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**Rehabilitation of accelerated long-term
forgetting using external memory aids: an
investigation of a diary and a wearable
automatic camera**

Thesis submitted for the degree of
Doctor of Clinical Psychology to
The University of Sheffield

By Karen Lee-Donaldson

July 2011

Declaration

This work has not been submitted either in part or as a whole for any other qualification or to any other institution

Structure and word count

This document contains two parts:

Section One: Literature review. This has been prepared in accordance with the Guide for Authors for NeuroRehabilitation. A copy of the 'guide for authors' and the approval letter for the journal can be found in Appendix A of Part I: Literature review.

Section Two: Research Report. This has been prepared in accordance with the 'Instructions for Authors for Epilepsia'. A copy of the instructions and the approval letter for the journal can be found in Appendix A of Part II: Research report.

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Thesis Abstract

This thesis consists of two sections. Section one is a review of the literature on the effectiveness of external memory aids for compensating for autobiographical memory impairment. It evaluates the existing research evidence for mechanical aids (pen and paper methods) and SenseCam (a novel technological device). The findings suggest that SenseCam can improve later ability to recall personal experiences. However, to date the device has only been evaluated in single case reports. Diaries have proved beneficial for clients with moderate to severe memory impairment and can be recommended as a practice guideline. Methodological limitations and recommendations for future research are discussed.

Section two presents an assessment of the effects of repeated rehearsal of autobiographical information recorded by a diary and a wearable automatic camera. One control subject with temporal lobe epilepsy and five participants who experienced accelerated long-term forgetting were recruited. Recall for personal events and memory vividness were significantly improved by using a diary in the control participant. Two participants with ALF significantly improved recall for personal memories or memory vividness using a diary. A further two participants showed measurable gains in the quality and quantity of personal memories using a memory aid, though the data did not reach statistical significance relative to the baseline. Improved performance of autobiographical memory was associated with an increase in perceived quality of life in three individuals. These findings suggest that ALF cases can show rehearsal-immunity for autobiographical information, which is of clinical and theoretic importance.

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Contents

| Section | Page |
|--------------------------|-------------|
| Declaration | ii |
| Structure and Word count | iii |
| Thesis abstract | iv |
| Acknowledgements | v |

Section One: Literature Review

Compensating for autobiographical memory disorders using external memory aids: a critical review of the literature

| | |
|------------------------------|-----------|
| 1. Abstract | 2 |
| 2. Introduction | 3 |
| 2.1. Aim | 6 |
| 3. Method | 6 |
| 3.1. Organising the evidence | 12 |
| 4. Results | 12 |
| 4.1. SenseCam | 12 |
| 4.1.1. Participants | 13 |

| | | |
|-----------|--|-----------|
| 4.1.2. | Nature of the SenseCam intervention | 14 |
| 4.1.3. | Measurement of participant behaviour and outcomes | 15 |
| 4.1.4. | Methodological critique | 17 |
| 4.1.5. | Level of evidence for SenseCam | 19 |
| 4.1.6. | Evaluation and conclusion | 18 |
| 4.2. | Mechanical Aids | 22 |
| 4.2.1. | Participants | 22 |
| 4.2.2. | Nature of the mechanical intervention | 23 |
| 4.2.3. | Measurement of participant behaviour and outcomes | 25 |
| 4.2.4. | Methodological critique | 29 |
| 4.2.5. | Level of evidence for mechanical aids | 31 |
| 4.2.6. | Evaluation and conclusion | 32 |
| 5. | Discussion | 33 |
| 5.1. | Synthesis of findings | 34 |
| 5.2 | Methodological critique | 35 |
| 5.3 | Clinical implications | 36 |

| | |
|--|-----------|
| 5.4 Further research | 37 |
| 6. References | 38 |
| 7. Appendix | 45 |
| 7.1 Appendix A: Journal approval letter and guide for authors for Neurorehabilitation | 46 |
| | |
| Section Two: Research report | 50 |
| | |
| Rehabilitation of accelerated long-term forgetting using external memory aids: an investigation of a diary and a wearable automatic camera. | |
| | |
| 1. Abstract | 51 |
| | |
| 2. Introduction | 52 |
| 2.1. Accelerated long-term forgetting | 52 |
| 2.2. Rationale for this study | 55 |
| 2.3 Aims | 56 |
| | |
| 3. Method | 57 |
| 3.1. Rationale for study design | 57 |
| 3.2. Research development | 57 |

| | | |
|--------|--|----|
| 3.2.1. | Service user review | 57 |
| 3.2.2. | Ethical approval | 57 |
| 3.3. | Participants | 57 |
| 3.3.1. | Selection criteria | 57 |
| 3.3.2. | Recruitment | 58 |
| 3.3.3. | Neuropsychological assessment | 58 |
| 3.3.4. | Assessment of ALF | 59 |
| 3.3.5. | Participant characteristics | 59 |
| 3.4. | Materials | 61 |
| 3.4.1. | Diary | 61 |
| 3.4.2. | Camera | 61 |
| 3.4.3. | Primary Outcome Measure | 62 |
| 3.4.4. | Long term evaluation | 62 |
| 3.4.5. | Pre and post intervention outcome measures | 63 |
| 3.5. | Procedure | 64 |
| 3.6. | Intervention | 66 |
| 3.6.1. | Diary | 66 |

| | | |
|-----------|-------------------------------|-----------|
| 3.6.2. | Camera | 66 |
| 4. | Results | 66 |
| 4.1. | Case 1 | 67 |
| 4.1.1. | Visual analysis | 67 |
| 4.1.2. | Statistical analysis | 69 |
| 4.1.3. | Long-term follow up | 71 |
| 4.1.4. | Standardised outcome measures | 72 |
| 4.1.5. | Anecdotal report | 72 |
| 4.2. | Case 2 | 73 |
| 4.2.1. | Visual analysis | 74 |
| 4.2.2. | Statistical analysis | 74 |
| 4.2.3. | Long-term follow up | 76 |
| 4.2.4. | Standardised outcome measures | 76 |
| 4.2.5. | Anecdotal report | 77 |
| 4.3. | Case 3 | 78 |
| 4.3.1. | Visual analysis | 79 |
| 4.3.2. | Statistical analysis | 80 |

| | | |
|--------|-------------------------------|----|
| 4.3.3. | Long-term follow up | 81 |
| 4.3.4. | Standardised outcome measures | 82 |
| 4.3.5. | Anecdotal report | 83 |
| 4.4. | Case 4 | 84 |
| 4.4.1. | Visual analysis | 85 |
| 4.4.2. | Statistical analysis | 86 |
| 4.4.3. | Long-term follow up | 87 |
| 4.4.4. | Standardised outcome measures | 87 |
| 4.4.5. | Anecdotal report | 88 |
| 4.5. | Case 5 | 89 |
| 4.5.1. | Visual analysis | 90 |
| 4.5.2. | Statistical analysis | 91 |
| 4.5.3. | Long-term follow up | 93 |
| 4.5.4. | Standardised outcome measures | 93 |
| 4.5.5. | Anecdotal experience | 94 |
| 4.6. | Case 6 | 95 |
| 4.6.1. | Visual analysis | 95 |

