant information and ignores irrelevant information. With increased exposure, our perception of a scene becomes stereotyped. In a similar fashion, if a particular act, such as driving is repeated, then the actions also become automatized. In other words, attention shifts from external to internal processes, where the individual becomes less aware of what is occurring in the environment and places greater reliance on internal schema's for driving.

Kerr noted that in this state the driver may appear to be monitoring their environment (such as, checking rear view mirror), but this information is not being processed.

Together these hypotheses indicate that automatic functioning in normal populations is associated with a transfer of attention and control to internal processing, in which the individual has lowered awareness of the external environment, and bases actions on an internal representation of what is occurring at the time. As a result, the under reliance on external feedback and low levels of vigilance often mean that errors go unnoticed and individuals may fail to act when required (Thiffault & Bergeron, 2003). This model of working under ‘automatic pilot’ is not exclusive to driving, with many activities in life being done in this mode, as will be demonstrated in individuals with narcolepsy.

#### **1.4.2 Automatic behaviour in individuals with narcolepsy**

As noted, automatic behaviour is a condition not exclusive to narcolepsy. However, due to the greater propensity to experience automatic behaviour, it has often been linked with the disorder. Automatic behavior is thought to affect 80% of individuals with narcolepsy (Aldrich, 1992; Mahowald, 2000). It is therefore surprising that little research has been devoted to examining this phenomenon. Early research described these episodes as, ‘amnesic states’ (Daniels, 1934). These ‘amnesic states’ often involved individuals with narcolepsy becoming completely unable to recall events that occurred only minutes to hours before. For example, Daniels reported a case of a patient with narcolepsy who found himself driving to a town he had no intention of going to, with no recollection of how he got there. It was reported that during these ‘amnesic’ episodes the patient would often feel sleepy and would gradually become unaware of his sleepiness,

only to regain alertness and find himself in a situation that he had no recollection of, often feeling well rested as if he had slept.

In 1958, Ganado further documented episodes of automatic behavior, however, the phenomenon was still not termed automatic behavior, rather he termed them ‘fugue – like episodes’. Similar to Daniels’ (1934) description, these ‘fugue – like episodes’ were often associated with performing familiar acts, such as walking, driving or talking, followed by complete amnesia for the acts. It was also reported that frequent mistakes would occur in this state. For example, “they spoke jargon and wrote illegible scribble” and these acts would only stop if the task became more difficult or an unexpected event interrupted the action resulting in a full return in alertness (p. 488).

In later years the phenomenon became known as automatic behaviour. Guilleminault et al (1975) qualitatively documented the experiences of individuals with narcolepsy in their clinic, identifying key factors in the syndrome. Patients from their clinic reported episodes of automatic behavior daily, lasting from a few seconds to several hours. The tasks involved with periods of automatic behavior often did not require extensive skill, and were quite monotonous. Automatic behaviour would go unnoticed for some time, until the task required more extensive skill, in which frequent mistakes would become evident, similar to that reported by Ganado (1958). Guilleminault et al reported that when the episode of automatic behavior began, individuals would often begin to feel half-awake and struggle to fight off drowsiness. In doing so, individuals would become less aware of their actions in which performance would deteriorate. Following the episode individuals would have complete amnesia of the event or the amount of time that had passed, having to deal with the sometimes

embarrassing or dangerous consequences of their actions. For example, patients of the clinic reported making a sandwich with a sponge and eating it, driving home from work finding themselves 50 miles from home, producing meaningless sentences in conversations and making errors at work costing employees thousands of dollars.

Further documentation of the automatic behaviour syndrome was presented in a qualitative study by Zorick, et al (1979), of a 55 year old woman who had been diagnosed with narcolepsy. In addition to reports of excessive daytime sleepiness for the past 25 years, the patient experienced cataplexy three times each day and occasionally experienced sleep paralysis while going to sleep at night. No evidence of hypnagogic hallucinations was present. In addition to the classic symptoms of narcolepsy, the patient reported frequent episodes of “reduced awareness” (p. 195). These lapses in awareness often occurred in her workplace. In addition to making mistakes at work and sending excessively large cheques to the wrong company when paying her bills, her most serious episode involved shoplifting. For example, the woman would fill her trolley cart with jars of pickles, take tools from a hardware store and take other items that she had no use for or would not usually purchase. The authors concluded that these periods involving a lapse in awareness were classic presentations of the automatic behavior syndrome, and were thought to be related to the patient’s narcolepsy disorder. As a result, the patient was given a trial of protriptyline 30mg each day and methylphenidate 5mg, two to three times daily. With the addition of these medications it was reported that the patient’s excessive sleepiness had decreased as well as episodes of automatic behaviour. That is, it was reported that there had been a 90% reduction in the interfering effects of automatic behaviour on her work life.

### **1.5 Rationale for present investigation**

As can be seen, automatic behavior is a serious symptom that can have many adverse effects on the individual's professional and personal life. Unfortunately, the research conducted on automatic behavior and narcolepsy, has not been extended in over 10 years. Research in the area still does not give a full understanding of the experiences of automatic behavior in individuals with narcolepsy. In order to gain a more comprehensive understanding of automatic behavior, more research needs to be conducted in the area.

### **1.6 Aim of current study**

The aim of the current study was to document the phenomenon of automatic behaviour in individuals with narcolepsy, using qualitative methodology. The current study will aim to examine the following:

- The relationship between automatic behavior, sleep wake patterns and medication intake.
- The factors improving or worsening automatic behaviour.
- The predictability and control of automatic behaviour episodes.
- The impact of automatic behaviour on individual's lives on a day to day basis.

## **CHAPTER TWO**

### **REVIEW OF CURRENT METHODOLOGY: QUALITATIVE RESEARCH**

As there is limited research conducted on automatic behaviour in individuals with narcolepsy the current study will be adopting a qualitative approach. The aim of this section is not to review all the possible methods of conducting qualitative research, but to provide an understanding of how the current methodology was chosen and to review issues relevant to the use of that methodology.

#### **2.1 Qualitative vs. quantitative research**

Traditionally, quantitative methods have been viewed as the preferred approach in the investigation of social phenomenon. Quantitative research adopts a positivist perspective and is based on the methodological principles of objectivity, replicability, causality and generalisation. Adherence to these principles is achieved through the use of rigorous experimental designs, survey data and questionnaire items. By adopting these methods it is believed that objectivity is preserved by maintaining distance between the researcher and participant; replication and generalisation can be carried out by employing the same questionnaire in another environment; and analysis of cause and effect can be conducted by using a variety of statistical measures (Bryman, 1984).

The qualitative researcher views the world through a very different lens. The key principle of the qualitative approach and how it differs from other approaches such as positivism is that it obtains an account of a phenomenon from the perspective of the individual. That is, it is believed that the individual directly dealing with the phenomenon of interest is best placed to analyse and describe their experiences and feelings in their own words (Denzin & Lincoln, 2000). By doing this researchers are able to obtain an

understanding of the social world from the 'inside'. In contrast the positivist seeks to develop concepts and theories to describe and explain social phenomenon by applying a natural science and studying the phenomenon from the 'outside', with little reference to each individual being investigated and the meanings they ascribe to the event under study.

The qualitative approach has increasingly been recognized and valued as a research tool in the social sciences. In particular, it gained popularity when social researchers observed that quantitative methods were limited by a number of factors and were not sufficient to explain the complexities of some social phenomenon (Flick, 1998). For example, it has been suggested that quantitative methods restrict the focus of study; it assumes that complete objectivity is possible; and it has been proposed that statistical significance ensure neither valid explanation, causation nor generalization (Allen – Mearns & Lane, 1990). Over time and many debates, the focus of the discussion has shifted from arguing over which is the superior research tool, to which research perspective is appropriate to answer a set of epistemological premises. It has been noted that qualitative research is often of great value for research that delves in depth into complexities and processes, and research for which relevant variables haven't been identified (Bryman, 1984). Miles and Huberman (1994) state that “the qualitative researcher embarks on a voyage of discovery rather than one of verification, so that his or her research is likely to stimulate new leads and avenues of research that the quantitative researcher is unlikely to hit upon, but which may be used as a basis for further research” (p. 13). Finally, qualitative research is often useful for the study of small clinical samples, or rare phenomenon, in which large scale studies are difficult, if impossible to conduct

(Bryman, 1984). It is these last two points (the importance of discovery and the use of small clinical samples) which makes qualitative research so well suited to the subject of the current research.

After a review of the possible qualitative approaches, the researcher selected phenomenology and the case study approach as the two preferred philosophical foundations and methodological strategies for the current study. Key issues in both are set out below.

## **2.2 Phenomenology**

Phenomenology was first attributed to the writings of Edmund Husserl (1857-1938) and has been developed by a number of writers since that time. Phenomenology is a philosophical approach that examines experiences and interpretations of the world from the perspective of the individual. Put simply, Becker (1992) stated that “phenomenologists study situations in the everyday world from the viewpoint of the experiencing person” (p. 7). The assumption that underlies this outlook is that truth and knowledge do not exist on their own. Rather, they exist within the social context in which they were generated. That is, relationships between variables occur as a merging of interactions between people, specific situations and specific times (Lemon & Taylor, 1998). Therefore, if truth and fact originate from each of these factors, then the subjective responses of the individual to a situation holds particular value. From this perspective, a phenomenon may be interpreted only in terms of the individual’s own personal characteristics and the context in which they encounter it. Additionally, variability in interpretations are equally valid within this context (Denzin & Lincoln, 2000).

Therefore, the phenomenological approach requires the researcher to consciously suspend all previous assumptions of the phenomenon under study and instead adopt a naïve approach to the understanding of individuals' experiences (that is, the researcher 'brackets' preconceptions). It should be noted that phenomenologists do not maintain that their perspective is the only useful setting for understanding experience. What they do claim is that it can be useful for certain areas of study and can provide a view of the phenomenon that can not be achieved through other methods. Phenomenology has served the basis for much qualitative research, particularly in the areas of health, illness and psychology (Denzin & Lincoln, 2000).

### **2.3 Case studies**

Another qualitative approach, which has played a central role in many disciplines, has been the case study. The case study approach can be characterised as the presentation and analysis of detailed information about single or multiple subjects, in relation to an event, culture or individual life (Platt, 1988). Through this analysis, the researcher is able to obtain an in depth understanding of the characteristics of cases in order to generate new insights (Willig, 2001).

Stake (2000) suggested that the "case study is not a methodological choice but a choice of what is to be studied" (p. 435). Others view the case study as an approach that may involve the use of a number of different methods of data collection and analysis. Although qualitative methods have been traditionally used to study the case, the case study can include a mixture of quantitative and qualitative data. Therefore, the case study can be used to answer a wide range of questions, and the varied approaches to the case study allow the researcher to use the method which is most appropriate to the study.

Perhaps the most important role of the case study is to describe phenomenon that are too complex for the survey or experimental situation (Willig, 2001).

### **2.3.1 Types of case study designs**

Due to variability in the types of cases that may be studied, there are a number of case study designs that may be used. Each of these designs allow the researcher to address a number of different questions in relation to the case under investigation. The following section is based on work by Willig (2001), who provided a useful categorisation of the different types of case studies.

#### **2.3.1.1 Intrinsic vs. instrumental case studies**

Researchers may chose to conduct case study research for the purpose of finding out more about the individual case. That is, the case is chosen purely for interest and for its particularity, rather than about the more general phenomenon or problem. This is called an intrinsic case study. By contrast, an instrumental case study selects a case of interest in order to understand more about a phenomenon. In this instance the case develops models of a more general phenomenon. Rather than focussing on the case itself, instrumental studies examine specific phenomenon (such as automatic behaviour) within a particular case (such as an individual with narcolepsy).

#### **2.3.1.2 Descriptive vs. explanatory case studies**

Case study research can also be defined as descriptive or exploratory. The descriptive case study is associated with describing how the phenomenon exists in the everyday world. An explanation of the phenomenon or understanding the relationships between variables is not made. Rather, the aim of descriptive case studies is to provide enough detailed description so that a better understanding of the phenomenon is made

and one is able to develop new insights. Unlike the descriptive study, the exploratory case study aims to not only provide a description of the case, but also attempts to provide an explanation of the phenomenon.

### **2.3.1.3 Single vs. multiple case studies**

Case study research may be conducted using single or multiple participants. The single case design has frequently been chosen for rare or extreme cases. It has also proven effective when testing well formulated theories. Therefore, the single case design is intrinsic in nature and is useful for testing the “applicability of existing theories to real world data.” (Willig, 2001, p. 74). The multiple case study design differs from the single case in that it does not just test existing hypotheses, but allows the researcher to generate new hypotheses. That is, through the comparison of individual cases, the researcher has the opportunity to develop and refine these new formulations. Yin (1994) suggested that one may consider the multiple case design as multiple experiments. That is, the examination of each case modifies the emerging theory in some way. For example, if there is uniformity in the data derived from five cases, then there is compelling evidence for the initial proposal. However, if these cases are in some way contradictory, then the theory must be modified to accommodate for these differences. In this way a replication logic is used and the study may be viewed similarly to how the positivist deals with contradictory experimental findings. Therefore, multiple case studies are often considered to yield more impressive data, and the overall study is therefore regarded as being more robust.

## **2.4 Limitations of qualitative methods: Phenomenology and the case study**

Although qualitative research has been viewed as a valuable research tool, some researchers have proposed that it is of little use in scientific inquiry. Again, the view that quantitative methods are essential to the production of warrantable knowledge has been the basis of much of the criticism of qualitative methods. That is, the principles underlying quantitative research, including objectivity, falsification and generalisation, have been reported to be lacking in the qualitative approach (Runyan, 1982).

Another issue that has been addressed by quantitative researchers has been the threat to internal validity due to researcher bias. Many critics report that the absence of experimental controls and the possibility of the researcher developing ‘feelings’ for their participants, can result in biases in interpretation (Kazdin, 1981). Additionally, qualitative research has inadequate measurement of independent and dependent variables and relies on retrospective data, therefore leaving data open to a variety of interpretations based on the researcher’s perspective (and therefore biases) (Rubaie, 2002). It has also been asserted that with the presence of investigator effects, there is no “assurance of either reliability or internal validity” (Stoecker, 1991, p. 91). In addition to the limitations with internal validity, researchers have questioned the external validity of qualitative methods, such as the case study, in that it is difficult to generalise findings to other settings (Runyan, 1982). Mitchell (1983) reported that it is clear that cases selected for case study research are not as representative as are probability samples. As a result, generalisation from the case to other unexplored cases could not occur in a direct sense.

## **2.5 Responses to the critique**

In order to combat these criticisms, researchers have adopted a variety of techniques aimed at increasing the sophistication and rigor of qualitative research. One technique that has been advocated is triangulation. Triangulation is a process of using multiple perceptions or methods of data collection within one case to reduce the likelihood of misinterpretations, clarify meaning and confirm the recurrence of an observation (Stake, 2000). That is, the researcher is able to integrate information from different sources and observe the phenomenon from different perspectives. This, in turn, provides enriched material and the internal validity of the study is increased. Flick (1998) pointed out that triangulation is a way of “transgressing the (always limited) epistemological potentials of the individual method” (p. 230). Alternatively, Kazdin (1981) proposed that one may increase internal validity by collecting data over time and on more than one occasion. This continuous assessment, such as when testing the effects of a particular treatment, provides an additional advantage that can strengthen internal validity of the case study. In addition to this method, Kazdin proposed using more than one case in the study. By doing this, uniformity in the data is demonstrated and the likelihood that an unconnected event is responsible for the change is decreased.

The second issue of researcher bias has been less easily combated. However, this bias and others are not limited to qualitative research. Even quantitative research has been argued to have biases. For example, large scale studies utilising survey or questionnaire data are biased by the fact that the questions may be interpreted in a number of ways and have different meanings for different respondents. By using a more flexible and

interactive approach, the researcher is able to understand how and why participants responded in a particular manner (Stoecker, 1991).

Finding a solution to the problem of external validity has also posed a challenge to qualitative researchers, particularly those using the case study (Stoecker, 1991). In order to accommodate for this limitation, researchers have adopted the use of multiple case study designs. By showing that a phenomenon is consistently represented over an array of cases (that is, moving beyond the single case study to case comparison), then generalisation can be more confidently applied (Platt, 1988). However, Willig (2001) argued that the aim of the case study is not to generalise in the first instance. Case studies can be used to develop or refine preexisting theories, which then have the potential to develop explanations that can be applied to new cases. In addition, the study of non - typical cases can provide examples of an ‘exception to the rule’ scenario, and therefore further refine theory. Taking another perspective Platt (1988) maintained that it is faulty to assume that the only worthwhile goal of research is to generalise, and that there can be a legitimate interest in studying the particulars of a case. In support of this position, Stake (1978) placed more emphasis on the case itself, and highlighted that it appeals to implicit forms of knowing, experiential ways of understanding and to naturalistic rather than formalistic generalisation. Case studies can therefore be more readily applied to individuals and their experiences and can be considered as a “natural basis for generalisation” (Simons, 1996, p. 227). Therefore, basing our decisions on whether to use case study and which case studies to use, should be focused on what information the case provides, rather than for its representativeness.

Much of the response to the critique of qualitative methods has focused on a direct critique of alternative approaches, namely the quantitative approach. For example, one of the criticisms of the qualitative approach is that it does not ensure accurate explanation and often requires a creative leap from data to explanation. However, it has been suggested that all research involves this process (Stoecker, 1991). The fact that quantitative methods use large numbers and therefore a more 'representative' sample does not mean that the relationship between particular variables is clearly evident. The ability to identify a relationship in the data is perhaps more dependant upon the plausibility of the relationship between variables, rather than the representativeness of the sample. It is this point that has lead many researchers to conclude that qualitative methods can more effectively analyse causation than quantitative cross sectional research. That is, what is often lost in quantitative research is the ability to see the operation of variables and the processes involved in these relationships.

The current review of research methodologies highlights the need for these issues to be considered when planning qualitative research. As demonstrated, if conducted in the appropriate manner, qualitative research can provide an in depth analysis of a phenomenon from the perspective of the individual. In doing this, one is able to generate hypotheses and suggest interpretations, which in some instances may then be studied at a later time via quantitative investigations. In particular, case studies can often be viewed as the building blocks of theory. That is, by showing that a phenomenon exists in a particular case, then we can suggest that similar features are present in other cases too (Platt, 1988). In addition, although at the expense of wide coverage, the case study approach provides an intense analysis of a phenomenon.

## **2.6 Overview of methodological approach used in the current study**

As mentioned, given that there has been little research in the area of automatic behaviour in narcolepsy, the current study will adopt a qualitative approach. It will be based on two approaches, phenomenological and case study approach. The phenomenological investigation will include data obtained from ten participants. From these ten cases, three participants will be used in a series of case studies to further outline the phenomenon (instrumental, explanatory and multiple case study approach). In order to increase the reliability and validity of the study, the principle of triangulation will be adopted. The study will also be based on retrospective data, as well as data recorded at the time of automatic behaviour and information will be gathered at two different time points. The following section will outline the approach to the current study, the tools and the procedures.