| | | |
|-----------|--|------------|
| 4.6.2. | Statistical analysis | 97 |
| 4.6.3. | Long-term follow up | 98 |
| 4.6.4. | Standardised outcome measures | 99 |
| 4.6.5. | Anecdotal experience | 100 |
| 5. | Discussion | 100 |
| 5.1. | Limitations | 104 |
| 5.2. | Clinical implications | 106 |
| 5.3. | Theoretical implications | 107 |
| 6. | Conclusions | 108 |
| 7. | References | 109 |
| 8. | Appendices | 116 |
| 8.1. | Appendix A: Journal approval letter and Instructions for authors for Epilepsia | 117 |
| 8.2. | Appendix B: Letter from Epilepsy Action | 128 |
| 8.3. | Appendix C: Scientific approval letter | 129 |
| 8.4. | Appendix D: Ethical approval letter | 130 |
| 8.5. | Appendix E: Research & Development approval letter | 133 |
| 8.6. | Appendix F: Announcement in Epilepsy Today | 135 |

| | | |
|-------|--|-----|
| 8.7. | Appendix G: Information sheet | 136 |
| 8.8. | Appendix H: Consent form | 139 |
| 8.9. | Appendix I: WTAR Record form | 140 |
| 8.10. | Appendix J: Repeatable Battery for the Assessment of Neuropsychological Status | 144 |
| 8.11. | Appendix K: The Autobiographical Memory Interview | 154 |
| 8.12. | Appendix L: Adult Memory and Information Processing Battery word list | 163 |
| 8.13. | Appendix M: Diary record sheet | 166 |
| 8.14. | Appendix N: Vicon Revue manual | 167 |
| 8.15. | Appendix O: Record sheet for memories recalled | 175 |
| 8.16. | Appendix P: Analysis of important event | 176 |
| 8.17. | Appendix Q: Hospital Anxiety and Depression Scale | 177 |
| 8.18. | Appendix R: Quality of Life in Epilepsy-31 | 178 |
| 8.19. | Appendix S: Instructions for using the diary | 183 |
| 8.20. | Appendix T: Instructions for using Vicon Revue | 184 |
| 8.21. | Appendix U: RCI Calculations for standardised measures | 185 |

Section One: Literature Review

**Compensating for autobiographical memory disorders using
external memory aids: a critical review of the literature**

1. Abstract

Autobiographical memory impairment is a frequent sequelae of acquired brain damage. This paper reviews the range of external memory aids that have been used to enhance memory for past events and the evidence for their efficacy in clinical populations. Fourteen studies were reviewed: four studies investigated SenseCam, a portable automatic camera which forms the basis of a virtual reality memory prosthesis; ten studies reported the use of “pen and paper” methods to improve recall for personal experiences. The findings suggest that SenseCam may be useful for clients who have high pre-morbid social and occupational functioning, profound impairment and are living with a supportive carer. However, whilst the results are promising there is limited evidence for its efficacy in clinical settings. Diaries and notebooks were reported to enable individuals to live independently. The literature suggests that traditional notebook methods may be useful when candidates require help with planning and organisation in addition to supporting their autobiographical memory. There is good evidence supporting the use of notebooks in memory impairment, but studies did not use recall for past experiences as a measure of outcome. Methodological limitations are considered along with recommendations for future research.

2. Introduction

Autobiographical memory has been conceived as the retention of knowledge representing the self over weeks, months, years and across the lifespan (Conway, 2002). This comprises many different kinds of specific memories which involve events, people, places and objects from daily life. Definitions of and distinctions between autobiographical, semantic and episodic memories differ amongst researchers and clinicians. A useful heuristic is that semantic memory concerns knowledge of concepts and facts, whilst episodic memory involves awareness of personally experienced events (Tulving, 1972). Episodic memory makes possible mental time travel, through subjective time, from the present to the past, allowing one to re-experience one's own previous experiences (Tulving, 2002). Although the term episodic memory provides a useful definition for clinical practice, years of research has demonstrated that it describes a family of processes (anterograde and remote memory, recall of verbal and non-verbal information and recognition of verbal and non-verbal information) rather than a single definable entity (Hodges & Graham, 2002).

Whilst the terms autobiographical and episodic are often used interchangeably (Kopelman & Kapur, 2002), in this review we will use the term autobiographical memory to define happenings in particular places at particular times. In terms of the neuropsychological literature, the ability to retrieve the temporal and spatial elements of a prior experience equates most closely to autobiographical memory (Hodges & Graham, 2002).

Autobiographical memory serves many functions. One particular function is to retain knowledge on the progress of personal goals thereby satisfying a broad range of motives, and act as a positive resource in times of stress (Conway, 2002). Conway hypothesises that the concept of self is defined by our knowledge about activities, locations and evaluations from specific lifetime periods e.g. secondary school. It is posited that recollections of remote personal experiences that enter conscious awareness facilitate decision making and intentional choice (Conway, 2002).

People with autobiographical memory impairment have difficulty in recollecting personally experienced events, circumstances or situations from their own lives and often cannot imagine their future (Tulving, 2002). This leads to a disruption in the highest level of self-awareness, through an inability to apply knowledge through personal relevance (Wheeler, Stuss & Tulving, 1997).

Despite the significance of autobiographical memory in maintaining a congruent healthy self, the effect of dysfunctions of recollective experience on the self have not been extensively studied. Marked memory disorders such as global or focal retrograde amnesia have been well-described but the occurrence of deficits in autobiographical memory as a general clinical feature has been underestimated or ignored (Kapur, 1997). There are no epidemiological studies which estimate how frequently the loss of past memories is observed in routine neuropsychological practice. Compared to the vast literature on other aspects of memory we know relatively little about autobiographical memory in brain injured patients (Hodges & Graham, 2002). It has, however, been suggested that autobiographical memory is one of the most frequently affected functions damaged by trauma or organic

changes in the brain (Svoboda & Richards, 2009; Mateer, 2009). Whilst isolating autobiographical memory as a distinct entity is somewhat artificial, there are many individuals for whom a difficulty in recalling past experiences is the predominant concern, even if this arises from deficits in various different cognitive processes.

Although there is little evidence that rehabilitation can restore lost memory functioning, there is considerable evidence that the disabilities arising from organic memory impairment can be treated. Helping people to compensate for their deficits through the use of external memory aids is one of the most effective methods of rehabilitation (Wilson, 2004). Aids provide the user with a way to limit demands on their memory by transferring the task to match a person's intact abilities (Sohlberg, et al., 2007). Recent reviews of the literature have shown that external aids can be valuable for improving the daily functioning of people with memory impairments (Ptak, Van der Linden & Schnider, 2010; Sohlberg, et al., 2007; Kapur, Glisky & Wilson, 2004; Grandmaison & Simard, 2003). These reviews covered a diverse range of memory prosthetics targeted at a broad range of tasks. However, the majority of the studies analysed investigated the use of organisers (e.g. diaries, calendars) to support prospective memory functioning (ie. remembering to do something in the future). Whilst several studies have shown that external aids can act as effective reminders, the question of which aids would be suitable for the many patients who complain that they cannot access memories of past life experiences remains to be addressed.

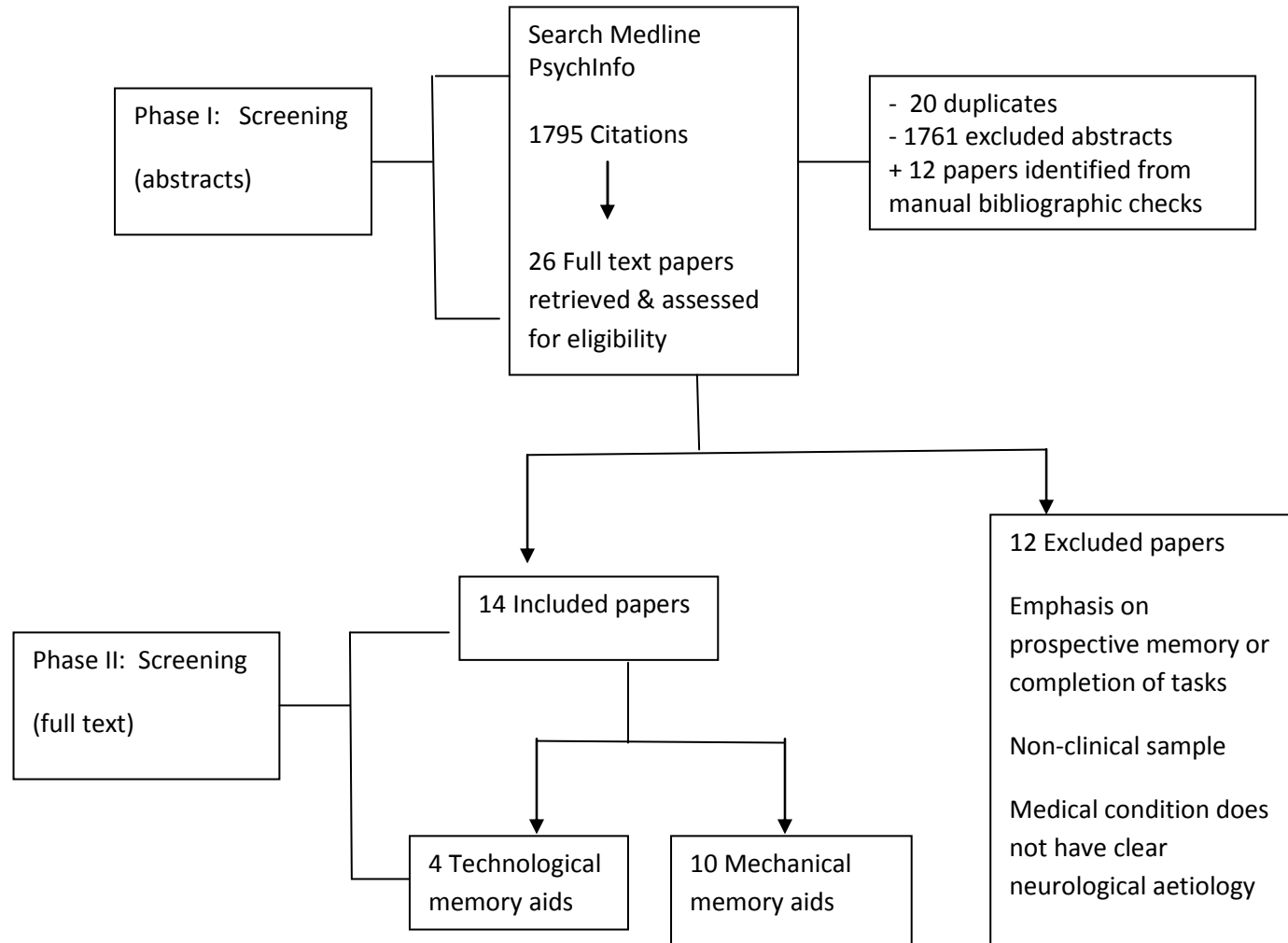
2.1 Aim

The purpose of this review is to examine the literature on the efficacy of using external memory aids to improve autobiographical memory among people with neurological deficits. As the features of a memory aid should be matched to a patient's clinical and neuropsychological profile (Ptak et al., 2010), a further aim is to consider whether different types of memory aid are suited to specific clinical or personal characteristics.

3. Method

Figure 1 illustrates the literature review process. Psychinfo and Medline databases were searched in order to identify relevant studies. Search terms that described treatment i.e. intervention, rehabilitation, remediation and therapy were combined with the term memory. These results were combined with terms that described external memory aids: notebook, diary, computer, camera and telephone. This resulted in 1,795 different articles. Abstracts were reviewed to eliminate reports that did not directly address the use of external aids as an intervention to enhance autobiographical memory. Studies with a focus on prospective memory, theoretical reports, use of internal memory strategies or completion of daily living tasks were not included in this review. Reports were excluded if participants were from a non-clinical population or if their medical condition did not have a neurological aetiology.

Figure 1: Flowchart of literature review process



Studies involving people with dementia were included as the common clinical syndromes are characterised by impairment in memory function. Studies where the researcher assessed recall for personal facts e.g. names of family members were excluded as this work is more aligned to semantic memory. The bibliographies of each paper were then reviewed to identify further relevant articles. This search process revealed 14 peer reviewed journal articles evaluating the effectiveness of external aids as an autobiographical memory compensation technique. Of the 14 studies identified, 10 were single case reports.

To assess the quality of reports and facilitate critical appraisal, the Single-Case Experimental Design (SCED) Scale (Tate, McDonald, Perdices, Togher, Schultz & Savage, 2008) was used. The SCED Scale provides a checklist for adequate description of: target behaviour, study design, adequate baseline, sampling behavior, raw data, interrater reliability, independence of assessors, statistical analysis, replication and generalisation. The total score demonstrates excellent interrater reliability using both individual and consensus ratings (Tate et al., 2008). All studies are briefly presented along with SCED scores, where applicable, in Table 1.

Table 1: Summary of the evidence base of external aids applied to improve memory for personal experiences

| Technological Memory Aids | | | | | | |
|--|--|---|----------|--|--|-------------------|
| Author | Participant(s) | Study Design | n | Outcome | Author conclusions | SCED Score |
| Hodges et al. (2006) | 63 year old female Severe amnesia following limbic encephalitis | Single-case ABC design SenseCam/diary/baseline | 1 | Recall greater in SenseCam condition maintained over 11 months | SenseCam is a valuable practical retrospective memory aid | 4 |
| Berry et al. (2007) | 63 year old female Severe anterograde memory impairment following limbic encephalitis | Single-case ABC design SenseCam/diary/baseline | 1 | Recall significantly greater ($p < 0.001$) in SenseCam condition. Diary and baseline discontinued prematurely. | SenseCam suitable for focal memory deficits in patients with preserved insight and motivation. | 6 |
| Pauly-Takacs et al. (2010) | 13 year old boy Anterograde amnesia subsequent to chemotherapy and radiotherapy for metastatic intracranial germ cell tumour. | Single case AB design SenseCam review/ no review | 1 | Significantly better ($p = 0.009$) recognition of places that were repeatedly viewed as SenseCam images after 15 week delay. | Known events supported by SenseCam show greater stability over time than unsupported known events. | 5 |
| Brindley, Bateman and Gracey (2011) | 28 year old man Social anxiety disorder with memory and executive difficulties following ABI | Single case ABC design Thought records vs. SenseCam images for supporting recall in CBT intervention | 1 | SenseCam supported retrieval superior to thought records and no strategy conditions | SenseCam is a useful memory aid for retrieving felt experience. However, there was no improvement in mood following study. | 7 |