## **CHAPTER THREE**

### **METHODOLOGICAL TECHNIQUES**

#### **3.1 Participants**

Participants in the current study were recruited through the Narcolepsy and Overwhelming Daytime Sleep Society of Australasia Inc. (NODSS), a support group for individuals with narcolepsy. To create interest, the researcher attended a NODSS meeting and gave a brief explanation of the study. Individuals who expressed interest in participating (N= 4) were given information regarding the study and a selection questionnaire. These were sent back to the researcher via a reply paid envelope. Selection questionnaires included a few items asking about the frequency and severity of automatic behaviour. The researcher also went through questionnaires from a previous study (Bruck & Costa, 2003) and selected those who reported automatic behaviour and invited them to be involved (N= 11). This was again taken from members of NODSS. It should be noted that members of NODSS indicate whether they would like to be available for research upon joining. Only participants who had chosen to be available for research were contacted. From these fifteen potential participants (all who had been given the selection questionnaire), ten individuals were initially selected. Two participants withdrew from the study (due to limited availability), two participants did not have a diagnosis of narcolepsy (one was diagnosed with hypersomnia and the other with Asperger's syndrome) and one participant could not be contacted due to change of address. The final participants included three males and seven females, ranging from 46 to 69 years of age (Mean = 59.8, SD = 7.41). Participants lived in both country Victoria (N = 2) and the Melbourne metropolitan area (N = 8). All participants in the current study had received a

formal diagnosis of narcolepsy (either via a neurologist or sleep study). Participants had at least a 10 year history of narcolepsy ( $M = 22.7$ ,  $SD = 9.88$ ) and all but one participant experienced cataplexy. The participant who did not experience cataplexy however had been diagnosed via a Multiple Sleep Latency Test. Participants included those who experience a high number of automatic behaviour episodes, as well as those that had a history of severe automatic behaviour that was now well controlled. Participant details and the aspects of the study they completed are provided in Table 1 (this table also includes participant details relating to other aspects of the study. These are included here to provide easy access to all participant details and will be discussed in subsequent sections).

Table 1

Participant details, including demographic details, Epworth Sleepiness Scale (ESS) score, areas of the study completed and automatic behaviour experienced.

Participants	Age	Sex	Years since narcolepsy diagnosis	Cataplexy	ESS (off medication condition)	ESS (on medication condition)	Interview 1	Interview 2	Journal 1	Journal 2 (minimum medication)
A	69	M	12 years	4	17	5	4	4	4	8
B	55	F	15 years	4	22	11	4	4	4	4
C	63	F	32 years	4	24	17	4	4	4	4
D	63	F	17 years	4	23	10	4	4	4	4
E	66	F	26 years	4	20	13	4	4	8**	8
F ^	46	M	10 years	4	23	19	4	4	4	8
G	62	F	30 years	4	22	13	4	4	8**	8
H ^	49	M	28 years	8*	22	9	4	4	8***	8
I	63	F	40 years	4	20	10	4	4	8***	8
J	62	F	45 years	4	22	16	4	4	4	4

^ These participants live in country Victoria, and therefore interviews were conducted over the telephone and journals sent by post.

\* This participant reported not experiencing cataplexy. However he had received a formal diagnosis of narcolepsy according to the DSM-5 criteria.

\*\* These participants were unable to complete the journal, as they did not currently experience automatic behaviour.

\*\*\* These participants attempted to complete the journal, but reported that they were unable to find the time to do it.

## **3.2 Tools and Procedures**

### **3.2.1 Screening Participants**

Following the receipt of permission from the Victoria University, Department of Psychology, Human Research Ethics Committee (see copy of letter dated 18<sup>th</sup> June 2002 in Appendix A), participants were approached at a NODSS meeting and questionnaires from a previous study were reviewed. Once participants were approached and expressed interest in the study, they were given information regarding the study, a consent form, the selection questionnaire and identification sheet to complete (Appendix B and C). The identification sheet included participant's contact details, in order for the researcher to notify them that they had been selected or not selected to participate in the study. Participants were informed that information from the selection questionnaire and their contact details would remain confidential and the two would be kept separate via a coding system.

### **3.2.2 Testing Procedures**

The researcher conducted the following procedures (all interviews and transcriptions).

#### **3.2.2.1 Interview One**

Initial interviews were arranged over the phone. Plain language statements detailing the purpose of the study, and consent forms were sent to participants prior to the meeting (Appendix D). For participants who lived in Melbourne, interviews were conducted in the individual's home at a mutually convenient time. Similarly, interviews were conducted over the phone at prearranged times for participants living in country Victoria (N = 2). The interview itself involved a semi-structured format. That is, after

reviewing the research on automatic behaviour, the researcher developed a number of questions based on information from these readings and based on issues that were not addressed in previous research (Appendix E). However, participants were given the freedom to bring up particular issues or features of automatic behaviour not addressed by the researcher. All interviews were conducted by the researcher and tape recorded with the consent of the participant. The researcher transcribed interviews within one week of the interview.

### **3.2.2.2 Journal**

In addition to the interviews, participants were asked to complete a journal for at least a week, writing down any episodes of automatic behaviour (Appendix F). These were either given at the time of interview, or sent prior to the interview (country Victoria participants only, so as to give them the opportunity to review the journal and have the researcher clarify any questions). Participants were given the choice of completing a written journal, or completing a combined written/ audio taped journal (Appendix G).

The journal consisted of two sections. This included the sleep wake diary and a record of instances of automatic behaviour (also using the Stanford Sleepiness Scale) (Hoddes, Zarcone, Smythe, Phillips & Dement, 1973).

The sleep wake diary was completed daily for the duration of the journal. It included information regarding the previous night's sleep, naps taken during the day, a medication record and food and alcohol intake.

The record of instances of automatic behaviour included two parts. Once participants experienced an episode of automatic behaviour they were first instructed to note the day, time of episode, level of sleepiness before and after the episode, time of last

medication, time of last nap and food intake in the last three hours. In order to record their level of sleepiness (both before and after the episode) participants were referred to the Stanford Sleepiness Scale (SSS) (Hoddes et al, 1973). The SSS is a self-rating scale, which is used to quantify changes in sleepiness. The scale consists of seven statements, measuring extremely high (7 - “almost in reverie; sleep onset soon; lost struggle to remain awake”) to extremely low (1 - “feeling active and vital; alert; wide awake”) levels of sleepiness. In the current study participants were also given the option of noting whether they had been asleep before or after the episode (X- Asleep). In the second part of the automatic behaviour record, information in relation to the actual episode was documented. Information that participants were instructed to provide included a description of what occurred before, during and after the episode, the estimated duration, and any signs or knowledge that they were having an episode. Finally, participants were given the opportunity to note any additional thoughts or issues associated with the episode.

The current study included the use of a journal so that conclusions could be made using not only retrospective data (interviews) but also data taken as the phenomenon occurred.<sup>1</sup>

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<sup>1</sup> Individuals with narcolepsy found it very difficult to complete this journal. That is, often they were unable to complete the journal as they often felt too tired after the episode of automatic behaviour. As a result participants were given the option of keeping the journal for a period longer than a week, to give them greater opportunity to note episodes of automatic behaviour. Despite this, four participants were unable to complete the journal. One participant chose to tape-record the journal, as she reported finding it difficult to write when in a sleepy state.

### **3.2.2.3 Interview two**

Following the completion of the journal, the researcher returned to the participants' house and collected the journal (or participants in country Victoria sent the journal to the researcher and were subsequently contacted via telephone). Once this occurred, the transcript of the first interview was reviewed and discussed in order to give participants the opportunity to add or clarify responses. A second interview was also conducted at this time in order to gain an increased depth of information. The rationale for this is that individuals may have become more aware of instances of automatic behavior after having completed a journal, as a result of increased focus on their automatic behavior. Therefore, more information may be uncovered in the second interview (Appendix H).

### **3.2.2.4 Spouse/ family member interview**

As episodes of automatic behavior may not be evident in individuals with narcolepsy, or they may not be fully aware of the extent of their behavior in these episodes, a spouse or family member was invited to be interviewed. Of the 10 participants, five agreed or were able to have a family member interviewed. Reasons for not including a spouse or family member included limited availability (due to other commitments), refusal, or the absence of a significant other to comment. Interviews were conducted without the presence of the participants and were confidential (Appendix I). Interviews with a significant other occurred at either the initial interview or the second interview.

### **3.2.2.5 Minimal medication journal**

The minimal medication journal was developed following an initial aim to use polysomnographic ambulatory recording devices in the participant's home to record the brain wave activity associated with automatic behaviour. During this recording participants were asked to take the lowest dosage of stimulant medication that they would take on a day (individuals with narcolepsy may take varying doses of their stimulant medication). However, due to equipment problems this phase was abandoned.<sup>2</sup> Instead, those who had agreed to participate in this phase of the study (N= 4) were given a journal to complete, which was to be completed on a day in which they were able to take a low dose of stimulant medication (participants were also given information regarding participation and a consent form, Appendix J).

Participants were instructed to complete the journal on a day in which they would not need to leave the house or drive. The minimal medication journal included a sleep wake diary (similar to the journal completed by all participants), however participants were also instructed to report any cataplexy attacks. They also were instructed to record daily meals, medication and caffeine or alcohol intake. Participants also wrote down any episodes of automatic behaviour (what occurred before, during and after). Additional information included the time of the episode, estimated duration, the level of sleepiness

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<sup>2</sup> Pilot work in this phase of the study revealed that there was too much interference to be able to examine EEG data. This was associated with the movements of the wire attached to the participants. Of note, previous researchers have been able to obtain EEG data (Guilleminault et al, 1975; Valley & Broughton, 1981; 1983), however, contrary to the current study, these recordings were conducted in an experimental setting (stationary recording). As the current study examined automatic behaviour in the home (ambulatory recording), accurate data was unable to be obtained.

before the episode (according to SSS) and a description of why they thought it happened. Participants were also given space to record any additional comments. Minimal medication journals were sent back to the researchers via a reply paid envelope (Appendix K)<sup>3</sup>.

### **3.2.2.6 Minimal medication journal follow up**

Upon the return of the day journal, participants were contacted via telephone for a brief interview regarding their experiences while keeping the journal.

The aspects of the study completed by each participant are included in Table 1.

### **3.2.2.7 Additional information**

After all the information was collected, participants were contacted via telephone in order to administer the Epworth Sleepiness Scale (ESS) (Johns, 1992). In the ESS, individuals must rate the likelihood of falling asleep in eight situations (such as “watching television”, “sitting and reading”, etc), according to four choices (from “0 = would never doze” to “3 = high chance of dozing”). This gives a score for each participant, between 0 and 24. According to Johns (1992), ESS scores greater than 16 are indicative of a high level of daytime sleepiness, often characteristic of individuals with narcolepsy, idiopathic hypersomnia and obstructive sleep apnea syndrome. Questions were given to participants first referring to how they were without treatment (off medication condition), and then again referring to how they were with treatment (on medication condition). This was included to obtain more information regarding the

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<sup>3</sup> The four participants who completed the minimal medication journal were going to be presented as case studies. However, given that one of the participants took her stimulant medication during an episode of automatic behaviour early on that day (and therefore, no data for automatic behaviour with minimal medication), it was decided that only three cases were completed.

severity of their narcolepsy and sleepiness. Results for each participant are presented in Table 1.

### **3.3 Method of data analysis**

#### **3.3.1 Phenomenological analysis**

Once all the information was gathered and transcribed the following steps were taken by the researcher to analyse the data.

Step 1. The researcher gained familiarity with the data by conducting numerous readings of the transcripts in order to become immersed in the data. Numerous readings of the journals was also conducted.

Step 2. Once this occurred the process of data reduction occurred. Data reduction is a process of selecting, focusing and simplifying raw data. This was achieved by assigning codes to the raw data (Miles & Huberman, 1994). A code is an abbreviation or symbol that is applied to a section of words in order to make classifications in relation to their themes, hypotheses, speculations or concepts. Coding enabled the data to be retrieved or compared to other similar data quickly and accurately. The first step of coding was associated with identifying similar concepts. For example, one category included the 'consequences of automatic behaviour'.

Step 3. Once all the data was coded, it was divided up into groups (according to the code it was assigned). Once in their conceptual group, the data was again coded into sub categories, but this time in relation to the themes that emerged from statements. To continue with the previous example, the category of 'consequences of automatic behaviour' was further divided into emerging themes, such as feelings of 'loss of control', etc.

Step 4: Once the key issues had been identified, the process of data interpretation was conducted. This involved linking themes and applying meaning to the data that had been collected. Conclusions were identified using the clustering method, in which an understanding of a phenomenon was gained by grouping, then conceptualizing statements that have similar patterns (Miles & Huberman, 1994). That is, the researcher noted regularities, patterns and explanations in the coded data.

### **3.3.2 Case study analysis**

A similar process was conducted in the analysis of data for the presentation of the case studies. This process, although conducted separately, involved the same method of data analysis for each case.

Step 1: The researcher became immersed in the data for the case (interviews and journals) through numerous readings.

Step 2: The next step involved data reduction, through coding emerging themes. In particular, areas of focus included themes that were similar to the general themes reported by the group as well as themes that differed from that reported by the group.

Step 3: Once the data was coded, the researcher began data interpretation. This involved linking themes and applying meaning to the data that had been collected. Unlike the analysis of the data in relation to group themes, the researcher interpreted themes in relation to the individual, and the meaning they ascribed to their experiences.

Step 4: Once all case studies were analysed and written up, they were compared for similarities and differences.

The use of phenomenological analysis and case studies was able to not only examine the similarities between individual's experiences, but also the variability in

responses. In particular, the features identified as being different between participants through phenomenological analysis (especially the strategies employed to prevent automatic behaviour) were able to be further investigated in the case studies.

The results of the phenomenological analysis and the case studies will be presented separately.

**CHAPTER FOUR**  
**RESULTS**  
**PHENOMENOLOGICAL ANALYSIS**

**4.1 Behaviours associated with automatic behaviour**

**4.1.1 Descriptions of automatic behaviour events**

Participants in the current study provided the following description of automatic behaviour.

*“You’re probably too young to remember a record going round and round, and if the needle slipped into another groove. And it’s just like that, it happens so unexpectedly... It’s just for a very short time... Yeh its just like I slip and then pick up again and go back on the natural rhythm.” [Participant J].*

*“For me it’s when I’m still going about doing what I’m doing, but my mind is not there” [Participant H].*

*“It’s like the consciousness of your brain switches off, that’s um, but your brain manages to keep going and do whatever you were trying to do, but the brain doesn’t get it quite right and you usually find yourself in a bit of a muddle.” [Participant D].*

All participants consistently reported that all types of automatic behaviour were associated with a loss of conscious awareness for their actions and subsequently experiencing a ‘blank’ for that period of time. That is, they were able to recall what occurred before and after the episode, however they had no recall for the actual period of automatic behaviour.

*“Automatic behaviour is when you’ve been doing something and either at the end of it or afterwards you can’t really remember what it was you did.”* [Participant F].

*“I’m never aware of automatic behaviour until after it has happened.”* [Participant E].

How participants knew they had been in automatic mode came from four sources. One included simply having no recall for a period of time.

(After describing episode) *“I had no memory of picking up the jar preceded by opening the cupboard; no memory of opening the drawer and getting the spoon; no memory of unscrewing the jar lid and putting the spoon into the jar.”* [Participant D – Journal].

Sometimes participants had partial awareness of their automatic behaviour. This was related to participants slowly regaining awareness of their actions. That is, they described regaining full alertness while in the middle of the automatic behaviour act.

*“I ‘awoke’ to find myself doing a totally ridiculous, irrational and unheard of act! I did not remember anything at all”* [Participant D – Journal].

*“I knew I was in automatic behaviour because I gradually became aware that I was repeating/ going back and forth”* [Participant F – Journal].

A third way participants knew they had been in automatic mode involved finding the outcomes of the automatic behaviour, such as missing objects. In this instance finding an error in behaviour may have occurred immediately after the event, or may have been found some time after the episode.

*“I am mostly unaware of automatic behaviour episodes until later when I find things in all the wrong places.” [Participant J- Journal].*

Finally, some participants reported that they would never be aware of some episodes of automatic behaviour if they did not have family members or friends point them out.

*“I knew I had had an episode of automatic behaviour from others commenting on things I had done/ not done. Denying events with others who could then prove otherwise.” [Participant F – Journal].*

#### **4.1.2 Consequences of automatic behaviour events**

In many cases, automatic behaviour was described as resulting in an unsuccessful activity. Individuals reported that they could often carry on doing a task successfully, and it wasn't until they were interrupted or an unexpected event arose that the errors in their behaviour occurred. This involved errors in sequencing, item/ environment intrusions, perseverations leading to nonsense and behaviours that were successful but context inappropriate.

##### **4.1.2.1 Sequencing errors**

Automatic behaviour often resulted in sequencing errors, which typically involved omission of a step in a sequence. This included not only missing a step in a behaviour, but also mixing up the order of the act.

*“I boiled the water up to make spaghetti... I wanted to stir the spaghetti in the water and I actually put my hand in it!” [Participant B].*

#### 4.1.2.2 Item/ environment intrusion

For all participants, automatic behaviour often was associated with putting objects in the wrong places. This appeared to be associated with individuals wanting to place an item somewhere and continuing with the act of ‘putting something away’, but mistaking environmental stimuli. For example, if an item was to be put in a cupboard the item often ended up in a place where a door opened, such as the fridge. Similarly, objects to be placed in drawers would be found in another drawer.

*“I could perhaps find a saucepan in the freezer, or really weird things like that. See your brain keeps working when you’re in automatic behaviour. It says put your saucepan away in your cupboard. But you get it a bit wrong, so you put it in the wrong cupboard, which happens to be your freezer. It’s really quite weird, that your brain carries on doing something, but it can’t get it quite right.”*

[Participant D].

*“Anyway after the meal I put the lamb in the blinking um dishwasher instead of our fridge! And then I couldn’t find it, and I didn’t even think to look in the dishwasher. I mean why would you?”* [Participant B].

*“It’s not unusual to find the kettle in the fridge and the milk sitting where the kettle should be.”* [Participant C].

There were however isolated examples of when items were put in places that were not associated with the desired environmental stimuli. This differed from the above example, in that individuals appeared to have a place that items were consistently placed inappropriately.

*“The family’s gotten in the habit of asking ‘have you looked in your ugg boots’... on more than one occasion I have lost something and later found it in my ugg boots.”* [Participant C].

#### **4.1.2.3 Perseverative actions leading to nonsense**

Individuals operating in automatic mode were also found to be perseverative in their actions. That is, participants reported continuing on with the actions of a task in a very specific manner, such as typing the same letter on a computer over and over again. Therefore, this often resulted in nonsense behaviour. At times it appeared to others that the individual was functioning appropriately, however once the product of the behaviour was examined it became clear that the individual had been in automatic mode. Participants noted that this most frequently occurred during conversations in which they perseverated on letters, words and topics of conversation.

*“I was a legal secretary...so I went along and had to take down the case short hand... and at one stage the magistrate asked me: ‘What did so and so say a few minutes back?’ and all I had was just scribble and I wasn’t able to answer them.”*  
[Participant J].

*“At dinner table... spoke gibberish... fighting to regain composure and apologised to company”.* [Participant J - Journal]

#### **4.1.2.4 Context inappropriate behaviours**

Participants reported that automatic behaviour did not always result in making errors in behaviour or nonsense. At times individuals were able to carry out a successful behaviour while in automatic mode, however actions were sometimes context inappropriate. This most often occurred when writing or in conversation with others.