| Mechanical studies | | | | | |
|-----------------------------------|--|--|----|--|--|
| Author | Participant(s) | Study Design | N | Outcome | Author conclusions |
| Fluharty & Priddy (1993) | 59 year old widowed man with ABI due to subarachnoid haemorrhage | Case report – no control | 1 | Two years after introduction notebook is still being used | Memory note book is acceptable and culturally normative tool |
| Burke et al. (1994) | 16 year old boy with impairments in memory and executive functioning following TBI. | Case report – no control | 1 | Use of journal to track meaningful events had personal value for patient | Memory book training can maximise independence |
| Schmitter-Edgecombe et al. (1995) | Individuals with severe closed head injury | Randomised controlled trial with no blinding Notebook training vs. supportive therapy | 8 | Notebook training significantly reduced everyday memory failures (p < 0.5) | Treatment effects no longer achieved significance at follow up |
| Wilson & Hughes (1997) | 20 year old man with ABI due to subarachnoid haemorrhage | Case report – no control Diary 7 notebook with mnemonics, rehearsal & chaining | 1 | Notebook system is an extremely effective compensatory system. | A considerable degree of sophistication can be achieved |
| Owensworth & McFarland (1999) | Participants with TBI and neurological injury vs. Control group with no brain-injury | Randomised into two treatment groups (diary only, diary and self-instructional training) | 20 | Self-instruction training group produced more diary entries | Rehabilitation of memory requires an established theoretical basis |

| Author | Participant(s) | Study Design | N | Outcome | Author conclusions |
|--|--|---|----|--|---|
| Yamamoto et al. (2000) | 46 year old man with severe amnesia following limbic encephalitis | Case report Qualitative assessment of clinical changes | 1 | Episodic memory improved | Active participation by spouse facilitated rehabilitation |
| Oddy & Cogan (2004) | 23 year old female with burst anterior communicating artery aneurysm | Case report Filiofax & specially designed forms , electronic organiser & mobile telephone | 1 | Compensatory procedures restored a considerable amount of independence | Intact implicit memory has helped acquire new skills |
| Schmitter-Edgecombe et al. (2008) | Individuals with mild dementia | Longitudinal study of group intervention – no control | 5 | Significantly more memory strategies used with notebook (p <0.5) | Multidisciplinary group can successfully be used to teach patients to use a memory notebook |
| Greenaway et al. (2008) Pilot study | Participants with amnesic Mild Cognitive Impairment with dementia | Within participant study 6 week curriculum for calendar and organisation system – no control | 20 | Medium effect size for improved functional ability (d= 0.55) | Memory support system may help with symptoms of memory decline |
| Duff et al. (2008) | Profound amnesia following closed head injury | Qualitative report | 1 | Successful self-initiated development of compensatory strategies | High functional outcome can be obtained following amnesia |

3.1 Organising the evidence

Four questions served as a structure for organising the evidence for this review:

- 1) Which participants received the intervention?
- 2) What was the nature of the intervention?
- 3) What were the outcomes and measures employed?
- 4) Are there methodological concerns?

4. Results

The literature describes two types of aids which differ in technical complexity:

SenseCam and mechanical “low Tech” paper/pencil notebook systems. This review analyses the evidence for each type of aid in turn.

4.1. SenseCam

Four studies were identified in which memory-impaired individuals used SenseCam, a portable camera which takes hundreds of photographs automatically, to support their recall of personal events (Brindley, Bateman & Gracey 2011; Pauly-Takacs, Moulin & Estlin, 2010; Berry et al., 2007; Hodges, et al., 2006). The rationale behind SenseCam is that in capturing a digital record of an event, it can subsequently be reviewed by the wearer, as movie on a computer, in order to cue and to rehearse their autobiographical memories. SenseCam images essentially serve a prosthetic function. All studies employed a single case experimental design.

4.1.1. Participants

All individuals were described as having moderate or severe anterograde memory impairment. Of the four studies, one reported using the device with a child (Pauly-Takacs et al., 2010). Two papers reported on the use of the SenseCam with the same individual (Hodges et al., 2006; Berry et al., 2007). The studies included individuals with varied aetiology: encephalitis (Hodges et al., 2006; Berry et al., 2007), traumatic brain injury (Brindley et al., 2011) and metastatic intracranial germ cell tumour (Pauly-Takacs et al., 2010).

Premorbid occupational and social functioning was reported as being high for all participants. Two participants were educated to degree level, though the young man, in one study (Brindley et al., 2011) did not graduate as he incurred his injury during his studies. An important consideration in individuals with severe memory impairment is dependence on families and in all studies the participants were not living independently.

Two studies reported the results neuropsychological testing conducted prior to starting intervention (Berry et al., 2007; Pauly-Takacs et al., 2010). In addition to significant memory impairment, two studies reported that participants experienced deficits in executive functioning, sustained attention and speed of processing (Pauly-Takacs et al., 2010; Brindley et al., 2011). One participant performed within normal limits for tests of executive function, attention and language (Berry et al., 2007).

Two studies (Berry et al., 2007; Brindley, Bateman, & Gracey, 2011) provided information on the participants psychological well being. Brindley, Bateman, & Gracey (2011) reported scores obtained on psychometric self report measures of mood. In this study the participant's emotional symptoms placed him in the clinical range for anxiety, panic and depression. Hodges et al. (2006) report that subjectively their participant was anxious and had low self esteem prior to intervention but formal assessments of mood were not reported.

Participants in all studies were compliant with using the aids as directed. This is perhaps somewhat surprising since in Brindley et al's (2011) study, the participant was required to wear SenseCam in a social situation which was anticipated to evoke a strong anxious reaction. Berry et al. (2007) were the only authors to consider the individual patient characteristics that might affect successful adoption of SenseCam as a memory aid. In line with the findings of Sohlberg et al., (2007) it was suggested that insight and motivation may be key mediators that influence positive outcome.

4.1.2. Nature of the SenseCam intervention

The focus of the studies was to assess the effectiveness of using Sensecam to support autobiographical memory. Three studies compared the use of Sensecam with other external aids: diary (Berry, et al., 2007; Hodges, et al., 2006) and thought records (Brindley et al., 2011). All studies compared the individual's recall using SenseCam with the effects of not using any other memory strategy. One study investigated the effectiveness of using of SenseCam to help alleviate social

anxiety, a secondary consequence of severe memory impairment (Brindley et al., 2011).

Three studies assessed the use of memory aids in real life settings (Hodges et al., 2006; Berry et al., 2007; Brindley et al., 2011). Hodges et al., (2006) and Berry, et al.,(2007) asked their participant to use the SenseCam whenever she anticipated a 'significant event'. Over the course of three months the camera was used to record nine different events. Brindley et al., (2011) assessed recall for a single event recorded by SenseCam (a meal out). One study used Sensecam in surroundings organised by the researchers. Pauly-Takacs et al., (2010) recorded a walk around a university campus which included predefined key locations with salient features e.g. a church. Whilst the laboratory design enabled researchers to control environmental variables, this study was not conducted in a naturalistic context. It is apparent that to date SenseCam has been studied with limited application. Future research should seek to assess its versatility in routine environments.

4.1.3. Measurement of participant behaviour and outcomes

All studies assessed performance on memory tasks and reported improved recall for personal events using the technological aids. A variety of dependent measures were used:

- Recall of personal events (Berry, et al., 2007; Hodges, et al., 2006; Brindley et al., 2011)
- Standardised self-report measures of mood (Brindley et al., 2011)

- Recognition memory as assessed by the number of images correctly identified as being captured by the participant using SenseCam vs. foils taken by another researcher (Pauly-Takacs et al., 2010)

Three studies assessed the proportion of information correctly recalled about a past experience (Hodges et al., 2006; Berry et al., 2007; Brindley et al., 2011).