*“Very often I join in the conversation and say something completely different to what [pause] to the person I’m talking to was talking about”. [Participant J].*

*“I mean the whole letter made sense but it just didn’t happen..... and I was so embarrassed and I had to pretend that I was writing to someone else. To this day I don’t know who it was I was talking about!”[Participant C].*

It may be speculated that the last quote may have been a mixture of automatic behaviour and a dream like state. Although not reported by this participant (Participant C), another participant noted that automatic behaviour and hallucinations occurred together. Other participants did not report this.

*“I was at a restaurant with my husband and I poured lemonade into my plate, instead of pouring it into a glass. But I was hallucinating. And I remember distinctly thinking that that was the glass... so I think I hallucinate at the same time or nearly the same time as the automatic behaviour.” [Participant J]*

#### **4.1.2.5 Successful actions**

Individuals with narcolepsy reported being able to perform successful actions while in automatic mode. That is, participants reported that they were able to complete an action successfully and it was only by retrospectively looking back and noting that they could not recall a period of time that they became aware that they had been in automatic mode. This type of automatic behaviour was often reported when driving.

*“There’s many a time I’ve pulled up in this driveway and thought ‘I cannot recall anything of the last 2 or 3 kilometers’ but I’ve driven and I’ve come home without having an accident.” [Participant C].*

## 4.2 Internal states during automatic behaviour

Participants described three instances or conditions in which automatic behaviour would be most likely to occur. These are described in three “types”. The types experienced by each participant is included in Table 1 (Chapter Three).

### 4.2.1 Type 1: Sleepiness with low cognitive load

Type 1 automatic behaviour was typically associated with a general feeling of sleepiness in all participants (N= 10).

*“I think it would definitely go with being sleepy.”* [Participant A].

*“I do know with me that it happens when I’m fairly tired.”* [Participant D].

*“Automatic behaviour happens when I am fighting off the sleepy feeling.”*  
[Participant J - Journal].

In Type 1 automatic behaviour, this general feeling of sleepiness was often associated with low stress levels or when completing routine tasks, which often required low cognitive demand/ stimulation.

*“Um [pause] probably like cooking, um if I’m [pause] got sort of time to prepare a meal this is when I have trouble because I’m slightly more relaxed.”*  
[Participant B].

*“I was feeling quite tired and in trying to get myself a coffee, I put a teaspoon of coffee in the peanut butter jar, instead of a teaspoon in my cup”* [Participant B – Journal].

*“I went into automatic behaviour while eating lunch and then fell asleep. I woke up, still holding plate with ¼ of lunch still on plate. Some of the crumbs will be*

*scattered down my chest and stomach. My memory only recalls the first 2 or 3 bites of my lunch.*” [Participant D- Journal].

This type of automatic behaviour was also often associated with falling asleep. That is, if the individual were placed in a position where sleep would be possible (such as a couch), then the automatic behaviour and feeling of sleepiness would progress to complete sleep (this was also indicated by ratings from the SSS in participant’s journals). In these instances individuals described sleep as an interruption to the automatic behaviour.

*“She can be sitting there with a knitting needle and continue happily until she falls asleep and then wakes and continue as if nothing happened.”* [Spouse – Participant G].

*“Sometimes, I used to eat automatically and then go to sleep while I was eating and then continue on without even being aware that I’d been asleep in the middle of it.”* [Participant E].

#### **4.2 Type 2: Sleepiness with high cognitive load**

Similarly, all participants (N = 10) described experiencing automatic behaviour that was associated with feelings of sleepiness, which occurred when completing tasks with high cognitive load (Type 2). Participants described being stressed during these instances, as a result of feeling pressured to get many tasks completed.

*“I find that if I’m trying to do too many things at once... you finish up with some interesting things happening.”*[Participant A].

*“It could be sleepiness... but I would say possibly that I’m under stress most times when it happens.”* [Participant C].

*“Stress to get things done tends to have a lot of bearing on the amount of episodes of automatic behaviour that I have”.* [Participant F].

Type 2 was also associated with individuals feeling sleepy and being aware of their sleepiness, but pushing on to get the task done. Participants reported that this was sometimes a conscious effort and a desire to complete a task. Alternatively the demands of work and family prevented them from taking the break they needed, and therefore automatic behaviour would occur.

*“Started to write some notes, finding it hard to write, but kept going. By the third line I was not making sense, became ‘stupid’ and I had to give up. I was drifting into automatic behaviour but trying to retain consciousness to finish writing.”*  
[Participant D – Journal].

*“She doesn’t push herself the way she did previously. And that’s when the automatic behaviour occurred previously, when she pushed herself further [pause] kept going”* [Spouse - Participant G].

Participants reported that they believed that if they stopped and had a nap, the automatic behaviour would not occur.

*“Getting a meal ready and knowing you’re tired and you just keep doing it because you want to get it done. It’s at these times where I need to stop.”*  
[Participant B].

*“This episode was at stage one of automatic behaviour before my conscious switched off; if I was seated it would not have become automatic behaviour, I would have fallen asleep.”*[Participant D – Journal].

The sleepiness associated with Type 1 and Type 2 was reported to be largely mediated by daily stimulant medication intake. All participants reported that daily medication intake had a large impact on the amount of automatic behaviour that occurred.

*“My episodes of automatic behaviour are definitely when my medication time is wearing off.”* [Participant D].

*“It does get worse if I’ve forgotten to take my medication. I know that at about 10 o’clock in the morning I’m thinking, “why am I feeling like this?” and suddenly realise I haven’t taken anything”* [Participant I].

As a consequence many believed that an effective way to control automatic behaviour was through appropriate management of medication.

*“The only thing that really snaps me out I think is the medication.”* [Participant J].

*“My sense of how I control automatic behaviour is partly medication, it could also be following a reasonable plan for sleep.”* [Participant E].

*“Once she got the tablets it seemed to control a lot of that (automatic behaviour).”* [Spouse - Participant G].

Participants noted that if they did not take their medication appropriately this had an impact on their automatic behaviour for that day, and in the days following. That is, if they were to continue on without medication they would experience a rebound effect and be worse in the following days. This was also reported to occur when individuals did not take time to rest and sleep when they needed.

*“I find it worse if usually the day before I’ve forgotten to take a dose of tablets... And it’s the next day that I seem to have more automatic behaviour.”* [Participant A].

*“I think it’s worse on days following when I’ve taken insufficient medication.”* [Participant H].

*“I can have 2 or 3 good days and bad days...I’ve sort of had to learn not to burn and bust because typically I used to feel good so I’d burn and then be crook for a week”* [Participant F].

It may be noted here that according to the ESS (results presented in Table 1), participants reported a high propensity to fall asleep in the given scenarios, with scores falling within the clinically significant range according to Johns (1991) (scores greater than 16). However, when asked to complete the ESS thinking about their propensity to fall asleep when well medication, many scores fell below the clinically significant range. This supports the notion that stimulant medication had a large impact on participant’s ability to control sleepiness as well as their automatic behaviour.

#### **4.2.3 Type 3: High cognitive load without sleepiness**

The third instance in which automatic behaviour occurred was when participants were pressured to complete a task, but felt they were not sleepy or drowsy at the time (Type 3). This type of automatic behaviour was not described by all participants (N = 3).

*“I’ll quite surprise myself sometimes that I must have had an episode because I haven’t felt drowsy.”* [Participant J].

*“I’ve had automatic behaviour when I’ve been well medicated and thought I was reasonably alert.”* [Participant C].

*“For this episode I was very well medicated and I believed that I was awake”*  
[Participant F – Journal].

It was interesting to note that the participants who experienced Type 3 automatic behaviour had higher ratings on the ESS than the other participants in the ‘on medication’ condition (in the ‘off medication’ condition ESS scores were comparable). That is, while the other participants received scores below the clinically significant level (below 16), only the three participants who reported Type 3 automatic behaviour received scores at or above this level (see Appendix C).

Finally, in both Type 2 and 3, participants believed that automatic behaviour occurred as a type of overload on the system.

*“It’s almost like [pause] you can’t sort of process everything that’s happening...It’s a bit like a coping mechanism. That I can’t cope with two things at once”* [Participant F].

*“I reckon stress triggers it because it’s just like too much for your system to cope with. It just starts to happen whenever you are doing any common thing. After a while it just starts to overload.”* [Participant B].

*“If I’m trying to do a lot of things at once, um it’s sort of like an overload.”*  
[Participant H].

### **4.3 Controlling automatic behaviour**

Participants described attempting many strategies to try and control the automatic behaviour. Of the ten participants, only two participants (Participants E and G) reported that the frequency of their episodes of automatic behaviour had decreased over the years and this was related to gaining greater control over the other symptoms of narcolepsy,

particularly the daytime sleepiness. The other eight participants also described methods that they used to control automatic behaviour (including methods reported by the other two participants who had less automatic behaviour now), however these methods were applied inconsistently or did not work on all occasions. These included controlling daytime sleepiness (through appropriate medication use), stopping an activity and having a sleep, developing habits or routines, and keeping active.

#### **4. 3. 1 Controlling the other symptoms of narcolepsy**

Three participants reported that by controlling the other symptoms of narcolepsy (particularly daytime sleepiness) the automatic behaviour also seemed to be under better control. This was achieved mainly through appropriate medication intake (as mentioned in the previous section) and following a reasonable sleep pattern (such as, getting up the same time each morning).

*“I think overall I’ve developed a strategy to handle narcolepsy better, and automatic behaviour goes with it.”* [Participant E].

*“If I keep the other symptoms under control um, I don’t have as many of the automatic behaviour.”* [Participant F].

#### **4. 3. 2 Stop and sleep**

Three participants reported that sometimes the only way to prevent an episode of automatic behaviour from occurring was to stop whatever they were doing and go to sleep. This was applied when individuals were able to recognise that they were very sleepy (which they noted was sometimes a precursor to automatic behaviour). However, on many occasions this strategy was not used either because they were unaware of their

level of sleepiness or because they did not have time to sleep and needed to get the task done.

*“If I feel I’m going to revert into it, I know just to stop and go to bed. I know that, but I don’t always do it.”* [Participant D].

*“Only sit down and have a sleep. That’s the only way I can control it.”*  
[Participant I].

*“I stop what I’m doing if I feel sleepy.”* [Participant H].

#### **4. 3. 3 Develop habits to follow**

Two participants reported that rather than develop strategies to prevent the episodes, the way they had managed to deal with automatic behaviour was by developing habits and relying on routines to minimise the adverse outcomes of the automatic behaviour.

*“I normally try to develop habits about where I put things, like the car keys. When I come in and they go in a certain place.”* [Participant A].

*“So I’ve made a habit of walking in the door and I put them [rings] on the little table in the hallway...but I don’t take them until I’m going to put them away, because goodness knows where I might put them!”* [Participant C].

#### **4. 3. 4 Keeping active**

Three participants reported that remaining active was a way to not only fight sleepiness, but also automatic behaviour. Minor or small activities included getting up from a sitting position and carry out an activity such as going to the toilet or getting a drink. If the sleepiness was more severe, then participants reported becoming more overtly active.

*“I know now how to prevent automatic behaviour. By getting up, making people a cup of coffee, going to the toilet.” [Participant G].*

*“If I get that feeling I go marching around the garden.” [Participant D].*

More dramatic strategies included taking steps to remain in a high state of anxiety and adrenaline. Only one participant reported this. This was achieved by completing tasks at the last minute, running late and changing the order or routine of daily activities.

*“I just live on all these funny things like doing things at the last minute... My adrenaline is better than anything, better than Ritalin.”[Participant B]*

#### **4. 4 Psychosocial impact of automatic behaviour**

Individuals with narcolepsy reported that automatic behaviour affected their life adversely. In particular, negative effects were reported to occur personally and in interactions with others.

##### **4.4.1 The impact of automatic behaviour on the individual**

All participants reported experiencing adverse reactions to episodes of automatic behaviour. These included feeling frustrated, annoyed, exasperated and angry that they had experienced another episode.

*“The automatic thing is just the most frustrating side of narcolepsy. Look I love to sleep, so you know I can’t say I hate that. I mean alright I sleep at inconvenient times, and I’ve slept half of my life away but I still like sleeping. But I hate this automatic behaviour. That and the cataplexy are the two worse things in narcolepsy.” [Participant C].*

These adverse reactions were often associated with a sense of loss of control. That is, participants reported that they felt angry that they were never able to fully control

episodes of automatic behaviour. Additionally, participants felt annoyed that it was possible for them to do something without their conscious knowledge.

*“I get really cross with myself when that happens. I get really frustrated because there’s nothing I can do to control it.”* [Participant H].

*“Annoyed is probably the word... you feel like for that block of time that you’re not in control. Things have happened that you can’t remember or recall happening or fully understand.”* [Participant F].

Adverse reactions to the automatic behaviour also stemmed from feeling trapped or held back by the episodes. That is, participants felt that automatic behaviour (and associated sleepiness) interfered so much during their day that they were unable to complete tasks they had set for themselves. This also included delayed completion of tasks due to frequently losing objects.

*“Its very frustrating because I can’t get all these things done that I want to do. That pile has been there since November. The other pile in the bedroom has been there for 4 years. I’ve got letters on the kitchen table that I’ve been trying to answer since Christmas, and it’s now March.”* [Participant D].

These feelings of loss of control over one’s life appeared to have a large impact on self-esteem in many participants. This came not only from not meeting expectations they place on themselves, but also from how they believed others perceived them. Participants often reported feeling less intelligent, crazy and embarrassed by episodes of automatic behaviour.

*“Um that to me takes away my self esteem hugely ‘cause I feel like I’m a real idiot. That’s what I hate and I spend a lot of my time and a lot of us do trying to*

*be a good person or a good member of a household. You spend a lot of your time apologising” [Participant B].*

At other times, participants reported that they found some of their automatic behaviours amusing and were able to laugh at what had happened. However, this usually occurred for minor events or after some time had passed. Additionally, some participants (N= 3) reported that although automatic behaviour did occur on a daily basis, it did not have an adverse effect on their life and were able to cope with it appropriately.

*“It is a bit frustrating, can be a bit depressing and sometimes very amusing. Because sometimes I’m writing letters and my brain switches off and after I read the letters and it’s really really amusing.” [Participant D].*

*“It doesn’t have any impact on my life at all really... I don’t think. Except people think I’m stupid when I say weird things.” [Participant J].*

#### **4.4.2 The impact of automatic behaviour on interactions with others**

Just as the automatic behaviour impacted on the participant’s self - perceptions, it also had a large impact on their interactions with others (N= 10). Participants reported that automatic behaviour had a large impact on family relationships, and it often interfered with their ability to fulfill their role in the family. For example, the automatic behaviour resulted in tasks, such as meal preparation, being incomplete or not complete on time.

*“I think it affected my marriage to some degree...my husband was annoyed and frustrated with me.” [Participant D].*

*“With family I end up having arguments with them. I think they’ve either told me something and then I can’t remember doing it. We’ll end up having an*

*argument... and I just become quite convinced that I've [pause] they haven't told me something or I hadn't been there."* [Participant F].

*"You know and my daughter as a teenager used to say, 'oh you do drag around the house mum' and you know, 'haven't you finished that yet?' that sort of thing. I used to feel very deflated by her."* [Participant D].

Participants reported that friends were quite tolerant of instances of automatic behaviour (N= 7). In social situations, errors in conversation were the most common form of automatic behaviour. Participants noted that friends were tolerant because (contrary to family members) they did not notice the automatic behaviours, or if it was noticed, they were too polite to comment.

*"I have one friend who has been very supportive and he's the one who usually catches heaps of my automatic conversations and he just lets it go. If I was talking silly rubbish he just says 'I don't remember what you were talking about either' and just makes me think he's as bad as I am."* [Participant C].

Despite this, participants reported that episodes of automatic behaviour held them back socially.

*"It's very embarrassing when I'm in company and say something that's completely, has nothing to do with the conversation."* [Participant J].

*"Well I can't go out as much. It certainly affected my social life... and I'm still very choosy about where I go."* [Participant D].

Automatic behaviour also had an impact on individuals' ability to function appropriately at work. Participants reported making major errors at work and in some cases loss of employment.

*“It’s affected my work and I don’t work anymore. Not by choice... a lot of the jobs that I did, I relied on being reliable in a sense of having done something well. I felt I couldn’t rely on myself in the end.”* [Participant F].

*“I did lose a job... And that was awful. I had two 16-year-olds pinching things. They were the defendants and um, we acted for the defendant. And I typed up the same brief applying to the same kids and I sent them to the wrong court, with the wrong barrister, on the wrong day.”* [Participant J].

#### **4.5 Overview**

From this presentation of the results, it can be seen that a number of features of the phenomenon of automatic behaviour emerged. In order to obtain a more in depth understanding of the phenomenon, the next section will present three case studies. These were chosen based on their ability to reflect the group themes, as well as their distinctiveness (of which some aspects were touched on in the phenomenological analysis). Each of the participants also completed the minimal medication journal, which provided an increased amount of information.

## **CHAPTER FIVE**

### **RESULTS**

#### **CASE STUDY ANALYSIS**

##### **5.1 Case study one – Participant C**

Participant C is a 63-year-old married mother of three. She was diagnosed with narcolepsy 32 years ago, however reported experiencing excessive sleepiness since her teen years. At the time of interview, Participant C reported that she was continually sleepy during the day and rarely felt rested upon waking from the night's sleep. She noted that her usual sleep wake pattern involved going to bed between 4am and 7am and sleeping on average seven to twelve hours. To help her manage her narcolepsy, she reported that she took two to three naps a 'day' (lasting from five to 60 minutes) and 20mg of Dexamphetamine twice daily. She also reported frequent cataplexy attacks, lasting from a few seconds to a few minutes. Examples given included feeling weakness in her limbs, such as her knee, arms or hands; her voice breaks or she can't speak; and at times her whole body goes weak and she can not move. The cataplexy was reported to be more likely to occur if she were sleepy or had not taken enough medication. Another prominent symptom was automatic behaviour. This case study will examine how automatic behaviour has changed over the years, internal states of automatic behaviour and the strategies Participant C uses to control it.