Assessment of recall of an event was based on ability to remember key points compared to a log of the same event kept by the carer. Berry et al., (2007)

demonstrated that frequent reviewing of images over a two week period enabled recall to triple to a point where nearly everything about that event was

remembered. At the end of the study (during which she did not see or discuss

images for three months) the participant showed a 76 % average recall of nine

significant events. In comparison, when using the diary, after 1 month the

memories were permanently lost. Brindley et al., (2011) report 94% of information

about a personal event was recalled using a Sensecam strategy over three weeks

and this compared with 39% using no strategy and 22% using a hand written

automatic thought record (based on cognitive behavioural therapy). There was no

significant difference between test conditions on emotional arousal based on heart

rate and measures of mood.

Pauly-Takacs et al.,(2010) employed a forced choice recognition memory paradigm

using pairs of images taken using Sensecam. One set of images was taken by the

participant whilst the foils were taken from the experimenters SenseCam at

different times and places. The participant recognised the correct image in 90 % of

trials when events were reviewed using a Sensecam movie compared to 70% of trials when the event was not reviewed.

The length of time between the recorded event and recall of the event varied between 7 days and 11 months across the studies. Brindley et al., (2011) assessed recall at 7 days post event. Pauly-Takacs, Moulin, & Estlin (2010) assessed recall at 2 weeks and 10 weeks with a 15 week follow up. Hodges et al. (2006) and Berry, et al. (2007) assessed recall for an important personal event following active rehearsal at three and six months. Long term recall was then assessed over time periods after rehearsal ceased over delays of one, two and three months (up to 11 months post event).

4.1.4. Methodological critique

Use of the SCED scale revealed that the single case reports were generally of a high calibre. All studies provided a precise description of an operationally defined target behaviour and incorporated methodology allowing for the examination of cause and effect relationships to demonstrate treatment efficacy. Statistical analysis of the results over the treatment phases was appropriately conducted in all studies. All studies included independent verification of recall for events. Images captured by SenseCam, can be considered a reasonably objective measure of an event and recording of the target behaviour on a computer may be considered to constitute an independent assessment (Mateer, 2009).

This review revealed a number of methodological concerns. Studies did not include sufficient baseline sampling to establish fluctuations in patterns of pretreatment behaviour. Berry et al., (2007) had planned for a baseline trial to take place after the treatment phase. However, the client found repeated questioning about events she had forgotten distressing so it was considered unethical to continue. One study did record baseline responses over a period of weeks but reported the data as a collapsed total score, insufficient to establish variability (Brindley et al., 2011). Similarly, another study did not present raw data in sufficient detail to accurately represent the variability of the target behaviour across treatment phases (Hodges et al., 2006). Detailed data on percentage of correct trials conducted over time were provided in three studies (Berry, et al., 2007; Brindley et al., 2011; Pauly-Takacs et al., 2010)

Only one study reported a measurement of interrater reliability (Pauly-Takacs et al., 2010). The need for interrater reliability increases with subjective ratings and this poses a significant challenge to researchers of autobiographical memory. Three studies compared their subjects recall with that of a written record provided by a carer (Hodges et al., 2006; Berry et al., 2007; Brindley et al., 2011). However, there was no indication that the data were checked to see if they were collected in a consistent manner.

One study aimed to demonstrate beneficial effects on symptoms of anxiety, depression and self esteem following memory training (Brindley et al., 2011). However, no significant treatment effect was found comparing scores pre and post intervention using psychometric measures of mood. An important consideration in

individuals with severe memory impairment is dependence on families and further research could elucidate if the carer's quality of life improves as indicated by a sustained reduction in caregiver strain.

Finally, no studies have been conducted which sought to replicate findings of a previous study. As the literature reports that SenseCam has proven to be a useful rehabilitation tool in only three individuals with autobiographical memory impairment, this should be a priority for future research.

4.1.5. Level of Evidence for SenseCam

The Oxford centre for Evidence Based Medicine has categorised efficacy studies according to five levels of evidence. All single subject design studies are classed at level IIIb. There is no class I or II evidence for the use of SenseCam as a rehabilitation tool in clinical populations. However, Sohlberg, et al. (2007) highlight in their review of evidence based practice for the use of external memory aids, Class III evidence may be considered helpful given the heterogeneity of the population and the need to consider the unique ecology of every person with brain injury. The SenseCam studies included by this review were characterised by experimental control and yielded important insights.

4.1.6. Evaluation and conclusion

Given the heterogeneous clinical presentation of the participants and variation in or lack of reporting of key variables such as co morbid cognitive impairment, mood and prior rehabilitation, it is difficult to assess on the available evidence what type

of client would respond to using SenseCam for clinical rehabilitation. One important consideration is that all studies focused on individuals whose memory impairment may be classed as profound and significantly disrupted their daily functioning. Premorbid social and intellectual functioning was estimated to be high for all patients recruited to SenseCam studies.

Another common characteristic is that none of the patients were living independently. In all SenseCam studies, a third party (carer or researcher) prompted the participants to review the SenseCam images. Berry et al., (2007) considered that the presence of a supportive carer enabled their participant to benefit from SenseCam as they were able to review together images from shared experiences. The preliminary reports do not indicate if individuals are able to spontaneously use the device independently and this would need to be demonstrated by future research.

It has been postulated that structured theory-driven training is required in order for individuals with significant memory impairment to benefit from commercial technology (Svoboda et al., 2010). SenseCam studies lacked description on the training offered to participants and their carers on the introduction of the device. Studies did not fully explain the amount and type of instruction that was provided to participants and/or carers on SenseCam technology. This omission is pertinent since learning to use a novel device is itself a memory task.

Technological problems were not specifically reported by any author. Research has confirmed that technical problems with electronic devices have had a negative effect for persons with memory impairments (Bowman, Bartfai, Borell, Tham &

Hemmingsson, 2010). One potential problem with the SenseCam device is that the product has to be linked to a computer to access the images and therefore users need to be comfortable and familiar with using a personal computer. This may be daunting for novices and also limit the use of the images to inside the home. However, Berry et al. (2007) confirm that their patient was successful in using the device without prior experience of computers.

The generalisability and clinical utility of SenseCam is restricted by the apparent limited application of the device in real world settings and long term follow up. There is a need to evaluate if the device can be used on a regular basis to reduce everyday memory failures. In line with Sohlberg et al.'s (2007) findings, there was a deficiency of objective validated measurements to assess functional outcome. Future research may aim to provide more systematic investigations of the use of technological devices to enhance autobiographical memory with larger samples.

It is worth noting that recently several studies have been published concerning the use of a mobile telephone as an external memory aid (Svoboda, Richards, Polsinelli, & Guger, 2010; Svoboda & Richards, 2009; Wade & Troy, 2001). The focus of these studies was to encourage patients to use the calendar function on the mobile telephone to remember appointments. The use of a mobile telephone to aid organisation and prospective memory was well demonstrated in these studies. In two studies, the authors reported that the patient's learning spontaneously generalised to the video application which enabled patients to record personal events (Svoboda & Richards, 2009; Svoboda et al., 2010). The authors reported an increase in the use of the Smartphone for "retrospective orientation" post

intervention, but unfortunately did not specify what this measure assessed. Whilst there is no empirical evidence for the application of mobile telephones to improve autobiographical memory, this is a promising avenue for future research.

4.2. Mechanical studies

Ten studies were identified that employed mechanical aids to improve recall for past experiences.