##### **5.1.1 Experiences of automatic behaviour in the past**

Participant C reported that she did not frequently experience automatic behaviour earlier in life. As time passed and the other symptoms of narcolepsy became more pronounced (particularly the daytime sleepiness), she began to experience episodes of

automatic behaviour and attributed these instances of decreased awareness to poor memory. *“We just thought it was memory. You know we sort of joked about it ‘cause it wasn’t anything severe then. You know everyone does the occasional silly thing, but mine just seemed to be a bit sillier, and a little bit more often. So it didn’t really have any great impact back then.”* Of note, Participant C reported that the daytime sleepiness and automatic behaviour became worse following the birth of her first child and increased in severity after the birth of each child. By the time of her diagnosis, she experienced automatic behaviour on a regular basis, however still did not connect it to narcolepsy. *“I thought I was going crazy, my mind was going, my memory was going I was forgetting things, I was losing things... it wasn’t until NODSS that we, so many of us talked about the memory problems, um that now it is a pretty much accepted symptom. Well automatic behaviour is. It’s not so much memory loss as automatic behaviour.”*

This loss of recall for a period of time that is often associated with automatic behaviour was a large component of the automatic behaviour described by Participant C. She reported that during an episode she was often unaware that she had been in automatic mode and would only become aware of the episode in the following days or weeks. For example, she would realise she had had an episode following the discovery that she had misplaced an item. At other times she would become aware of the episode purely by the lack of recall for a period of time. An example she provided was that of driving. *“There’s many a time I’ve pulled up in this driveway and thought ‘I cannot recall anything of the last 2 or 3 kilometers’ but I’ve driven and I’ve come home. Um and I haven’t had an accident. So I’m seeing what I’m doing but I just don’t have the recall of it.”* This loss of recall that accompanied automatic behaviour was reported to not only be disruptive to

day to day functioning, but it appeared to have a large impact on Participant C emotionally. *“A lot of our lives have been lost by not having recall of it... Even if you haven’t done anything bad or stupid, but just knowing you’re losing time out of your life that you know you have no recall of. You know its things that you’ve lost between that and the sleep, extra sleep you’ve lost a lot of your life time.”*

### **5.1.2 Current experiences of automatic behaviour**

Over time, Participant C reported that the automatic behaviour had become more frequent. She reported experiencing automatic behaviour on a daily basis. *“I’ve just got to the stage where half the time I [pause], you know I don’t really even notice it. I just fix whatever I’ve done.”* In addition to increased frequency, the automatic behaviour had changed its focus. That is, while in the past it was largely related to loss of recall for an act, currently it was reported to result in more errors in performance. However, she noted that loss of recall was still a prominent feature of her current automatic behaviour. *“It’s more a matter of doing things wrong and um like the milk on the hot plate and the kettle in the oven or something in the fridge. Whereas previously it just seemed that I used to forget things.”*

Currently, Participant C’s typical episodes of automatic behaviour involved writing and talking in automatic mode, driving to a destination with no recollection, putting items in the wrong place and losing objects. She reported that the most typical of these was misplacing objects. *“Um I’m always losing things. Putting things away where I won’t lose them um there’s always something missing in this house um and ah the family’s gotten in the habit of asking ‘have you looked in your ugg boots?’ Because one time we, I think we’d sold something on the, through the trading post and we had a bit of*

*cash money here and we were going out and I didn't want to take it and I had to put it somewhere very quickly and apparently I'd decided to put it in my ugg boots um [pause] and my husband was very angry you know 'all that money and you've lost it and' and I said 'it isn't lost I've just put it somewhere we will find it.' Come winter I got my ugg boots out and found it. So now they say 'have you looked in your ugg boots?'... Um and I've actually lost two necklaces. Not one but two. Um but I didn't miss them together so I thought I really did think I had lost those...and ah I found those one in each ugg boot... So you know these sort of things happen all the time. The losing things is so frustrating."*

This quote highlights not only the disruptive nature of automatic behaviour, but also how it can affect the individual personally. As with many other participants, Participant C noted that the automatic behaviour had an adverse impact on her emotional wellbeing. *"I get very angry at myself. I cry sometimes. Sometimes I can laugh about it, but usually much later."*

### **5.1.3 Internal states in automatic behaviour**

Participant C reported that automatic behaviour occurred largely when she was sleepy and was more likely to occur during the afternoon. While it could occur under low cognitive demand (Type 1), it was particularly prominent for Participant C when she was stressed (Type 2). *"I would say it's more the stress that does it to me, but certainly sleepiness can do it as well."* She reported that the automatic behaviour, which was precipitated solely by sleepiness, was more likely to occur at night. Whereas, the automatic behaviour that was associated with high stress levels was more likely to occur during the 'day', and this was noted to also occur without feelings of sleepiness. *"At night I don't [pause], I might have sleep attacks, certainly feeling very sleepy um up until*

*maybe 9 o'clock at night. After that any sleepiness I get is what I call normal sleepiness. And the automatic behaviour at night is only when I get sleepy and when I know I'm sleepy."* This type of automatic behaviour (that occurred as a result of increased stress) was evident in the low medication journal. She reported a high number of automatic behaviour episodes (N = 5), and attributed this to not only increased sleepiness (due to decreased medication intake), but also high stress levels. When asked to comment on why some of her episodes occurred she wrote: *"Maybe tired? But was under stress to get things done."*

Interestingly, Participant C reported that the automatic behaviour could occur when she did not feel sleepy and was well medicated (Type 3). *"It can come in the day without [pause] you know being sleepy."* She described two reasons for this. Firstly, she believed it was partly related to lack of concentration. That is, automatic behaviour was associated with decreased ability to attend to a task and she was more likely to revert into automatic mode if she were trying to do more than one thing at a time. *"I guess there's probably times when I'm not really sleepy but I'm trying to concentrate on something [pause]. Because I'm still thinking about what I'm doing and trying to concentrate on that. Yeh I can go into automatic mode. And I might not be sleepy then so yeh, definitely it could be from a lack of concentration... I think sometimes we do have to try hard to concentrate."* Alternatively, she reported that it could be associated with decreased awareness of one's sleepiness. That is, as decreased awareness of sleepiness leads to 'sleep attacks', so too did reduced awareness of sleepiness result in automatic behaviour at unexpected times. *"I can come in from shopping and I'm fine, but the instant I sit down in the chair to have a coffee I get sleepy, or that's how the automatic behaviour*

*comes one. The same sort of way. And yet you maybe not even be aware of it at the time that you are sleepy.”*

In addition to stress, Participant C described depression as a precipitant to automatic behaviour. This was however, largely associated with the sleepiness. *“They [other symptoms] probably pretty much go hand in glove... Certainly if I’m depressed the sleepiness is worse and the automatic behaviour in worse and the cataplexy is certainly worse.”*

#### **5.1.4 Strategies to control automatic behaviour**

Participant C reported that due to the unpredictable nature of automatic behaviour, she reported difficulty being able to prevent it. That is, she knew that if she were sleepy and not medicated that it was more likely to occur, however she was also able to identify instances in which automatic behaviour occurred when she felt reasonably alert and well medicated. Therefore, in order to gain some control over the automatic behaviour, she reported to have adopted particular strategies, not to prevent the automatic behaviour, but to help her deal with the consequences of it. Her strategy included developing set routines or habits for all activities. In this way she would be able to identify whether she had been in automatic mode by recognising that objects were out of place from their usual spot, and she was able to rely on the routine nature of automatic behaviour to have the correct action completed. *“When my system’s broken like there’s shopping in the back of the car, um that’s when trouble arises... I’ve gone shopping and left the keys in the back of the car [pause]. But that’s when my normal routine in upset. So I do try to do that all the time. Put certain things in certain places and if they’re not there um well you know I’ve either lost them or you know upset my normal routine. Um [pause] most things in the*

*cupboards in the kitchen I could almost go there in the dark and get things because that's where they have to go. But um if I don't do that I'm in trouble, you know because I put things away in the wrong cupboard."*

### **5.1.5 Summary**

The current case study highlights the impact of automatic behaviour on an individual with narcolepsy. In this case, automatic behaviour has changed over the years and increased in frequency. For Participant C this was largely related to difficulty remembering what she had done and often resulted in negative consequences. The unpredictable nature of automatic behaviour (that is, that it can occur when sleepy and not sleepy) renders it difficult to control, however Participant C appeared to have some strategies in place, including relying on routine.

### **5.2 Case study two – Participant B**

Participant B is a 55-year-old married mother of six. She was diagnosed with narcolepsy only 15 years ago, however began experiencing excessive sleepiness around the age of 16 years. She reported that she knew she had narcolepsy for many years prior to her diagnosis by a neurologist. *"I didn't even realise you could have narcolepsy till some [pause], one of my relatives worked it out...I went to a medical library and brought home three articles on narcolepsy which you wouldn't believe. I mean I would never have ever connected all those strange things together, ever...it was clear that I had it, but then to convince it to the medical profession!...He said 'if you had narcolepsy you'd be falling asleep all the time'. And I never have in front of a doctor, ever! "* After her diagnosis she was given stimulant medication to manage her symptoms. Currently she takes 90mg of Methylphenidate HCl daily (15mg, six times a day) and her symptoms include excessive

daytime sleepiness, cataplexy and automatic behaviour. The current case study will focus on the development of automatic behaviour over time, the importance of stimulant medication and food intake patterns, the use of stress as a preventative measure and the psychological impact of automatic behaviour on an individual with narcolepsy.

### **5.2.1 The development of automatic behaviour**

Participant B reported that she had experienced automatic behaviour for as long as she had narcolepsy. She reported that earlier in her life she experienced regular episodes of automatic behaviour, and the frequency of these episodes remained relatively consistent over a number of years. However, by the time she had children, the other symptoms of narcolepsy and the automatic behaviour became much worse. *“You know I had a responsible job before I was even diagnosed. But that was before I had kids. Once I had children I had full, absolute. By the time the twins were two, I was fully developed.”*

Participant B explained that her increase in automatic behaviour might have been associated with an increase in severity in her narcolepsy symptoms, however she believed that it was also largely due to the amount of work that she had to do in the house. That is, the responsibilities of running a household often left her with little time to sleep. *“If you can not have those naps and I think that might be another reason why you’re having automatic behaviour, ‘cause maybe occasionally you should have that nap. But you spend your life trying not to go to bed because you can’t.”* As much of her day was associated with domestic tasks, she noted that many of her early episodes of automatic behaviour were associated with making errors in household tasks and misplacing objects. *“My first episode was before I was diagnosed and my children were babies. When I was about 33 or 32... anyway after the meal I put the lamb in the blinking um dishwasher*

*instead of our fridge. And then I couldn't find it, and I didn't even think to look in the dishwasher. I mean why would you?"* In addition to making errors, she reported having a loss of recall for time or for having done household tasks. *"I would go into it and then I'd think I don't even remember hanging clothes on the line or folding those clothes like that and then I wouldn't fold them in the right pile and it would be all messed up."*

Currently, Participant B reported that her automatic behaviour was quite severe. Recent episodes of automatic behaviour included errors in cooking or meal preparation, driving, writing and eating in automatic mode. For example, she recorded an episode of automatic behaviour in the minimal medication journal in which she *"put a teaspoon of coffee in the peanut butter jar, instead of a teaspoon in my cup"*. Consistent with reports by other participants, Participant B's episodes consisted of loss of recall for a period of time and errors in task performance. Additionally, she reported difficulty concentrating on a task for a period of time. *"I used to have beautiful handwriting and you'd start to go off and you couldn't prevent that and then also my biggest problem was to maintain my thread of thought which I'm even having trouble with now."* Although not classically considered automatic behaviour, poor ability to concentrate was reported to be associated with automatic behaviour.

Interestingly, Participant B reported that although her automatic behaviour was quite severe, she did experience periods where she seemed to be episode free. For example, she noted that prior to participating in the current study she was not aware of having experienced any automatic behaviour for a while. However, after hearing about the study, she experienced a number of episodes. *"It seems to me like once you develop the symptoms of narcolepsy they never really go away. But there are times when you feel,*

*you're so good and you're so pleased with yourself. It's actually when it was mentioned about being a subject and I thought, 'I haven't had automatic behaviour for ages'... when you're on medication you can sort of cope, but then I had a whole run [pause], you know a lot of things happened."*

### **5. 2. 2 Importance of medication, time of day and diet on automatic behaviour**

The previous quote highlights the importance individuals with narcolepsy place on their stimulant medication in managing not only narcolepsy, but also automatic behaviour. Participant B reported that she relied heavily on her stimulant medication to get through the day and believed that not taking it caused an increase in automatic behaviour episodes. *"Not having enough medication is another thing...If I now went from one and a half back to one, apart from wanting to eat the house down, I can't walk straight. I can't focus... I just think it's a hugely necessary thing."* Consistent with this, Participant B reported a high number of episodes of automatic behaviour when completing the low medication journal.

In addition to her medication, Participant B reported that the food that she ate had a big impact on the amount of automatic behaviour that she had, and reported following the 'hay' diet. This involves not eating foods high in starch, such as potato or rice, with foods high in protein, such as meat. *"Definitely doing the 'hay' diet really helped me and ah I get my best alertness after a protein meal...if I have starch and protein together I have such a huge sleep attack, and semi cataplexy and automatic behaviour. So the 'hay' diet has been a huge factor in almost eliminating automatic behaviour"*. She noted that at times she could eat in automatic mode, and often when in this state would eat high starch food, which caused her to have even more episodes.

Amongst these factors, the time of day also had an impact on the amount of automatic behaviour that occurred, and this was largely related to the increased level of sleepiness at that time. *“During that time when you’re about to power down... two times, like late afternoonish or round about that time and maybe later on and they are the two times when I have got to watch myself.”*

### **5.2.3 The impact of stress on automatic behaviour**

In addition to medication and food intake, Participant B reported that stress was another method she used to prevent episodes of automatic behaviour. That is, by maintaining a state of high stress and anxiety, she was less likely to be relaxed and therefore, less likely to have automatic behaviour. *“If I’m [pause], got sort of time to prepare a meal this is when I have trouble because I’m slightly more relaxed... I would spend all day in automatic behaviour and do the strangest things!”* In order to create this state of anxiety, Participant B reported trying to do tasks at the last minute, such as running late to meetings or giving herself little time to complete tasks such as the evening meal. She noted that instances in which she had given herself time to complete a task had resulted in automatic behaviour and even sleep. *“I did play the organ for church... How I used to get there, I used to be running late... this one time I got there in the car park, I was 20 minutes early... and I fell asleep. I had barely got the wretched hand brake on and I was gone just like that.”* Alternatively, another strategy she used was doing activities out of routine. That is, she would adopt different approaches to tasks in order to make the task novel and therefore render her less likely to rely on automatic pilot. An example she provided was that of taking a different route when driving. *“I would be so*

*anxious and I had to read the Melways a hundred times and um stuff. And so that's a trick for driving. Try a different route."*

Participant B reported that she felt that this strategy had been a successful method for controlling the automatic behaviour, comparing it to her stimulant medication. *"I just live on all these funny things like doing things at the last minute... my adrenaline is better than anything better than Ritalin... Anxiety is our best friend. Adrenaline helps you function."* She noted that because of this, individuals were often unable to tell that she had narcolepsy, as the case with her delayed diagnosis from a medical professional. *"I am very severe. It's hard to believe that I am 'cause I'm like this [pause]. But as verbose as I am now, I'm as severe at the other end [pause] and agitated... And they used to say 'why is she either chatter boxing or sleeping' ... I'm looking back and thinking why the doctor was saying 'this mother is very agitated' [pause]. But you've got to be like that to actually get yourself to a doctor."*

Interestingly, although Participant B used stress as a preventative measure, she also reported that stress was another factor that could trigger automatic behaviour. *"Stress really pulls you more likely into it but like with any [pause] with any malfunctioning. I reckon stress triggers 'cause its just like too much for your system to cope with... After a while it just overloads."*

#### **5.2.4 The impact of automatic behaviour on emotional functioning**

Of all the participants, automatic behaviour seemed to have the most negative impact on Participant B emotionally. At times during interview, she became teary when discussing how it affected her psychologically. In particular, she noted that it had a large impact on her self-esteem. *"That to me takes away my self esteem hugely 'cause I feel*

*like I'm a real idiot you know and that's what I hate... It's not like your dumb or stupid [pause] 'cause its hard to explain because its not as though you can't be a responsible person."* The adverse impact on her self-esteem was also noted in the low medication journal. After reverting into automatic mode while writing a letter, she soon after experienced another episode involving eating, which she related to not only low medication but also feelings of disappointment with the outcome of the letter. Due to this, Participant B believed that automatic behaviour was one of the worst symptoms of narcolepsy. *"Automatic behaviour, well it's ghastly thing and I know that everybody does it at times, because everybody gets sleep deprived, but when it's part of your life all the time, wow!"*

### **5.2.5 Summary**

The current case study indicated that automatic behaviour was quite severe early in Participant B's life and appeared to increase in intensity over time, particularly after the birth of her children. However, she noted periods in which automatic behaviour did not occur, but was unable to identify a pattern to this. Strategies that she had used to control the automatic behaviour included high reliance on stimulant medication, modifying diet and maintaining a state of stress and anxiety (that is, doing tasks at the last minute to ensure increased alertness to the task and little reliance on routine). Although she reported using a number of strategies, automatic behaviour still occurred on a regular basis and this had quite a large impact on her psychological functioning, in that she reported having a low self-esteem as a result.

### **5.3 Case study three – Participant D**

Participant D is a 63-year-old widow of four years who has two children. She was diagnosed with narcolepsy 17 years ago. Her current symptoms include excessive daytime sleepiness, cataplexy (involving leg and facial collapse) and automatic behaviour. To manage these symptoms she takes 5 mg of Methylphenidate three to four times a day. The following case study will present an individual's model of automatic behaviour, focusing on how it has changed over the years, factors precipitating automatic behaviour, how automatic behaviour ends and preventative measures.

#### **5.3.1 Change in automatic behaviour**

Participant D reported that her automatic behaviour had become more frequent over the years and noted that this was perhaps related to the fact that her other symptoms of narcolepsy had also gotten worse. Interestingly, she also noted that at times she had less automatic behaviour, which she related to an increase in the number of naps she had and her ability to do what her body wanted. *“I was widowed 4 years ago. When he [husband] was around, there was always this urge to have the lunch ready for him, or be ready to go out with him, to consider or whatever. And I think that possibly kept me awake more than my body would have liked to be kept awake. But now for 4 years I haven't had that person around me. Sort of prompting me...Whereas now I tend to say 'oh dear your falling asleep again, never mind. Have a sleep and when you wake up you'll feel better again.' So I think there is a difference. I am now allowing myself to do what my body wants to do.”*

### 5.3.2 Description of Participant D's automatic behaviour

Participant D was able to describe a number of instances in which she experienced automatic behaviour. For example, she reported writing, eating, driving, cooking, talking and misplacing objects when in automatic mode. Consistent with other participants, she reported that she had no recall for the episode and was often surprised by the outcome. In her regular medication intake journal, she wrote: *“I got a jar of fruit chutney out of the cupboard... and began putting the fruit chutney on top of the fruit salad... I ‘awoke’ to find myself doing a totally ridiculous, irrational and unheard of act! I did not remember anything at all! No memory of picking up the jar preceded by opening the cupboard; no memory of opening the drawer and getting the spoon; no memory of unscrewing the jar lid and putting the spoon into the jar.”* In other examples, she was able to describe instances of automatic behaviour in which she did not ‘awaken’ during the act. As a result, she only became aware of the episode after finding the mistakes she had made.

Participant D also reported more subtle forms of automatic behaviour. Although not classically considered automatic behaviour, she described experiencing lapses or difficulty concentrating for periods of time. *“If I were talking to you say at 2 o’clock in the afternoon, I would be losing concentration, going around in circles and not remembering your questions. See that’s another consequence of automatic behaviour. Like all the tasks that need concentration and reading, fairly rational sort of thinking I have to do those in the morning... My concentration gets foggy and my difficulty to retain things in my head gets very very poor.”*

### 5.3.3 Factors precipitating automatic behaviour

The last quote highlights the importance of time of day factors in experiencing automatic behaviour. As noted, Participant D reported that she was more likely to experience automatic behaviour in either the early or late evening, as it was these times in which she was most sleepy. Although reported to occur less often, automatic behaviour was also noted to occur during the day. She reported that stimulant medication intake had a large part to play in the development of automatic behaviour during the day. *“I suppose, but I don’t really know, that the more medication one has the less likely one is to have [pause] switch into automatic behaviour. Because my episodes of automatic behaviour are definitely when my medication time is wearing off. Which for me is kind of 3 to 3 ½ hours. And that’s when I’m eating my lunch, which is 3 to 3 ½ hours after my tablet. Similarly in the evening. So you could say if I took it every 3 hours perhaps I wouldn’t have any automatic behaviour. But I choose not to take the tablets. Unless there’s a definite need to take them, such as driving.”* This quote is similar to what was reported by many of the other participants, that stimulant medication was important in the control of automatic behaviour.