4.2.1. Participants

One case report described work with a 16 year old student who suffered a traumatic brain injury in a road traffic accident (Burke, Danick, Bemis, & Durgin, 1994). The remaining reports concerned adults with memory impairment arising from varied aetiology: subarachnoid haemorrhage (Fluharty & Priddy, 1993; Wilson & Hughes, 1997) an anterior communicating artery aneurysm (Oddy & Cogan, 2004), limbic encephalitis (Yamamoto, Izumi, Shimakura, Sawatari, & Ishida, 2000), dementia (Schmitter-Edgecombe, Howard, Pavawalla, Howell & Reuda, 2008 ; Greenaway, Hanna, Lepore & Smith, 2008) and traumatic brain injury (Duff, Wszalek, Tranel & Cohen, 2008; Schmitter-Edgecombe, Fahy, Whelan & Long, 1995; Ownsworth & McFarland, 1999).

Despite good clinical, social and occupational descriptions of clients, full neuropsychological profiles were only provided in four reports (Yamamoto et al., 2000; Oddy & Cogan, 2004; Schmitter-Edgecombe et al., 2008; Duff et al., 2008).

This represents a weakness in the literature since it has been established that the

pattern of deficits displayed by a patient in memory tests is crucial for the choice of the intervention (Ptak et al., 2010). Some reports specified that executive functions were generally intact e.g. (Yamamoto et al., 2000; Wilson & Hughes, 1997; Duff et al., 2008; Schmitter-Edgecombe et al., 2008); whilst others highlighted that in addition to memory impairment their participants had notable difficulties with impulse control, verbal comprehension, social judgement, attention and concentration (Oddy & Cogan, 2004; Burke et al., 1994).

4.2.2. Nature of the mechanical intervention

A range of mechanical external aids were reported:

- Variations of filofax systems including a daily log and different coloured sheets or sections for personal notes, domestic management, social events, favourite places, directions, menus and work (Wilson & Hughes, 1997 ; Oddy & Cogan, 2004; Schmitter-Edgecombe et al, 1995)
- Journals (Burke et al., 1994)
- Diaries with highlighted prompts : names/details (Ownsworth & McFarland, 1999)
- Simple notebooks for recording conversations and activities (Yamamoto et al., 2000)
- Commercially available memory books (Greenaway et al., 2008; Schmitter-Edgecombe et al., 2008; Fluharty & Priddy, 1993)
- Notes stored in different folders for different types of information e.g. work, social activities(Duff et al., 2008)

Three studies outlined group training programmes for a memory aid (Schmitter-Edgecombe et al., 2008; Schmitter-Edgecombe et al., 1995; Greenaway et al., 2008). The curricula were delivered between 12 and 16 sessions. Training programmes replicated the earlier work of Sohlberg & Mattheer (1989), structuring the learning of the intervention over four phases: anticipation, acquisition, application and adaptation. Within each stage didactic lessons and homework assignments were incorporated to reinforce learning.

Overcoming barriers to the adoption of a journal has also been the focus of individual work. (Burke et al., 1994; Fluharty & Priddy, 1993; Yamamoto et al., 2000) Strategies included increasing self awareness to highlight the frequency of memory failures through provision of group and individual feedback (Burke et al., 1994), showing a video of a team conference discussing the client's difficulties (Fluharty & Priddy, 1993) and behavioural positive reinforcement from members of the community to provide a consistent pattern of praise when the client used his journal (Burke et al., 1994). Alarms were provided to cue clients to make entries in their journal in two studies (Schmitter-Edgecombe et al., 1995; Yamamoto et al., 2000).

Owensworth & McFarland (1999) evaluated two different methods of training which were delivered by a single telephone call: functional diary training and self-instructional training. In the functional diary only condition participants learned a behavioural sequence of making a diary entry, checking and then using the information as required. The self instructional training condition emphasised developing capacity for self awareness and self regulation. The taught strategy

consisted of four steps: What are you going to do; select a strategy; try out the strategy and check how that strategy is working. Diaries were sent out in the post with letters which outlined the strategy discussed over the telephone.

Details about memory aid training procedures are a vital component of the methodology that allows researchers to replicate the study or clinicians to apply a technique to their practice (Sohlberg et al., 2007). A full description of the training or rehabilitation programme provided the basis many of the articles and this is a strength of these reports. However, the emphasis on the formal instruction offered in the majority of these papers contrasts with the case report of a client with dense amnesia who developed her own note taking system without any professional involvement (Duff et al., 2008).

4.2.3. Measurement of participant behaviour and outcomes

Sohlberg et al. (2007) highlight that memory books have been designed to help with multiple tasks such as organising, initiating and planning prospective tasks in addition to assisting recall of personal experiences. This is reflected in the literature which revealed a broad range of target behaviours and outcome measures:

- Serial testing on laboratory-based measures: e.g. Rivermead Behavioural Memory Test (Wilson, Cockburn & Baddeley & Hiorns, 1989; Schmitter-Edgecombe et al., 1995; Schmitter-Edgecombe et al., 2008); Miyake Verbal Retention Test (Miyake & Uchida, 1923; Yamamoto et al., 2000); Adult

Memory and Information Processing Battery (Coughlan & Hollows, 1985; Oddy & Cogan, 2004)

- Measures of functional ability (Greenaway et al., 2008; Schmitter-Edgecombe et al., 2008)
- Self-report questionnaires assessing memory failures (Schmitter-Edgecombe et al., 1995; Schmitter-Edgecombe et al., 2008; Ownsworth & McFarland, 1999)
- Self-report questionnaires assessing participant or caregiver distress (Schmitter-Edgecombe et al., 1995; Greenaway et al., 2008; Schmitter-Edgecombe et al., 2008)
- Number of diary entries made (Ownsworth & McFarland, 1999; Greenaway et al., 2008)
- Anecdotal reports of effectiveness of the aid (Duff et al., 2008; Burke et al., 1994; Oddy & Cogan, 2004; Fluharty & Priddy, 1993; Wilson & Hughes, 1997)

Fluharty & Priddy (1993) underscored that the application of the aid to accomplish meaningful tasks should be emphasised. In line with this, four reports cite that diary systems enabled clients to live independently and work (Duff et al., 2008; Wilson & Hughes, 1997 ; Oddy & Cogan, 2004; Fluharty & Priddy, 1993). Functional outcome was formally assessed in two studies (Schmitter-Edgecombe et al., 2008; Greenaway et al., 2008). Schmitter-Edgecombe et al. (2008) employed the Activities of Daily Living International Scale (ADL-IS; Reisberg et al., 2001) to examine possible effect of notebook intervention on completion of everyday activities for people

with mild dementia. Greenaway et al. (2008) employed the Every Day Cognition (E-Cog; Farias et al., 2008) and Record of Independent Living (ROIL; Weintraub, 1986) as dependent measures. Post intervention there were no significant changes recorded using these instruments. However, on closer analysis of the E-Cog, a medium effect size for improvement in memory related activities of daily living was observed.

Several authors suggested that compliance with completing the journal was a valid indicator of the usefulness and acceptability of the intervention. Independent use of the aid was a key outcome reported in all studies. Ownsworth & McFarland (1999) counted the number of diary entries made in the two intervention groups, but found that there was no significant difference between a “diary only” group and “diary plus training” group. The training taught use of the diary using higher cognitive skills of self-awareness and self-regulation. Both methods were successful in reducing the number of reported memory problems during treatment period. Their findings also revealed a significant decline in the number of diary entries made after two weeks suggesting that participants may have found maintaining the intervention effortful. Greenaway et al. (2008) developed a compliance rating for their memory support system. Participants made significantly more entries following training and this was maintained at 8 week follow up. However, the authors noted that the journaling section was the most difficult to maintain and hypothesised that, day to day, individuals with mild cognitive impairment remember significant events and felt they did not need to write them down.

Schmitter-Edgecombe et al. (2008) were able to demonstrate improvement in cognitive status using the Rivermead Behavioural Memory Test. This measure has alternate forms which were administered pre and post treatment. However, testing instructions were modified to allow for note taking during RBMT-II test instruction. Oddy & Cogan (2004) conducted serial testing every six months on the FAS, a test of phonemic fluency, and the Adult Memory and Information Processing Battery. All scores remained consistently below the 5th percentile and showed little or no signs of improvement over 4 years. In contrast, functional outcome had improved to the extent that she has a full weekly routine including courses, evening classes, voluntary work and fitness activities. A similar lack of improvement on laboratory based measures (WMS-R and WAIS-R) was reported by Schmitter-Edgecombe et al. (1995). These findings concur with the observations of other researchers that improvement in daily functioning may correlate little with scores obtained on neuropsychological batteries (Freeman, Mittenberg, Dicowden, & Bat-Ami, 1992).

Self-report methods were demonstrated to provide a valid measure of everyday memory problems (Ownsworth & McFarland, 1999; Schmitter-Edgecombe et al., 1995). Ratings between caregivers and patients were shown to correlate highly ($r=0.89$) (Schmitter-Edgecombe et al., 1995). Training methods were successful in reducing the number of self-reported memory problems during the treatment period and post-treatment in studies of brain injured clients (Ownsworth & McFarland, 1999; Schmitter-Edgecombe et al., 1995). However, clients with very mild dementia did not endorse significant changes pre and post treatment (Schmitter-Edgecombe et al., 2008).

Owensworth & McFarland (1999) measured mood weekly using the Profile of Mood States questionnaire (McNair, Lorr & Droppleman, 1971). All participants reported lower levels of distress associated with memory problems relative to baseline conditions. A significant reduction in symptom distress, measured by Symptom Checklist-Revised (Derogatis, 1980) was also reported by Schmitter-Edgecombe et al. (1995). In contrast, Schmitter-Edgecombe et al. (2008) failed to find any significant changes in mental health of patients with very mild dementia, as assessed by the Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995).

4.2.4. Methodological critique

Although training programmes are relevant to memory rehabilitation, this review does not set out to evaluate their effectiveness. One difficulty with the group studies is that reduction in memory failures was attributed to the use of a notebook. However, some authors noted that participants may have benefited from group work where they had the opportunity to meet with others with similar problems (Schmitter-Edgecombe et al., 1995). A group setting can be advantageous as it enhances social interaction. In these studies the effects of the participation in training programs cannot be isolated from the effects of the aid. Removal of the treatment environment may reduce the spontaneous implementation of learned skills (Freeman et al., 1992).

This highlights the need for long term follow up which was lacking in group studies. It was unclear if patients and carers were able to continue to use the strategies once the intensive support of the training programme was withdrawn. Squires,

Hunkin, & Parkin (1997) describe how, despite good intentions of continuing the use of a notebook after successful completion of a training intervention at long term follow up the client had discontinued filling diary entries. Ownsworth & McFarland, (1999) reported that over a period of just two weeks the number of diary entries made declined significantly. Maintaining motivation and commitment to use a diary over long time periods is challenging.

The mean times since injury for participants recruited from a brain injury group was 15 years in one study (Ownsworth & McFarland, 1999) Schmitter-Edgecombe et al. (1995) evaluated their intervention in clients who were more than 2 years post injury. However, many of the case reports could not isolate effects of memory rehabilitation as treatment was conducted during time when spontaneous recovery might be anticipated (Yamamoto et al., 2000; Fluharty & Priddy, 1993; Burke et al., 1994; Wilson & Hughes, 1997). For those clients who were provided the memory intervention years after the onset of brain injury, details on prior rehabilitation, although pertinent, was sparse. An exceptional case report describes how one client developed her own external memory aids as highly successful compensation strategies for profound amnesia without any formal rehabilitation (Duff et al., 2008).

Three individual case reports outlined a patient's progress following memory rehabilitation programmes that occurred over several years. However, the aids were adapted by clients in the natural environment over time and community interventions were not monitored by researchers (Yamamoto et al., 2000; Wilson & Hughes, 1997). Whilst these often illustrate good clinical practice, it is not possible

to make inferences of cause and effect and attribute improvements to a particular type of memory aid.

The assertion that self report measures are the most sensitive to detecting effects of external remediation training (Schmitter-Edgecombe et al., 1995) appears to have been supported by this review. However, one fundamental problem is that they rely on the participant to detect and record their own memory failures. This may be particularly problematic in individuals with cognitive impairment, who may find it difficult to give accurate reports of their own memory lapses (Schmitter-Edgecombe et al., 1995). Furthermore there was a notable lack of reporting of the psychometric properties of the measures used which had not been specifically validated with the studied populations. Future research is required to verify the validity of self report memory measures in different populations.

Two notebook training procedures employed a dyadic approach, where the patient's caregiver becomes instrumental in supporting or carrying out cognitive improvement strategies. Such strategies have been found to facilitate the recall of significant life events (Grandmaison & Simard, 2003). Carers act as coaches, heavily involved in providing the intervention. It is less clear, how an appropriate locus of control can be fostered when responsibility for using a strategy is shared, as this may increase caregiver burden. Approaches that provide self-instructional training were effective in increasing compliance with diary completion in a sample of people with long- term acquired brain injury (Ownsworth & McFarland, 1999).

4.2.5. Level of evidence for mechanical aids

There is fair (level IIb) evidence to support that notebook training provides a successful compensation technique for rehabilitation of memory deficits in clients with acquired brain injury. Two randomised controlled trials were identified. However, the sample size in both studies was small (n = 8 and n= 20). Schmitter-Edgecombe et al.(1995) found that notebook training reduced everyday memory failures including forgetting and confusing past experiences compared to supportive therapy for clients with closed head injury. However, this finding no longer reached significance at 6 month follow up and suggests that a larger sample size may be needed to confirm longer term effects. Long-term follow up evaluations of diary compliance should be a prerequisite in future RCT designs. Both studies were published in the last century and surprisingly little work of similar calibre has been done since.

4.2.6. Evaluation and conclusion

Patient characteristics that researchers considered facilitated rehabilitation included independence at the time of insult, patience, ingenuity, commitment and intact or superior general intellectual ability (Duff et al., 2008; Wilson & Hughes, 1997). Schmitter-Edgecombe et al.,(2008) highlighted motivation as a key factor: all participants were aware of their difficulties and interested in learning compensation strategies. Attributes of confidence and an easy going temperament may also be facilitative (Oddy & Cogan, 2004).

The involvement of a spouse or caregiver improved journal use in several studies (Burke et al., 1994; Greenaway et al., 2008; Schmitter-Edgecombe et al., 2008;

Fluharty & Priddy, 1993 Yamamoto et al., 2000). The family can also provided a high level of structure and regular activity for the client in addition to prompts for using strategies (Oddy & Cogan, 2004). However, two reports outlined that the rehabilitation took place in the context of considerable family strain (Yamamoto et al., 2000; Duff et al., 2008). These articles highlighted successful adoption of memory notebooks despite the adverse interpersonal relationships experienced by the clients.