Interestingly, Participant D reported that when she experienced sleepiness at the extreme end (in which automatic behaviour typically occurred) she would also experience a ‘warning’ or a sense that she was going to either have an episode or fall asleep. She reported that it was *“like another version of feeling extremely tired, but there’s something a little bit different... Sometimes it’s a flat feeling as some sort of warning... For example, if I’m driving and if I am tired, I get a strong warning bell which gives me time to sing, yell, stamp a foot or do something which keeps me awake until I*

*can park and then sleep in the car.” She noted that she experienced this ‘warning’ approximately 10 – 20 % of the time, while the majority of cases she simply switched off. In the example provided earlier in which Participant D reported placing fruit chutney on a fruit salad while in automatic mode, she noted that this was an instance in which she did not get the warning feeling. She noted that “this time I “switched off” very unexpectedly and quickly.”*

Despite having a ‘warning’, Participant D reported that she did not always use this to avoid an episode of automatic behaviour. She reported that she would often ignore the warning in order to complete a task (identified as Type 2 automatic behaviour). *“I feel ‘oh you’re tired, you’re going to fall asleep, so stop right now and go straight to bed.’ But because I’m a bit of an achiever and at times a workaholic, I want to finish what I’m trying to do... Then it’s too late and I make a mess of something. And then I wake up and I feel very tired and but I sometimes manage to finish whatever I was trying to do, and eventually I get to bed.”*

#### **5. 3. 4 Completion of automatic behaviour**

In the examples provided, Participant D reported that automatic behaviour would either result in correct completion of a task, incorrect completion of a task, or she reported that it could result in sleep. The instances in which it would be likely to progress to sleep, were noted to be associated with being in a position conducive to sleep. *“If I was standing up trying to read the same thing, I may have stayed awake and given up reading, or I may have walked around and reverted to complete automatic behaviour. In other words it was stage one of automatic behaviour before my conscious switched off; because I was seated it did not become continuing automatic behaviour.”*

In other instances in which automatic behaviour did not progress to sleep, Participant D reported that there were two ways in which the episode would end. In the first instance it was likely to end following interruption by some noise or alarm. *“The reason I woke up was I was actually bending down and I was lifting a bowl out of a pile of bowls. I wanted the middle bowl in the pile and what happened was all the bowls fell on the floor and some smashed and broke. And the sound of the breaking woke me up.”* Alternatively, she reported that it was not dependent on environmental stimuli, but an internal switch. *“If there is no noise to wake me, which there often isn’t, um, it’s just that my brain suddenly switches on again. It’s literally like switching off and on a light switch.”* A summary of Participant D’s automatic behaviour is outlined in Figure 1.

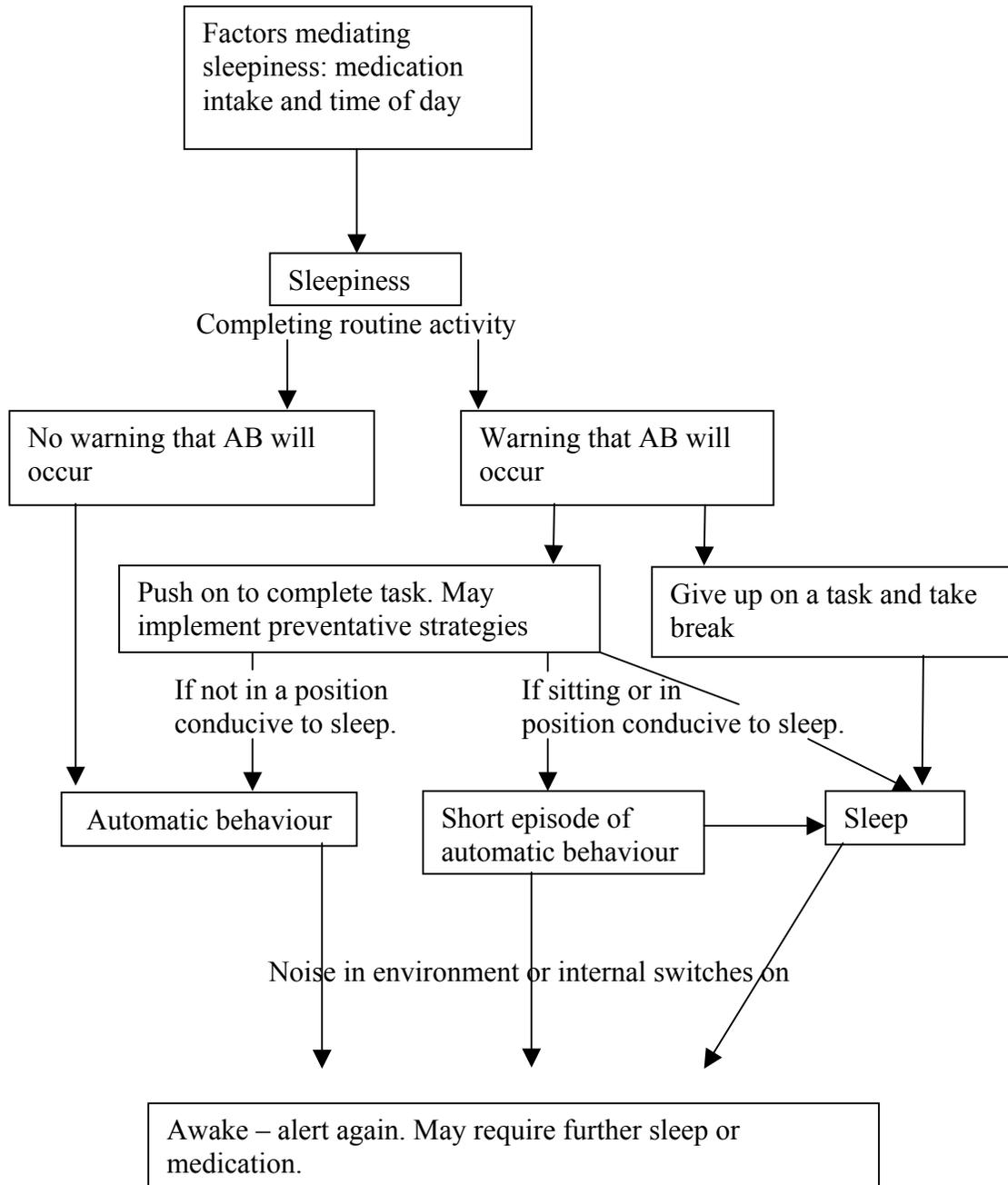


Figure 1.

Summary of Participant D's Experience of Automatic Behaviour.

### 5.3.5 Strategies used to prevent automatic behaviour

Similar to other participants, Participant D had developed her own strategies to try and prevent automatic behaviour from occurring. She reported performing a number of steps to prepare herself and maximise the chances of staying alert, such as having a nap beforehand. Despite using these methods, she noted that automatic behaviour was still likely to occur and that the only real way to control automatic behaviour was to go “*to bed and have a sleep*”. However, when she experienced a ‘warning’ and was able to act on that warning, she would participate in activities that would increase her alertness in order to prevent automatic behaviour. “*The other thing is if I go marching around the garden. I did that one night last week. I thought ‘right, you’re going to fall asleep and you don’t want to’. So I went straight out the back door, marched around the garden, picked a few vegetables and made sure I took some deep breathes and some strong active movements and I came out of it.*” This quote highlights the importance Participant D places on doing outdoor activities in order to remain alert. She reported a number of instances in which she was able to prevent automatic behaviour by remaining active. “*I think especially the activities outside is a very good deterrent for sleepiness and automatic behaviour and any problems falling asleep. In fact I’ve gone on one-week holidays, with sleeping in the morning and activities in the afternoons. Like walking, boat trip, cycling... And I’m convinced that the action and the fresh air all day and every day was a very big boost. And again you can’t always be outdoors everyday. And I had no automatic behaviour during those weeks.*”

Again, despite using the above-mentioned strategy, Participant D noted that this method was limited. That is, she reported that she often didn’t get enough warning to get

active. *“Your rational thinking is often not strong enough to make you do it usually. You know your need for sleep is much stronger than your rational thinking and common sense.”* On the other hand, when she was able to get active and prevent automatic behaviour she reported experiencing a negative impact on her sleepiness in the days following. She described an event in which she remained alert for an entire day, which she attributed to remaining active. She noted, *“but the next day I was very tired. I can’t actually remember if I had more automatic behaviour, but I felt very tired... so if you try to prevent automatic behaviour or sleep, I don’t think it’s a very good outcome long term.”*

### **5.3.6 Summary**

The current case study outlined a detailed description of what occurs before, during and after an episode of automatic behaviour (as outlined in Figure 1). Automatic behaviour was reported to occur in a number of instances (eating, writing, driving, etc) and was also noted to be related to decreased ability to concentrate (such as reading the same paragraph of a book over and over again). Precipitants to automatic behaviour included increased sleepiness, low medication intake and time of day factors (with the mid to late afternoon being the worst time of day). At high levels of sleepiness, Participant D reported sometimes getting a ‘warning’. If she experienced this warning, she would give up on a task and sleep or, push on and experience automatic behaviour. If in a position conducive to sleep she would sleep or experience a brief episode of automatic behaviour, which would then progress to sleep. If not, the automatic behaviour could continue, until she was interrupted by a noise in the environment, or an ‘internal signal’ would wake her up. Currently, she reported many instances in which the

automatic behaviour would end in sleep, due to the limited demands placed on her in her home. She reported some preventative measures (prepare self, get active) but noted that any activity that prevented her from sleep often resulted in increased sleepiness and automatic behaviour in the days following.

#### **5.4 Case study considerations**

Three case studies were described in detail in the current study. In each of the cases it was observed that the automatic behaviour seemed to increase in frequency over time. This increase in automatic behaviour was reported to occur as a result of the other symptoms of narcolepsy becoming more frequent and severe. This is in contrast with recent research, indicating that over time individuals with narcolepsy experience a decrease in the frequency of their cataplexy and SOREMPS, with an increase in their mean sleep latency (Dauvilliers et al, 2004). This discrepancy may best be accounted for by longitudinal research by Bruck and Costa (2003). Bruck and Costa noted that excessive daytime sleepiness had a greater impact on life activities in 2001 than 1991, in their sample of 47 individuals with narcolepsy. It was postulated that this was related to the age-related changes in sleep wake patterns and behaviour (including change in sleep pattern or reduction of stimulant medication) and their interaction with excessive daytime sleepiness, rather than an increase in symptom severity. A similar explanation may be applied to the current study. For example, Participant A and C's increase in symptom severity was noted to occur after the birth of the participant's children. It was believed that having children lead to an increase in household tasks, and therefore less opportunity to sleep. As a result, participants were forced to push on and complete a task despite feelings of increased sleepiness (consistent with Type 2 automatic behaviour). The three

cases presented consistently reported that even though they felt the need to sleep, they often were unable to do this and fulfill the needs of the family. As a result, automatic behaviour had a large impact on their emotional functioning.

Much of these feelings came from not only making many errors in a day, but also from the fact that they were unable to maintain their attention on even simple tasks for a period of time. Interestingly, two cases (Participant D and B) described concentration lapses as forms of automatic behaviour. For example, they described examples of not being able to follow conversations or remember pages just read in a book, as episodes of automatic behaviour. This lapsing in concentration is not classically considered automatic behaviour as it does not involve a behaviour per se. However, it is possible that the levels of vigilance are similar during these states, in which they appear awake, but in fact are quite on their way to sleep. It is also likely that this decreased attention also plays a role in automatic behaviour, particularly when trying to divide one's attention to complete two tasks at once when in a low arousal state (Type 2).

A further issue to consider in relation to the case studies is that all participants reported the need to implement strategies to try and prevent automatic behaviour. Consistent with group themes, the three case studies reported that stimulant medication had a large impact on the amount of automatic behaviour experienced. This was perhaps best illustrated in the minimal medication journal. A simple comparison of the number of episodes is indication enough that limited use of medication increases episodes of automatic behaviour. However, each case also indicated that other strategies were necessary (in addition to stimulant medication), as automatic behaviour was a difficult phenomenon to control. That is, not only does one need to be able to accurately appraise

their level of sleepiness in order to identify whether it might occur, but one also has to be able to put in place a number of actions or interventions to prevent it from occurring. This is illustrated in the case of Participant D who reported experiencing a warning, but not always being able to act upon that warning. Again, the issue arises that individuals may not always have the liberty of having a nap, or engaging in another task until more alert. As a result individuals often had difficulty completing daily tasks efficiently due to automatic behaviour episodes.

## CHAPTER SIX

### DISCUSSION

As the current study adopted a qualitative approach, the findings of the study required much discussion in the Results section. Therefore, rather than repeat what was reported in the Results, the Discussion will provide a brief summary of the findings and will pull the main points together. These points will also be discussed conceptually and linked back to relevant literature.

The aim of the current study was to obtain a better understanding of the phenomenon of automatic behaviour in individuals with narcolepsy. After analysing interviews (with individuals with narcolepsy and family members) and journals (both on and off medication) several important features of the phenomenon emerged.

#### **6.1 Loss of recall associated with automatic behaviour in narcolepsy**

All participants consistently reported that automatic behaviour was associated with a loss of recall for a period of time. That is, while in automatic mode participants did not have conscious awareness of their actions and as a result were unable to describe what had occurred, often describing the episode as a 'blank' period. This feature of the phenomenon is not a new concept, with similar reports also found in the literature. Early research reported that individuals described an inability to recall events occurring only minutes to hours prior (Daniels, 1934; Ganado, 1958). The initial use of the terms 'amnesic states' and 'fugue – like episodes' to describe automatic behaviour is also indicative that complete amnesia for the events of the episode is key to the syndrome. In other research, Guilleminault et al (1975) and Zorick et al (1979) noted that participants in their studies reported inability to recall the period of automatic behaviour.

In addition to loss of recall for the period of time in which automatic behaviour had occurred, in the current study individuals also had ‘amnesia’ for the act itself. That is, participants were not always aware of having had an episode. Even with a number of cues available to indicate that they had been in automatic mode (such as the presence of a ‘blank’ period or later finding the outcome of the automatic behaviour) many episodes went unnoticed. Often, it wasn’t until a family member or friend indicated that it had occurred that individuals became aware of an episode. In some instances, even after being told of the episode, some individuals would deny having completed the behaviour. Guilleminault et al (1975) observed similar reports from their participants. That is, upon questioning, participants denied having been ‘asleep’ even when obvious decrements in performance were evident and they were unable to recall what had just occurred. Together, this further supports the notion that when in this state individuals can have complete loss of conscious awareness, despite having conducted a number of activities.

The loss of recall associated with automatic behaviour may assist in explaining the subjective memory problems consistently reported in this population. Research has shown that although individuals with narcolepsy report diminished memory functions, assessment using objective measures, such as those found in a battery of memory tests, have been unable to demonstrate a memory deficit in this group (Hood & Bruck, 1996; Ollo et al, 1987; Rogers & Rosenberg, 1990). The reason for this discrepancy between subjective and objective measures of memory function continues to interest researchers. Hood and Bruck (1996; 1997) suggested that appropriate performance on objective memory tests in individuals with narcolepsy is associated with an individual’s ability to maintain wakefulness during testing periods (and therefore these testing situations do not

account for the effects of sleepiness on cognition). It may also be suggested that objective memory tests have limited external validity in relation to everyday memory performance. Alternatively, this self perceived impairment has been suggested to be associated with the way in which the individual appraises their memory functions (Hood & Bruck, 1996). Based on the current research, it is suggested that automatic behaviour may also play a key role in this issue.

In the current study, many participants reported that prior to their diagnosis, they experienced automatic behaviour, however given their lack of knowledge of their condition, they attributed these episodes to poor memory. It is possible that the high frequency of automatic behaviour and the associated failure to recall events could result in constant negative feedback in relation to one's abilities and subsequently lowered self-efficacy of memory abilities. This is consistent with research by Hood and Bruck (1996), in which individuals with narcolepsy demonstrated significantly greater anxiety and less confidence in their memory abilities. In line with this finding, it is possible that reports of diminished capacity may be symptomatic of negative feedback or self evaluations from other aspects of life, such as failure to function at school, work or home. Together, the frequent inability to recall an event (as shown in automatic behaviour), plus negative feedback regarding memory functioning (associated with inability to function at work due to excessive daytime sleepiness and automatic behaviour) may distort the perception of their actual ability (measured to be within normal limits on objective measures).

## **6.2 Consequences of automatic behaviour in narcolepsy**

Given this loss of awareness, it is no wonder that many errors in performance occur during this state. Participants reported a number of instances in which mistakes

occurred while in automatic mode. Similar to the literature, participants reported frequent errors while performing routine activities at home, work or while interacting in social situations (Guilleminault et al, 1975; Zorick et al, 1979). Previous research has demonstrated that errors are frequently associated with automatic behaviour, however, none have provided a classification of the types of errors that can occur. Rather, a description of the errors they observed was provided, such as, “they spoke jargon and wrote illegible scribble” (Ganado, 1958, p. 488). The current study was able to define and classify unsuccessful and successful actions in automatic behaviour. Errors were found to occur as a result of an omission or inappropriate sequencing of a step in a task; appropriate action using the inappropriate item/ environment (as often is the case when objects are misplaced); and perseverative actions. In addition to these errors, individuals were able to perform a simple behaviour that was context inappropriate, such as verbal responses not consistent with the topic of conversation. Finally, individuals were able to carry out appropriate actions while in automatic mode. As in the case with driving, a task that becomes quite automatic with experience, individuals were able to describe instances in which they had driven appropriately (to the best of their knowledge).

In cases where automatic behaviour resulted in errors, these were reported to occur as a consequence of an increase in the complexity to the task. That is, with the advent of a new step to consider, the individual would either regain full alertness, or continue in automatic mode and make an error in performance. This is consistent with previous research, which notes that automatic behaviour occurs when completing simple, routine behaviours (Guilleminault et al, 1975; Zorick et al, 1979).

### **6.3 Types of automatic behaviour in narcolepsy**

The current study was able to further define episodes of automatic behaviour in terms of the conditions or internal states in which automatic behaviour was most likely to occur. These were described as three types: sleepiness with low cognitive load (Type 1); sleepiness with high cognitive load (Type 2); and high cognitive load without sleepiness (Type 3). Types 1 and 2 were described by all participants and were the type of automatic behaviour described in the literature (Guilleminault et al, 1975). That is, automatic behaviour was associated with increased sleepiness while conducting either simple (low cognitive load) or complex tasks (or perhaps involving the completion of two routine tasks at once; high cognitive load).

Interestingly, three participants reported instances of automatic behaviour in which they did not feel sleepy (Type 3). In fact, they reported feeling quite alert and reasonably well medicated. These episodes were also associated with demanding tasks. It is unclear whether this type of automatic was truly unaccompanied by feelings of sleepiness, or whether it represents an individual's inability to accurately appraise their level of sleepiness during these instances. That is, individuals with narcolepsy often are not completely aware of the level of tiredness, as they become accustomed to a chronic state of sleepiness (Dement, Rechtschaffen, & Gulevich, 1966). Therefore, it may be hypothesised that it is this factor (sleepiness not noticed by the individual), that cause Type 3 automatic behaviour to occur. It should be noted here that the participants who reported Type 3 automatic behaviour had the highest scores on the ESS for the 'on medication' condition of all participants, with scores falling at or above the clinically significant range (see Table 1). This indicates that perhaps these participants experienced

quite severe narcolepsy (which was less well controlled with stimulant medication than others) and therefore it is possible that they were at times less aware of their sleepiness. It is possible that these individuals also experienced a rapid transition into sleep (making awareness of their sleepiness state more difficult) and therefore greater susceptibility to automatic behaviour when feeling reasonably alert.

An alternative explanation to Type 3 automatic behaviour is that it is independent of sleepiness and occurs as a result of environmental factors. For example, many participants reported that the onset of Type 3 automatic behaviour occurred as a type of information overload. That is, Type 3 was likely to occur when individuals were trying to complete a number of tasks, and when participants were unable to cope with processing two or more tasks at once. Therefore, it is possible that difficulty completing a number of routine activities at once, resulted in an inattentive or automatic state, as noted to occur in driving conditions in normal individuals (Kerr, 1991). That is, despite feeling alert, when trying to do many routine tasks at once, individuals may rely on automatic processing of familiar information. By doing this, attention toward external stimuli is reduced and this is what causes the episode of automatic behaviour. At present it is not clear as to what processes are involved in Type 3 automatic behaviour and further research is required.

#### **6.4 Level of vigilance associated with each type of automatic behaviour**

Although the current study did not examine EEG changes associated with these types of automatic behaviour, it may be useful to consider these types in relation to existing research findings, particularly those examining performance errors and sleepiness.<sup>4</sup> For example, sleepiness was noted to cause Type 1 automatic behaviour.

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<sup>4</sup> The following section will discuss the microsleep and fluctuating vigilance hypotheses, as outlined in Chapter One. That is, microsleeps refer to short bursts of increased alpha (9 – 12 Hz)

Interestingly, Type 1 automatic behaviour was also noted to sometimes end in sleep. That is, individuals reported that if they were sitting or in a comfortable position in which they could fall asleep during automatic behaviour, then it was possible for the episode to end in sleep. This indicates that these types of episodes may be associated with sleepiness at the extreme end of the continuum. If this is the case, then it is possible that this type of automatic behaviour is akin to the episodes described by Guilleminault, Billiard, Montplaisir and Dement (1975). Guilleminault et al reported that performance errors on tasks in their study were associated with repetitive microsleep episodes occurring in close groups. In addition, during microsleeps, participants were observed to have slow rolling eye movements and to stop performing the task at hand, indicating extreme sleepiness. As argued by Valley and Broughton (1983), this study was designed to induced sleepiness in their participants and it was suggested that microsleeps represent the extreme end of declining vigilance levels. It is therefore postulated that Type 1 automatic behaviour may represent a mixture of fluctuating vigilance levels and repetitive microsleeps that may progress to complete sleep.

In relation to Type 2 and 3, the microsleep hypothesis is not sufficient to account for these episodes given that individuals are able to maintain a level of vigilance to continue with a task without falling asleep. The hypothesis proposed by Valley and Broughton (1981; 1983), therefore, might best account for Types 2 and 3 automatic behaviour. Valley and Broughton reported that performance deficits in narcolepsy were associated with fluctuating vigilance levels. The fact that participants reported a need to ‘push on’ despite feelings of sleepiness indicated that they were placing specific effort to

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and theta (4 – 8 Hz), whereas the fluctuating vigilance levels represents slow oscillation between wakefulness, stage 1A (slow and diffusing alpha) and stage 1B (theta activity).”

fight declining vigilance levels. The reports by some individuals that there were times when they were partially aware of the automatic behaviour, indicates that individuals can experience automatic behaviour at varying vigilance levels and therefore different degrees. In addition, Valley and Broughton reported that individuals with narcolepsy demonstrated performance deficits not only at low vigilance levels, but also at high vigilance levels. These findings would support both hypotheses presented in relation to Type 3 automatic behaviour. That is, it is possible that individuals who experience Type 3 may experience quite a rapid transition into lower levels of sleepiness, in that vigilance is fluctuating between high and low levels, but the individual is less aware of entering a low vigilance state and subsequently, experiences automatic behaviour ‘unexpectedly’. Alternatively, individuals may be operating at a high vigilance level, and it is the high cognitive demands experienced by the individuals which produce this inattentive state. The current classification is depicted in Figure 2.

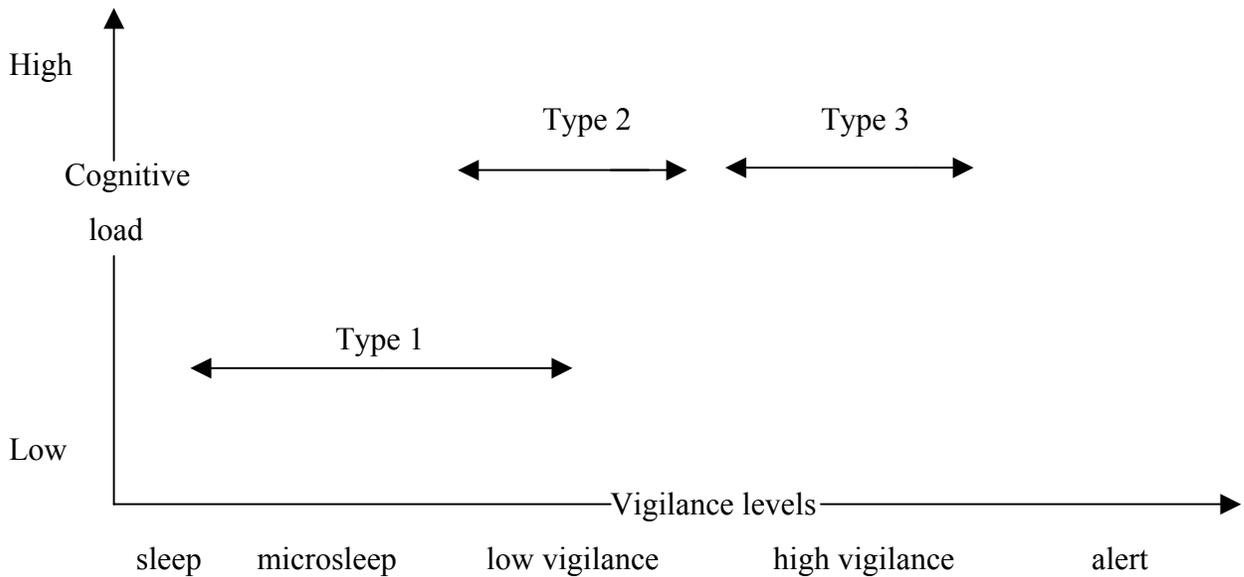


Figure 2.

The Relationship Between Hypothesized Vigilance Levels and Cognitive Load Associated with the Different Types of Automatic Behaviour.

Figure 2 demonstrates the proposed placing of each type of automatic behaviour at the differing levels of vigilance. Therefore, it may be postulated that some automatic behaviour represents a transition state between wakefulness and sleep, where the brain goes into ‘power save’. However, as was noted by participants in the current study, the manifestation of automatic behaviour is dependent not only on the level of sleepiness, but also the amount of cognitive effort or load that is being used to complete the tasks. As shown in Figure 2, the different types of automatic behaviour occur for different levels of cognitive load.

Another factor to consider in the manifestation of automatic behaviour is the characteristics of the individual. That is, the underlying severity of narcolepsy may make

some individuals more susceptible to automatic behaviour. It may be that an individual's underlying severity of narcolepsy results in greater sleepiness, less awareness of sleepiness and therefore increased susceptibility to automatic behaviour. For example, results of the ESS indicated that those participants who reported Type 3 had less success controlling sleepiness with stimulant medications than those who did not report having Type 3. Therefore, underlying severity may increase one's threshold for experiencing automatic behaviour. In order to present this relationship the following formula is proposed:

$$\text{AB:} \\ F_{ie}(\text{EDS, CL}) \geq T_i$$

AB = Automatic behaviour

$F_{ie}$  = Function of individual and environment

EDS = Excessive daytime sleepiness

CL = Cognitive load

$T_i$  = Threshold for automatic behaviour onset (individually variable)

It is argued that automatic behaviour is not simply a transition state between sleep and wakefulness, but rather a composition of factors, which includes the level of sleepiness, cognitive load, environmental factors and the individual's underlying severity or susceptibility to automatic behaviour. The manifestation of automatic behaviour is dependant on these exceeding a particular threshold. Finally, the type of automatic behaviour experienced by individuals with narcolepsy is dependent on the balance or composition of these factors (sleepiness, cognitive load and threshold for automatic behaviour), which is represented in Figure 3.

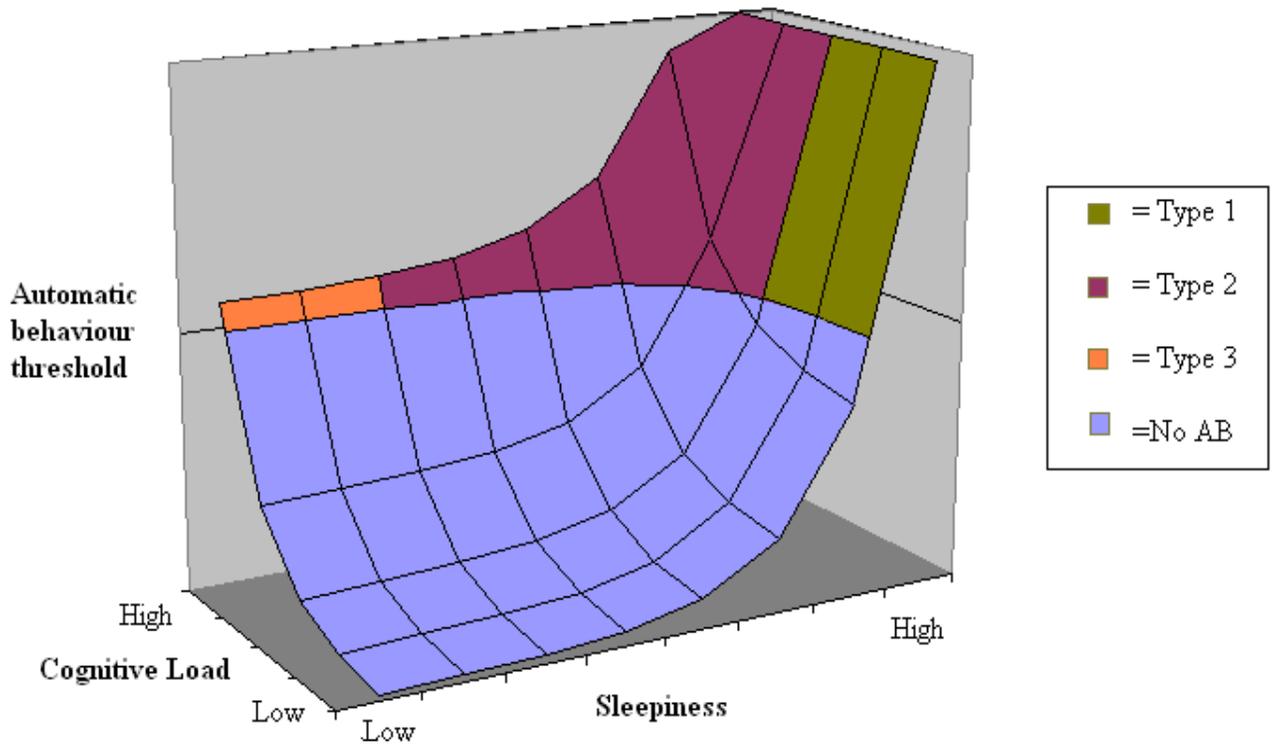


Figure 3

The Relationship Between Sleepiness, Cognitive Load and Threshold for Experiencing Automatic Behaviour.

As can be seen in Figure 3, Type 1 and 3 appear to have simple linear relationships (automatic behaviour occurs with a high level of sleepiness or cognitive load, respectively). Type 2, however is dependent on a combination of both high sleepiness and high cognitive load. In addition, each type occurs once the individual's automatic behaviour threshold is reached.

**6.5 Descriptive model of automatic behaviour**

The following discussion will provide a descriptive model of automatic behaviour, which is illustrated in Figure 4. An episode of automatic behaviour may begin with the individual feeling or being aware of their increased sleepiness, but continuing

with a task (Type 1 and 2). In some cases, the individual is unaware of their level of sleepiness and feels that they are reasonably alert (Type 3). While in this state they may be completing tasks of low cognitive demand (Type 1) or high cognitive demand (Type 2 and 3). In each of these conditions, the individual is making an effort to fight declining vigilance levels and is putting in extra effort (or believes to be putting in extra effort) to finish a task. To fight this feeling of sleepiness, individuals may employ a number of strategies, one of which may include conceding to the sleepiness they are feeling, have a nap and try again later. Alternative strategies may be put in place to increase alertness (such as stimulant medication), however in some cases this does not work and the individuals experience an episode of automatic behaviour, lasting several minutes or longer. Once in automatic mode, individuals appear to be functioning appropriately, but in fact their behaviour is of a repetitive and stereotyped nature, and subsequent deterioration in performance becomes evident. Inappropriate responses often result when the task requires active decision making or more complexity in the task. The episode ends with individuals falling asleep (Type 1) or regaining alertness, through themselves or some interruption in the environment (All Types). Here, individuals are amnesic for what has occurred and often has to try to figure out what occurred by examining the environment, often having to face the embarrassing or dangerous consequences of their actions.

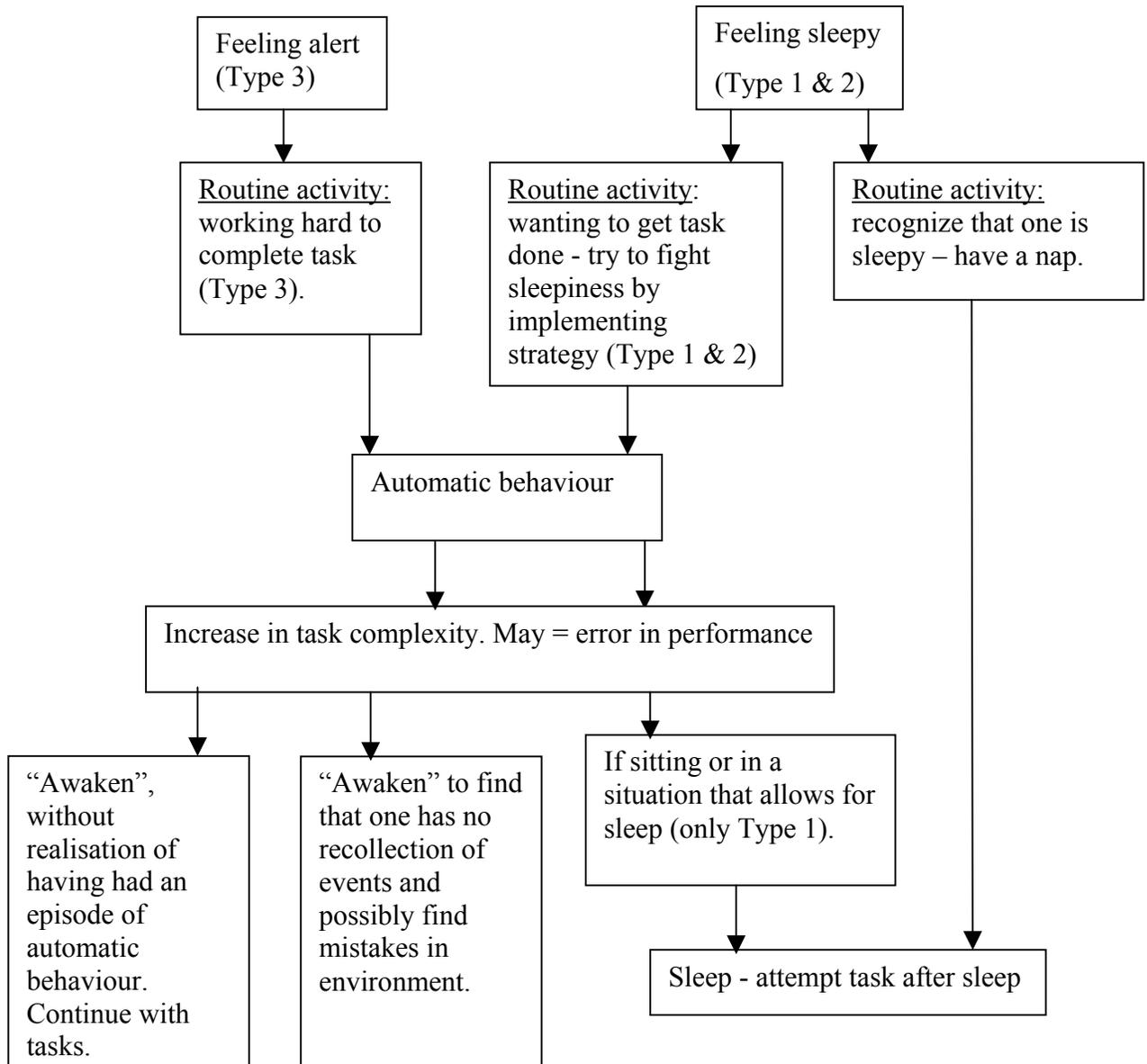


Figure 4.

Descriptive Model of Automatic Behaviour.

This model has many similarities with previous literature. Early work by Daniel (1934) and Ganado (1958) share a number of similarities with current findings. In particular both researchers recognised that automatic behaviour in narcolepsy was associated with an inability to recall a period of time in which a familiar action was

completed. In addition, it was recognised that the action would stop if interrupted by a more difficult or unexpected event. However, reports from Daniel (1934) that individuals felt well rested after the episode of automatic behaviour was not found in the current study. It is more the case that once an individual is feeling alert again (as a result of being startled by an interruption in the environment, stimulant medications beginning to work, etc) that this is when the automatic behaviour becomes noticeable, particularly if one is in the middle of the act while this increase in alertness occurs.

The accounts of automatic behaviour provided by Guilleminault et al (1975) and Zorick et al (1979) also provided good descriptions of the phenomenon, of which many elements were also found in the current study. However, the current study was able to add to these definitions. For example, the identification of Type 3 automatic behaviour has not been noted previously. In addition, the progression of Type 1 automatic behaviour to sleep has also not been documented. The notion of cognitive load, or the attempts by individuals to continue with tasks, despite feeling sleepy was not recognised in previous work. This is perhaps one of the more important factors in the phenomenon. That is, the fact that individuals attempt to go on with a task, despite knowing what the consequences could be, may be partly the cause of the high incidence of this phenomenon in narcolepsy.

## **6.6 Explanation from a cognitive perspective**

The question arises as to what mechanisms are operating while acting in automatic mode? Drawing from the literature examining normal automatic behaviour, one of the key aspects in this phenomenon appears to be the use of feedback. As noted by Wertheim (1991), the use of feedback has a fundamental role in the learning of new

tasks. As an individual becomes skilled at a task, feedback is used less consistently, and the performance becomes automatic. That is, the ability to complete a task becomes based on an internal representation of that activity, and the individual becomes less reliant on external events. As a result, feedback is used only when required, such as when an unexpected event occurs. In most day to day activities, this process serves a beneficial function, in that many activities can be completed efficiently and with little effort. However, with little reliance on external feedback during automatic tasks, it is easy to see how errors in performance may arise, particularly when sleepiness is also a factor.

The minimal effort that is required for automatic tasks (due to the sporadic need to use feedback) has been shown to have a negative effect on arousal (Daniel, 1967). This is due to the limited need to invest more than the required effort into an easy task. The reduction in effort then leads to a decrease in alertness and arousal (Wertheim, 1991). As demonstrated by Daniel (1967), the need to produce frequent responses to limited or familiar tasks potentiates habituation and this increases one's pressure to sleep. Therefore, in normal populations, automatic behaviour occurs as a result of decreasing arousal associated primarily with task monotony and the under reliance of external error feedback. Similar to narcolepsy, it is suggested that automatic behaviour in non narcoleptic individuals results in errors in performance. However, contrary to narcolepsy, in many cases the level of vigilance is high enough (although still reduced in comparison to optimum levels of vigilance) to be able to quickly recognise the behaviour and take precautionary actions. For example, it is often easy for individuals without excessive sleepiness to recognise that they are reading the lines of a book without actually taking in

the information. However, as noted in the current study, this is something individuals with narcolepsy find more difficult; their feedback is reduced.

In individuals who already have an increased propensity for sleepiness, as in narcolepsy, the automatic behaviour is reported to be more severe, in that the frequency of episodes and the ability to recognise episodes is worse. When an individual is sleepy, he/she becomes more dependent on the environment to maintain alertness and sustain attention and as a result, becomes more susceptible to the effects of environmental monotony (Dinges & Kribbs, 1991). Across the literature it has been demonstrated that individuals with narcolepsy often have more difficulty performing tasks that are unstimulating, repetitive, simple and of long duration than tasks that pose a challenge to the individuals and are conducted in a setting which facilitates high arousal (Hood & Bruck, 1996; Rogers & Rosenberg, 1990). Therefore, it may be suggested that the sleepy brain is less likely to be able to sustain attentive wakefulness with low environmental stimulation. This ability to maintain a high amount of interest in a task is not easily done in the everyday world, in which any task can lose its novelty after being performed routinely. Motivation and incentives can override sleepiness and this environmental effect, but only to a certain extent (Dinges et al, 1992; Horne & Pettitt, 1985). As a result, when individuals with narcolepsy are completing tasks that are repetitive and occurring on a regular basis, habituation is accelerated, sleep tendency is further increased, and the individual lapses into automatic mode. Therefore, it may be speculated that in automatic behaviour in narcolepsy the level of sleepiness is higher and therefore, the use of feedback is lower and subsequently they are less aware of their actions, than for non-narcoleptics.

The following scenario is presented to illustrate the current explanation of automatic behaviour in individuals with narcolepsy. A number of participants in the current study reported that automatic behaviour often involved putting objects away in the wrong place. For example, the milk was often found on the stovetop where the kettle should be and the kettle was found in the fridge where the milk should be. In the act of completing this routine task (putting equipment away after making a cup of tea) the already sleepy individual becomes even sleepier due to the limited effort required to complete this unstimulating activity. In this state, the actions required to complete the task are accurate (put item on stovetop, open fridge, place item in fridge), but now no feedback in the environment is being received in relation to the individual's performance. The error that occurs often is not recognised until the individual's level of alertness is increased (which may occur immediately due to some environment interruption, or it may occur later). The fact that the individual has a lowered ability to recognise mistakes makes it likely that the behaviour will continue until a point in which some factor increases alertness and the individual is able to again receive external feedback. As these factors are present regularly (routine activities and in particular sleepiness) in the day to day life of an individual with narcolepsy, it is easy to see why this phenomenon is prevalent in this population.

### **6.7 Development of a questionnaire to measure automatic behaviour**

Currently, there are no formal methods available in which to assess automatic behaviour, despite there being a number of advantages of having such a scale. Firstly, as automatic behaviour is linked to excessive daytime sleepiness and stimulant medication efficacy, a scale assessing automatic behaviour could provide a useful indication of

whether stimulant medications were sufficient in that individual to control their symptoms. That is, by answering a set of questions in relation to their automatic behaviour when on and off their medications, one is able to obtain a better understanding of how effective this management option is and it may help guide dosage decisions.

Secondly, a formal assessment of automatic behaviour would be useful to researchers. For example, future research may use such a tool to examine the relationship between automatic behaviour and other variables, as well as to examine the change of automatic behaviour over time, its extremes and the prevalence of the phenomenon.

Finally, a formal assessment may be important in counseling settings and assisting in the psychological health of the individual. All participants in the current study reported that automatic behaviour had a negative impact on their psychological functioning. The impact of automatic behaviour was reported to impact on every aspect of life, from work to school to social interactions to family interactions. By devising a formal questionnaire, the identification of these problems may occur earlier rather than later and the individual is able to receive the psychological support they need.

Therefore, a formal questionnaire needs to be able to identify mild to severe cases of automatic behaviour. The format for this questionnaire may best be suited to the format of the Epworth Sleepiness Scale (Johns, 1991). This format is useful as it attempts to overcome the fact that individuals have different routines and automatic behaviour can occur in a number of different settings. It also allows graded assessments of severity in different situations. The following directions and scale may be a useful starting point:

*“The following questionnaire is related to episodes of automatic behaviour. Automatic behaviour involves performing familiar or routine activities, such as driving, with little awareness of one’s actions. That is, the body continues to complete a set of actions (correctly or incorrectly) while the mind is not there, resulting in complete inability to recall the events that occurred while in this state.*

*Please answer the next section referring to the time during your life when your automatic behaviour was MOST SEVERE, taking NO treatment for excessive daytime sleepiness. If you are on treatment at present and find it difficult to remember how severe any problem was when you were not taking treatment, please try to judge how you would be now without treatment.*

*How likely are you to experience an episode of automatic behaviour in the following situations? 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 experience automatic behaviour; 1 = slight chance of experiencing automatic behaviour; 2 = moderate chance of experiencing automatic behaviour; 3 = high chance of experiencing automatic behaviour.”*

**Situation**

**Chance of experiencing automatic behaviour**

1. *Cleaning (putting utensils away after meal, washing, laundry, etc)*.....\_\_\_\_\_
2. *Meal preparation (cutting and cooking food)* .....\_\_\_\_\_
3. *Driving (residential streets)* .....\_\_\_\_\_
4. *Walking* .....\_\_\_\_\_
5. *Talking (face to face or on the phone)*.....\_\_\_\_\_
6. *Writing (including with a pen and paper or on the computer)* .....\_\_\_\_\_
7. *Eating*.....\_\_\_\_\_
8. *Shopping (department store or grocery shopping)*.....\_\_\_\_\_

Before this scale can be used further research is required to establish its validity and reliability. In addition, it will be important to identify the score ranges in which the automatic behaviour is ranked as mild, moderate or severe through comparing scores to behavioural reports.

**6.8 Methodological issues**

The current research provided many interesting findings. However, some methodological issues require consideration when examining the results. The current sample used in this study involved an older sample selected from a support group (NODSS). It may be argued that using an older sample (individuals aged between 46 and 69 years of age) is disadvantageous. For example, perhaps some participants were experiencing some age related decline in cognitive abilities (specifically, memory ability) which may not have been identified as separate from their narcolepsy symptoms, which then altered their perception of their experiences and of automatic behaviour. Although

this is a possibility to consider, in qualitative research of the type used here, the use of an older sample can serve many advantages. As the study used retrospective data to obtain an in depth understanding of automatic behaviour, it was essential that the participants were able to reflect on past experiences. An older sample, therefore, was able to provide such data. That is, not only do they have more life experience, but also they are able to reflect on their experiences and are able to give an understanding of the phenomenon over the life span as they experienced it. This is not to say that examining younger individuals is not worthwhile, and may be the goal of future research. However, it is unlikely that data from a younger sample would have yielded information as rich as the current data.

In relation to the recruitment of participants from NODSS, it may be suggested that being a member of a support group biased responses in some way. That is, there are a number of factors to consider when examining individuals from a support group. For example, are they part of the group because they are more severe, less resilient or more invested in their problems? Additionally, does this mean that they are more informed on automatic behaviour? What is certain is that not all participants were active group members. Of those that were active in the group, each demonstrated varying levels of involvement, from running different aspects of the group to irregularly attending meetings. Therefore, while the current study did use a selective sample, it was a mixed group in terms of their involvement in NODSS, the severity of their narcolepsy and the severity of their automatic behaviour.

A further methodological consideration is the limitations that have been associated with qualitative research. These criticisms were outlined in Chapter Two

(Review of Current Methodology). To briefly summarise, the main criticism of qualitative research is that it lacks internal and external validity, and given the small samples that are often used, data can not be generalised to other cases (Rubaie, 2002). Over the years a number of techniques have been adopted to increase the rigor of qualitative research, which were adopted in the current study. One step that was taken was the use of triangulation. To achieve triangulation, several different forms of data collection were used, including interviews (before and after completing the journal, with family members) and journals (both on and off medication). In addition, transcripts of interviews were reviewed and discussed with participants. As noted by Stake (2000), these methods increase the internal validity of qualitative research by clarifying meaning, reducing the likelihood of misperceptions and supporting the repeatability of observations.

The generalisability of findings is another issue to consider. It may be suggested that the use of ten cases is not sufficient to generalise to the larger population. However, as noted previously, the aim of qualitative research is not to generalise. Rather it is to obtain an in depth understanding of a phenomenon, from the perspective of the individual, taking into consideration the interaction between people and their environment (as per the phenomenological perspective). In addition, although the study used only ten participants, these participants were able to provide a rich account of the phenomenon, particularly those used in the case studies. As noted by Stoecker (1991) “the case study provides evidence to show how both the rule, and its exception, operate” (p.94). Thus it is argued that the current research has been successful, as it allowed for a more in depth understanding of a lesser known, or documented phenomenon. It is not

claimed that the specific findings are generalisable to the population of people with narcolepsy, only that the increased conceptual understanding of the phenomenon is a valuable contribution.

## **6.9 Implications for clinical practice and further research**

The current research has been able to document and answer some questions in relation to automatic behaviour in narcolepsy. However, further research is still needed. In particular, Type 3 automatic behaviour requires further consideration, as the mechanisms by which it occurs are not fully understood, such as whether it is a state independent of sleepiness. Of note, although not found in the current study, it is possible that a Type 4 automatic behaviour (low cognitive load without sleepiness) also exists. This is something that may possibly be documented in a larger sample, or within automatic behaviour of other etiologies. Similarly, further examination of the underlying neurophysiological processes involved in automatic behaviour is need. That is, the issue of whether microsleeps or reduced vigilance levels are associated with episodes of automatic behaviour has not been resolved (Guilleminault et al, 1975; Valley, & Broughton, 1981; 1983). In particular, research into the hypothesised levels of vigilance associated with each type of automatic behaviour requires further study. Finally, further study is required for the development of the proposed standardised questionnaire on automatic behaviour. That is, the proposed scale requires a pilot study to further develop a valid and reliable scale.

The findings of the current study provided insights that may have implications not only for individuals with narcolepsy, but also in other groups, such as chronically sleep deprived individuals. It was postulated that the automatic behaviour in both individuals

with narcolepsy and normals differed in the level of sleepiness and in the level of awareness of their actions when in automatic mode. If this is the case, then automatic behaviour in sleep deprived individuals may mirror that of individuals with narcolepsy. This hypothesis stems from research demonstrating that cognitive functioning following sleep deprivation parallels that of the narcolepsy literature. Further research into this area is important as automatic behaviour is likely to be a common occurrence in individuals working during night hours when completing routine activities (such as nurses, taxi drivers). Thus, the propensity for making errors is increased, costing people time, money and sometimes an individual's safety.

Most importantly in the study of any phenomenon is the impact that it has on the individual. As automatic behaviour is one of the more difficult symptoms to control in susceptible individuals, it is important that future research examine the strategies that are most successful in controlling this phenomenon. This is particularly important as automatic behaviour can have a pervasive negative effect on daily functioning. With a better understanding of the errors that occur, employees and family members may be better equipped to deal with the consequences of the behaviour and a setting of tolerance and understanding may be fostered. Not only is this important in work or family life, but also with health professionals, who can provide easy access to the information that so many require. Most importantly, individuals with narcolepsy can have a better understanding of themselves and can reduce the personal impact of automatic behaviour, such as poor self esteem and emotional wellbeing.

## **6.10 Conclusion**

To conclude, the current study provided the first in depth analysis of automatic behaviour in individuals with narcolepsy. Using qualitative methodology, the current study was able to identify a number of important features of the phenomenon. An in depth analysis of the loss of recall associated with episodes of automatic behaviour was discussed and the consequences of being in this state (sequencing errors, item/environment intrusions, perseverative action leading to nonsense, context inappropriate behaviours, appropriate behaviours) were defined. Different types of automatic behaviour were identified and included Type 1 (sleepiness with low cognitive load), Type 2 (sleepiness with high cognitive load) and Type 3 (high cognitive load without sleepiness). The vigilance levels associated with these types were discussed, making comparisons with previous research in the area (Guilleminault et al, 1975; Valley, & Broughton, 1981; 1983). Subsequently, a formula for automatic behaviour was hypothesised. This formula included various factors associated with the manifestation of automatic behaviour, including excessive daytime sleepiness, cognitive load, and individually determined threshold for automatic behaviour. An explanation from a cognitive perspective was provided, linking the automatic behaviour experienced in narcolepsy to automatic behaviour in normals. A descriptive model of automatic behaviour was developed and compared to previous research. Finally, a questionnaire to measure automatic behaviour was developed, for further research to pilot.

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**APPENDIX A**

**LETTER OF APPROVAL TO CONDUCT STUDY FROM HUMAN ETHICS  
RESEARCH COMMITTEE**

**APPENDIX A**

**LETTER OF APPROVAL TO CONDUCT STUDY FROM HUMAN ETHICS  
RESEARCH COMMITTEE**

**APPENDIX B**

**INTRODUCTORY LETTER TO PARTICIPATE AND CONSENT FORM**

## **APPENDIX B**

### **INTRODUCTORY LETTER TO PARTICIPATE AND CONSENT FORM**

My name is Michelle Morandin and I am completing a Masters of Psychology (Clinical Neuropsychology) at Victoria University of Technology. As part of my degree I am undertaking a research project under the supervision of Dr. Dorothy Bruck to examine the phenomenon of automatic behaviour in individuals with narcolepsy. Automatic behaviour involves performing a series of actions without conscious awareness. That is, the body continues to function while the mind has partially retreated to sleep. A classic example is reaching a destination, without realizing how one got there.

I would like to invite you to participate in the study titled ‘Automatic behaviour in individuals with narcolepsy: a multiple case study approach’. If you agree to participate you will be asked to complete a short questionnaire indicating the frequency of your automatic behaviour and severity of these episodes, which will be mailed back to me with your contact details. Based on this information, you will be notified at a later date, as to whether you have been selected to participate in the study.

If you are selected you will be asked to participate in two interviews and complete a journal. The interviews will take no more than one hour, and will be audio taped, with your consent. These interviews will ask questions related to your experiences with narcolepsy and factors associated with episodes of automatic behaviour. If possible, information may be provided by a family member or spouse about your automatic behaviour, through an interview in which only the interviewer and the spouse /partner will be present. In between these two interviews you will be asked to keep a daily journal, for a period of five days. You will be asked to record details of any automatic episodes you may experience, what you were doing before it occurred, what happened when it ended, time of day, estimations of sleepiness, times of sleep across the day and night and information regarding medication intake. This part is phase one of the study.

The present study is also examining the brain wave frequency associated with automatic behaviour. After participation in the first phase of the study, you will be asked to participate in the second phase of the study if you live in metropolitan Melbourne. If you agree to participate in the second phase of the study, electrophysiological (EEG) recording will be conducted in your home environment for one day. This will be a day when you are able to spend the whole day at home. The investigators will come to your house and place electrodes on your scalp and face with a paste. These do not pierce the skin and are painless. During the day you will also be asked to complete a journal, similar to the journal completed in the first phase of the study. At the end of the day the researcher will return and remove the electrodes for you. While this brain wave recording is safe and pain free, if you do experience any problems with the equipment, you will be provided with the investigators contact details, who will answer any questions, or if need be, return to your house and remove the equipment.

Your participation in this project is voluntary and you are under no obligation to take part. If you feel uncomfortable or no longer wish to participate, in either phase of the study, you are free to withdraw consent and to discontinue participation in the study at any time, as well as withdraw any data that you contributed to the study. In addition, participation in phase 1 of the study does not mean you are obliged to participate in the second phase of the study.

All information, which you provide, will be strictly confidential. Information given will be treated as confidential by the researchers, and initial questionnaires will be separated from personal details via a coding system. No identifying details from the interviews will appear in the report and interviews with a family member or spouse will also remain confidential. If you would like to participate, please complete and sign the accompanying questionnaire and consent form, plus provide your contact details and post it to the address provided.

Should you have any concerns regarding the manner in which this research project is conducted, please do not hesitate to inform the researchers directly. I can be contacted on \*\*\*\*\*. Dr Dorothy Bruck can be contacted on \*\*\*\*\*. The Victoria University Human Research Ethics Committee are on (03) 9688 4710 if you have any ethical concerns about this project.

**CERTIFICATION BY PARTICIPANT**

I,  
Of

certify that I am at least 17 years old\* and that I am voluntarily giving my consent to participate in the study entitled:

**Automatic behaviour in individuals with narcolepsy: A multiple case study approach.**

being conducted at Victoria University of Technology by:  
**Dorothy Bruck and Michelle Morandin**

I certify that the objectives of the study, together with any risks to me associated with the procedures listed below to be carried out in the study, have been fully explained to me by:

**Michelle Morandin**

and that I freely consent to participation involving the use of these procedures.

**Procedures:**

Screening questionnaire  
Provide contact details

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: ..... }

Witness other than the experimenter (as appropriate) } **Date:**

.....

.....}

Any queries about your participation in this project may be directed to the researcher (Name: Michelle Morandin ph. \*\*\*\* \*). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001 (telephone no: 03-9688 4710).

**APPENDIX C**

**SELECTION QUESTIONNAIRE AND IDENTIFICATION SHEET**

## APPENDIX C

### SELECTION QUESTIONNAIRE AND IDENTIFICATION SHEET

Code: \_\_\_\_\_

Age: \_\_\_\_\_

Number of years diagnosed with narcolepsy: \_\_\_\_\_

How were you diagnosed: \_\_\_\_\_

Do you experience cataplexy: \_\_\_\_\_

Medication taken for narcolepsy (if any): \_\_\_\_\_

1. Do you or have you ever experienced an episode of automatic behavior (for example, performing a complex act, such as driving a car to the wrong destination and not remembering how you did it)?

Yes  No

2. How often do you experience episodes of automatic behavior?

- a) Once a day
- b) 2 or more times a day
- c) Once a week
- d) 2 or more times a week
- e) Less than once a month
- f) Once a month
- g) 2 or more times a month

3. How long do these episodes of automatic behavior last (on average)?

- a) Less than 1 minute
- b) 1 – 5 minutes
- c) 5 – 15 minutes
- d) 15 – 30 minutes
- e) More than 30 minutes

4. How severe are these episodes of automatic behavior?

- a) Not very severe
- b) Severe
- c) Very severe

**Identification sheet:**

Code: \_\_\_\_\_

Name: \_\_\_\_\_

Contact phone number: \_\_\_\_\_

Best time to contact : \_\_\_\_\_

Email address (if preferred mode of contact): \_\_\_\_\_

**APPENDIX D**

**SECOND INFORMATION LETTER AND CONSENT FORM TO  
PARTICIPANTS (FOR INTERVIEWS AND JOURNAL)**

## APPENDIX D

### SECOND INFORMATION LETTER AND CONSENT FORM TO PARTICIPANTS (FOR INTERVIEWS AND JOURNAL)

My name is Michelle Morandin and I am completing a Masters of Psychology (Clinical Neuropsychology) at Victoria University of Technology. As part of my degree I am undertaking a research project under the supervision of Dr. Dorothy Bruck to examine the phenomenon of automatic behaviour in individuals with narcolepsy. Automatic behaviour involves performing a series of actions without conscious awareness. That is, the body continues to function while the mind has partially retreated to sleep. A classic example is reaching a destination, without realizing how one got there.

I would like to invite you to participate in first part of the study titled 'Automatic behaviour in individuals with narcolepsy: a multiple case study approach'. If you agree to participate you will be asked to participate in two interviews and complete a journal. The interviews will take no more than one hour, and will be audio taped, with your consent. These interviews will ask questions related to your experiences with narcolepsy and factors associated with episodes of automatic behaviour. If possible, information may be provided by a family member or spouse about your automatic behaviour, through an interview in which only the interviewer and the spouse /partner will be present. In between these two interviews you will be asked to keep a daily journal, for a period of five days. You will be asked to record details of any automatic episodes you may experience, what you were doing before it occurred, what happened when it ended, time of day, estimations of sleepiness, times of sleep across the day and night and information regarding medication intake.

Your participation in this project is voluntary and you are under no obligation to take part. If you feel uncomfortable or no longer wish to participate, in either phase of the study, you are free to withdraw consent and to discontinue participation in the study at any time, as well as withdraw any data that you contributed to the study. In addition, participation in phase 1 of the study does not mean you are obliged to participate in the second phase of the study.

All information, which you provide, will be strictly confidential. Information given will be treated as confidential by the researchers, and initial questionnaires will be separated from personal details via a coding system. No identifying details from the interviews will appear in the report and interviews with a family member or spouse will also remain confidential. If you would like to participate, please sign the accompanying consent form.

Should you have any concerns regarding the manner in which this research project is conducted, please do not hesitate to inform the researchers directly. I can be contacted on \*\*\*\*\*. Dr Dorothy Bruck can be contacted on \*\*\*\*\*. The Victoria University Human Research Ethics Committee are on (03) 9688 4710 if you have any ethical concerns about this project.

**CERTIFICATION BY PARTICIPANT**

I,  
Of

certify that I am at least 17 years old\* and that I am voluntarily giving my consent to participate in the study entitled:

**Automatic behaviour in individuals with narcolepsy: A multiple case study approach.**

being conducted at Victoria University of Technology by:  
**Dorothy Bruck and Michelle Morandin**

I certify that the objectives of the study, together with any risks to me associated with the procedures listed below to be carried out in the study, have been fully explained to me by:

**Michelle Morandin**

and that I freely consent to participation involving the use of these procedures.

**Procedures:**

- Two semi structured interviews
- Daily journal kept for five days
- Interview with family member (if possible)

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: ..... }

Witness other than the experimenter (as appropriate) } **Date:**  
.....

.....}

Any queries about your participation in this project may be directed to the researcher (Name: Michelle Morandin ph. \*\*\*\* \*). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001 (telephone no: 03-9688 4710).

## **APPENDIX E**

### **POSSIBLE QUESTIONS FOR INTERVIEW ONE WITH PARTICIPANTS**

## APPENDIX E

### POSSIBLE QUESTIONS FOR INTERVIEW ONE WITH PARTICIPANTS

#### Questions for individuals with narcolepsy:

1. Can you please describe a typical episode of automatic behaviour (AB)?
2. Can you tell me what usually occurs before, during and after an episode of AB?
3. Are there any triggers or signs that an episode of AB will occur?
4. What usually 'snaps' you out of an episode of AB?
5. Can you control episodes of AB? If so, what strategies do you use to prevent it?
6. Do you find that episodes of AB are particularly prominent at particular times of the day?
7. What effect does your medication have on AB?
8. Are there any situations that improve or worsen episodes of AB?
9. What effect does sleep deprivation have on your AB?
10. What was your first episode of AB like? Please describe it if you can remember. Did you realise what had just happened? How did you react? What were the consequences of this?
11. Has your AB changed over the years? If so, how?
12. What is the relationship between automatic behaviour and the other symptoms of narcolepsy? That is have you noticed a pattern in the development of your symptoms and how does AB fit in with this?
13. Have episodes of AB ever stopped for a period of time and then returned? If so, what do you attribute this to?
14. Does AB interfere with everyday functioning? If so, how?
15. Has an episode of AB placed you in a dangerous situation?
16. How do episodes of AB make you feel, emotionally?
17. How do episodes of AB make you feel, physically?
18. What are the social consequences of AB, now and earlier in your life?
19. What are others' reactions to your AB, how do they cope with it?
20. In your experience, how do you explain episodes of AB?

**APPENDIX F**

**JOURNAL COMPLETED BY PARTICIPANTS**

## **APPENDIX F**

### **JOURNAL COMPLETED BY PARTICIPANTS**

#### CONTENTS

Section A – Sleep Wake Diary

(completed daily)

Section B – Journal Details

(completed after episodes of automatic  
behaviour).

Section C – Stanford Sleepiness Scale

(completed in conjunction with journal)

**SECTION A**  
**SLEEP WAKE DIARY (x 5)**

**COMPLETE EACH MORNING:** **Day of Week** \_\_\_\_\_

NIGHT SLEEP:  
I went to bed at (am/pm) \_\_\_\_\_  
I tried to fall asleep at (am/pm) \_\_\_\_\_  
I fell asleep within about (minutes) \_\_\_\_\_  
I remember awakening during the night (times awakened) \_\_\_\_\_  
My total time awake during the night was about (minutes) \_\_\_\_\_  
I woke in the morning from my nights sleep at (am/pm) \_\_\_\_\_  
I got out of bed at (am/pm) \_\_\_\_\_

CIRCLE ONE:  
My type of sleep was:  
1 = very restless  
2 = tired  
3 = neither refreshed nor tired  
4 = sound  
5 = very sound

How I felt on awakening:  
1 = exhausted  
2 = tired  
3 = neither refreshed nor tired  
4 = refreshed  
5 = very refreshed

**COMPLETE EACH EVENING:**  
DAYTIME NAPS (Please show time of falling asleep and estimated minutes asleep.)  
Nap 1. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 2. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 3. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 4. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.

MEDICATION RECORD (Please list the type, dose and time of day of any medications taken today).  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

ALCOHOL INTAKE (Please record type of drink, quantity and time of day).  
\_\_\_\_\_  
\_\_\_\_\_

**SECTION B**  
**JOURNAL (x 10)**

To be completed after episodes of automatic behaviour.

1. ID \_\_\_\_\_
2. Journal entry number \_\_\_\_\_
3. Day of the week \_\_\_\_\_
4. Time (am/pm) \_\_\_\_\_
5. Level of sleepiness before the episode of automatic behaviour. (Please refer to the Stanford Sleepiness Scale – SECTION C) \_\_\_\_\_
6. Present level of sleepiness. (Please refer to Stanford Sleepiness Scale – SECTION C). \_\_\_\_\_
7. Time of last medication intake plus the dosage in mg  
\_\_\_\_\_
8. Type of medication \_\_\_\_\_
9. Time of last nap (am/ pm) \_\_\_\_\_
10. Duration of the nap in minutes \_\_\_\_\_
11. Food/ drink intake in last three hours:
  - i) snack or drink (describe)  
\_\_\_\_\_
  - ii) meal (describe, eg. Dinner) \_\_\_\_\_  
- type of meal (please tick)
    - i)  light
    - ii)  medium
    - iii)  heavy
12. Describe what you were doing before the episode. (Eg, writing, cooking, cleaning the house, walking the dog....)  
\_\_\_\_\_  
\_\_\_\_\_

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13. Try to explain what happened during the period of automatic behaviour?

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14. What were you doing when you realised that you were in or coming out of automatic behaviour?

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15. How long did the episode last? .....sec/ min/ hours

16. What happened after the episode of automatic behaviour?

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17. How did you know that you were having or had an episode of automatic behaviour?

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18. Feel free to record any additional points/observations.

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**SECTION C**  
**STANFORD SLEEPINESS SCALE (x 1)**

LEVELS:

1 = Feeling active and vital; alert; wide awake.

2 = Functioning at a high level; but not at peak; able to concentrate.

3 = Relaxed; awake; not at full alertness; responsive.

4 = A little foggy; not at peak; let down.

5 = Fogginess; beginning to lose interest in remaining awake; slowed  
down.

6 = Sleepiness; prefer to be lying down; fighting sleep; woozy.

7 = Almost in reverie; sleep onset soon; lost struggle to remain awake.

X = Asleep

**APPENDIX G**  
**OPTIONAL AUDIOTAPED JOURNAL**

**APPENDIX G**  
**OPTIONAL AUDIOTAPED JOURNAL**

CONTENTS

Section A – Sleep Wake Diary

(completed daily)

Section B – Journal Details

(completed after episodes of automatic  
behaviour).

Section C – Journal – Tape Recording

(completed after episodes of automatic  
behaviour).

Section D – Stanford Sleepiness Scale

(completed in conjunction with journal)

**SECTION A**  
**SLEEP WAKE DIARY (x 5)**

**COMPLETE EACH MORNING:** **Day of Week** \_\_\_\_\_

NIGHT SLEEP:  
I went to bed at (am/pm) \_\_\_\_\_  
I tried to fall asleep at (am/pm) \_\_\_\_\_  
I fell asleep within about (minutes) \_\_\_\_\_  
I remember awakening during the night (times awakened) \_\_\_\_\_  
My total time awake during the night was about (minutes) \_\_\_\_\_  
I woke in the morning from my nights sleep at (am/pm) \_\_\_\_\_  
I got out of bed at (am/pm) \_\_\_\_\_

CIRCLE ONE:  
My type of sleep was:  
1 = very restless  
2 = tired  
3 = neither refreshed nor tired  
4 = sound  
5 = very sound

How I felt on awakening:  
1 = exhausted  
2 = tired  
3 = neither refreshed nor tired  
4 = refreshed  
5 = very refreshed

**COMPLETE EACH EVENING:**  
DAYTIME NAPS (Please show time of falling asleep and estimated minutes asleep.)  
Nap 1. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 2. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 3. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 4. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.

MEDICATION RECORD (Please list the type, dose and time of day of any medications taken today).  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

ALCOHOL INTAKE (Please record type of drink, quantity and time of day).  
\_\_\_\_\_  
\_\_\_\_\_

**SECTION B**

**Journal Details (x10)**

To be completed after episodes of automatic behaviour (AB).

1. ID \_\_\_\_\_

2. Journal entry number \_\_\_\_\_

3. Day of the week \_\_\_\_\_

4. Time (am/pm) \_\_\_\_\_

5. Level of sleepiness before the episode of automatic behaviour. (Please refer to the Stanford sleepiness scale – SECTION D).

\_\_\_\_\_

6. Present level of sleepiness. (Please refer to Stanford sleepiness scale – SECTION D). \_\_\_\_\_

7. Time of last medication intake plus the dosage in mg \_\_\_\_\_

8. Type of medication \_\_\_\_\_

9. Time of last nap (am/ pm) \_\_\_\_\_

10. Duration of the nap in minutes \_\_\_\_\_

11. Food/ drink intake in last three hours:

i) snack or drink (describe) \_\_\_\_\_

ii) meal (describe, eg. Dinner) \_\_\_\_\_

- type of meal (please tick)

i)  light

ii)  medium

iii)  heavy

PLEASE REFER TO SECTION C TO COMPLETE ENTRY

## SECTION C

### **Begin Tape Recording**

1. Please record on the tape, the journal entry number and your ID.
2. Describe what you were doing before the episode. (Eg, writing, cooking, cleaning the house, walking the dog....)
3. Try to explain what happened during the period of automatic behaviour?
4. What were you doing when you realised that you were in or coming out of automatic behaviour?
5. How long did the episode last? .....sec/ min/ hours
6. What happened after the episode of automatic behaviour?
7. How did you know that you were having or had an episode of automatic behaviour?
8. Feel free to record any additional points/observations.

**SECTION D**  
**STANFORD SLEEPINESS SCALE (x1)**

LEVELS:

1 = Feeling active and vital; alert; wide awake.

2 = Functioning at a high level; but not at peak; able to concentrate.

3 = Relaxed; awake; not at full alertness; responsive.

4 = A little foggy; not at peak; let down.

5 = Fogginess; beginning to lose interest in remaining awake; slowed  
down.

6 = Sleepiness; prefer to be lying down; fighting sleep; woozy.

7 = Almost in reverie; sleep onset soon; lost struggle to remain awake.

X = Asleep

## **APPENDIX H**

### **POSSIBLE QUESTIONS FOR INTERVIEW TWO WITH PARTICIPANTS**

## **APPENDIX H**

### **POSSIBLE QUESTIONS FOR INTERVIEW TWO WITH PARTICIPANTS**

1. What were your experiences with automatic behaviour (AB) over this past week?
2. Were you able to record all your episodes of AB?
3. Did the exercise of writing down your episodes of AB have any effect on AB?  
That is, did it increase you awareness of it?
4. Did you notice anything that you had not noticed about your AB before?
5. Go over past questions of interest.

**APPENDIX I**

**POSSIBLE QUESTIONS FOR INTERVIEW WITH SPOUSE/ FAMILY  
MEMBER**

## **APPENDIX I**

### **POSSIBLE QUESTIONS FOR INTERVIEW WITH SPOUSE/ FAMILY MEMBER**

1. Have you ever witnessed an episode of automatic behaviour (AB) in your spouse/ family member?
2. What do you usually observe when your spouse/ family member is experiencing an episode of AB?
3. How does AB affect you, your family and your relationship?
4. Can you tell if your family member/ spouse is going to have an episode of AB? If so, what are the tell tale signs?
5. Are you able to identify when your family member/ spouse is experiencing an episode of AB, before it becomes evident through errors in performance or speech?
6. Are there certain times of the day, week or month in which episodes of AB are particularly prominent?

**APPENDIX J**

**INFORMATION LETTER REGARDING MINIMAL MEDICATION JOURNAL  
AND CONSENT FORM**

## **APPENDIX J**

### **INFORMATION LETTER REGARDING MINIMAL MEDICATION JOURNAL AND CONSENT FORM**

My name is Michelle Morandin and I am currently completing a Doctor of Psychology (Clinical Neuropsychology) at Victoria University of Technology. As part of my degree I am undertaking a research project under the supervision of Dr. Dorothy Bruck to examine the phenomenon of automatic behaviour in individuals with narcolepsy. Automatic behaviour involves performing a series of actions without conscious awareness. That is, the body continues to function while the mind has partially retreated to sleep. A classic example is reaching a destination, through walking or driving, without realizing how one got there.

I would like to invite you to participate in phase 2 of the study titled 'Automatic behaviour in individuals with narcolepsy: a multiple case study approach'. You have just participated in the first phase of the study and have been asked if you would like to participate in the second phase of the study. If you agree to participate in the second phase of the study, you will be asked to keep a journal for the day, similar to the journal completed in the first phase of the study. On this day, if you are on some medication you will be asked the lowest dosage that you could take. Because of this you will be asked to complete the journal when you are able to spend the whole day at home.

Your participation in this project is voluntary and you are under no obligation to take part. If you feel uncomfortable or no longer wish to participate, you are free to withdraw consent and to discontinue participation in the study at any time, as well as withdraw any data that you contributed to the study. All information, which you provide, will be strictly confidential. Information given will be treated as confidential by the researchers. If you would like to participate, please complete the accompanying consent form.

Should you have any concerns regarding the manner in which this research project is conducted, please do not hesitate to inform the researchers directly. I can be contacted on \*\*\*\*\*. Dr Dorothy Bruck can be contacted on \*\*\*\*\*. The Victoria University Human Research Ethics Committee are on (03) 9688 4710 if you have any ethical concerns about this project.

**CERTIFICATION BY PARTICIPANT**

I,  
Of

certify that I am at least 17 years old\* and that I am voluntarily giving my consent to participate in the study entitled:

**Automatic behaviour in individuals with narcolepsy: A multiple case study approach.**

being conducted at Victoria University of Technology by:

**Dorothy Bruck and Michelle Morandin**

I certify that the objectives of the study, together with any risks to me associated with the procedures listed below to be carried out in the study, have been fully explained to me by:

**Michelle Morandin**

and that I freely consent to participation involving the use of these procedures.

**Procedures:**

Journal kept for one day, with minimal stimulant medication.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: ..... }

Witness other than the experimenter (as appropriate) }

**Date:**

.....

.....}

Any queries about your participation in this project may be directed to the researcher (Name: Michelle Morandin ph. \*\*\*\* \*). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001 (telephone no: 03-9688 4710).

**APPENDIX K**  
**MINIMAL MEDICATION JOURNAL**

**APPENDIX K**

**MINIMAL MEDICATION JOURNAL**

Participant: \_\_\_\_\_

Date: \_\_\_\_\_

Day of the week: \_\_\_\_\_

**Complete in morning**

NIGHT SLEEP:

I went to bed at (am/pm) \_\_\_\_\_

I tried to fall asleep at (am/pm) \_\_\_\_\_

I fell asleep within about (minutes) \_\_\_\_\_

I remember awakening during the night (times awakened) \_\_\_\_\_

My total time awake during the night was about (minutes) \_\_\_\_\_

I woke in the morning from my nights sleep at (am/pm) \_\_\_\_\_

I got out of bed at (am/pm) \_\_\_\_\_

CIRCLE ONE:

My type of sleep was:

1 = very restless

2 = tired

3 = neither refreshed nor tired

4 = sound

5 = very sound

How I felt on awakening:

1 = exhausted

2 = tired

3 = neither refreshed nor tired

4 = refreshed

5 = very refreshed

**Complete after each nap/ attack/ meal**

**DAYTIME NAPS**

Nap 1. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 2. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 3. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 4. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.  
Nap 4. Fell asleep at \_\_\_\_\_ am/ pm. Slept for \_\_\_\_\_ min.

**CATAPLEXY ATTACKS**

Cataplexy 1. Occurred at \_\_\_\_\_ am/ pm. Lasted for \_\_\_\_\_ min.  
Cataplexy 2. Occurred at \_\_\_\_\_ am/ pm. Lasted for \_\_\_\_\_ min.  
Cataplexy 3. Occurred at \_\_\_\_\_ am/ pm. Lasted for \_\_\_\_\_ min.  
Cataplexy 4. Occurred at \_\_\_\_\_ am/ pm. Lasted for \_\_\_\_\_ min.  
Cataplexy 5. Occurred at \_\_\_\_\_ am/ pm. Lasted for \_\_\_\_\_ min.

DAILY MEALS

1. Time of meal \_\_\_\_\_  
Please rate size of meal: Small  Medium  Large   
Food eaten

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2. Time of meal \_\_\_\_\_  
Please rate size of meal: Small  Medium  Large   
Food eaten

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3. Time of meal \_\_\_\_\_  
Please rate size of meal: Small  Medium  Large   
Food eaten

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4. Time of meal \_\_\_\_\_  
Please rate size of meal: Small  Medium  Large   
Food eaten

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5. Time of meal \_\_\_\_\_  
Please rate size of meal: Small  Medium  Large   
Food eaten

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6. Time of meal \_\_\_\_\_  
Please rate size of meal: Small  Medium  Large   
Food eaten

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