The level of emotional adjustment of participants was not stated in the majority of reports. Formal assessment of mood was only conducted in two reports (Schmitter-Edgecombe et al., 2008; Fluharty & Priddy 1993). Schmitter-Edgecombe et al. (1995) excluded participants if they had a psychiatric history. This review supports the claim that characterising the emotional lives of patients with memory impairment has been hitherto neglected in research (Duff et al., 2008).

5. Discussion

Treatment directed towards establishing the use of external aids for memory compensation may be considered a practice guideline for individuals with brain injury (Sohlberg, et al., 2007). However, knowledge about the best compensation techniques for autobiographical memory deficits is still lacking.

5.1 Synthesis of findings

The pertinent question is: What works best for whom? The findings in individual case reports are conflicting. For some patients SenseCam was less effortful and

therefore more successful than pen and paper methods (Berry, et al., 2007; Hodges, et al., 2006). In contrast other studies suggest that filofaxes are quicker and easier to use than electronic aids (Oddy & Cogan, 2004). The SenseCam literature is the only evidence that provides direct comparison between different types of external aids. All SenseCam studies reported that the device was superior to written records for aiding recall of personal events. However, none of the clinical SenseCam studies used the device on a day to day basis.

The primary objective of memory rehabilitation is to render patients as independent as possible in activities of daily life (Ptak et al., 2010). Clinical rehabilitation therefore can target disorders of episodic memory, prospective memory and executive deficits together. This concept is well illustrated in the memory notebook research, where aids are designed to achieve multiple functions. This literature provides some evidence to suggest that traditional notebook methods may be useful when candidates require help with planning and organisation in addition to supporting their autobiographical memory. The use of a memory notebook might be indicated to improve self-management if its use is repeatedly exercised in a structured acquisition program. It has been suggested this strategy is feasible providing executive deficits are not severe and confabulation is absent (Oddy & Cogan, 2004). On the other hand, SenseCam may be beneficial for individuals who have severe autobiographical memory impairment but relatively intact executive functioning. It may also be advantageous for individuals who have problems with reading or writing.

Compliance with using the memory aid may be a valid indicator of its usefulness. In a retrospective study, Wilson (1991) found that patients who gained independence following brain injury were likely to be using more than five memory aids simultaneously. The most frequently used memory aids were notes and note books. The results of these studies suggest that using aids that are also adopted by the general population may increase their acceptability. Diaries are ubiquitously used in developed countries which offer an advantage over SenseCam, a less familiar device.

5.2. Methodological critique

By far the greatest proportion of studies included in this review were of single-subject design with a number of associated difficulties. One important limitation is that only tentative conclusions can be drawn on how much a particular variable (ie. use of a memory aid) affects the outcome of a particular case and may contribute to outcomes in a group of cases (George & Bennett, 2005). Other difficulties summarised by Mateer (2009) include a lack of control conditions, researcher bias in the selection of cases and establishing effect sizes to verify treatment efficacy.

Several authors incorporated laboratory tests and measures of daily living as dependent variables. Whilst some researchers claim that exhaustive neuropsychological evaluations at baseline and end of study may assess the generalisation potential of procedures (Grandmaison & Simard, 2003), this review

suggests that this is not the case. Such measures may not be pragmatic measures of outcome as they are not sensitive to the impact of a therapeutic intervention aimed at improving recall of past experiences. However, given the finding that some patients benefit from one type of intervention while others do less or not at all, it remains vital to incorporate these as part of a broad assessment of patient characteristics. Only when neuropsychological variables are systematically reported can we clarify whether or not benefits of memory aids are predictable based on a pattern of cognitive and functional deficits.

Diary studies did not empirically evaluate recall for past experiences. Success in this aspect was reported anecdotally that the development of habits for target tasks, generalised to autobiographical memory. Even when recording personal experiences in a journal was a specific component of the intervention, success was determined according to the number of entries made as opposed to the ability of the entries to cue recall. In contrast all the SenseCam studies incorporated a method that enabled recall for past experiences to be quantified and these studies highlight that despite the lack of repeatable standardised autobiographical memory assessments, such evaluation is both feasible and desirable.

5.3. Theoretical and Clinical Implications

No single framework is sufficient to address the complex problems faced by people with cognitive problems. Rehabilitation draws on contributions made by theories of behaviour, recovery, plasticity and models of emotion. However, in the literature included in this review, learning theory is particularly pertinent. The use of memory

notebooks were taught in discreet stages using errorless learning techniques over a number of weeks. Prevention of errors during acquisition of information leads to better learning than trial-and-error conditions (Wilson 2004). Formal training procedures may be even more important for the rehabilitation of autobiographical memory which places a greater demand on the learner than simply cueing a discreet behaviour e.g. taking medication.

Memory rehabilitation has become a standard of care following acquired brain injury. However, it is not offered consistently to patients presenting with other neurological diagnoses such as temporal lobe epilepsy and mild cognitive impairment (Stringer, 2011). Even when memory aids are considered, they are often given to patients to use with minimal instruction and no further intervention from the therapist (Wilson, 2004). Without support, some patients might eventually develop sophisticated compensatory systems (Duff et al., 2008) but this is an exception rather than the rule. Delivering training in a group format may permit more individuals to benefit from intervention.

5.4. Further research

It is notable that despite the widespread use of diaries for memory enhancement, the evidence of their effectiveness in long term use is limited to case reports and has received little interest in research. Long term follow-up evaluation should be a prerequisite in future designs.

This review did not identify any randomised controlled studies that compared the efficacy of different types of aids (e.g. mechanical vs. technological). It is well

established that one difficulty with conducting such studies is the substantive heterogeneity of the patient population (Ptak et al., 2010). Despite the difficulty of conducting randomised control group studies in settings where clinicians have an imperative to intervene with whatever rehabilitation strategies seem likely to work, such studies are necessary as they provide the strongest evidence of clinical efficacy (Stringer, 2011). Clearly, there is a need for research involving larger numbers of participants, and arguably these need to involve patients with different characteristics. Only then can we elucidate which type of patients will respond to a mechanical or technological intervention.

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Section Two: Research Report

**Rehabilitation of accelerated long-term forgetting using
external memory aids: an investigation of a diary and a
wearable automatic camera**

1. Abstract

Accelerated long-term forgetting (ALF) is an identifiable memory disturbance associated with temporal lobe epilepsy (TLE). To date research has focused on establishing the clinical features and underlying pathological causes of this memory disorder. This study explores the possibility of alleviating ALF using two different types of external memory aids: a wearable automatic camera and a diary. Reviewed in this report is a single case series of ABAC experimental design in six individuals with TLE, five of whom demonstrated ALF. Intervention focused on recording of personal experiences with a diary or camera and rehearsing recorded material on a daily basis. Measurements included the total number of events recalled and subjective vividness of memories. Assessment of mood and quality of life was conducted pre and post each intervention. In all cases salient memories were retained at one month follow up. An increase in the quantity and quality of day to day episodic autobiographical memories was observed in four individuals. The results of this study show promising outcomes and demonstrate the protective effect from abnormal forgetting of active review of recent autobiographical memories. Furthermore, an improved ability to recollect personal experiences was associated with an increase in quality of life in three individuals. Theoretical and clinical implications are considered.

2. Introduction

Complaints of memory difficulties are common in people with temporal lobe epilepsy (TLE) since memory related brain structures are affected by seizure activity. It has been recognised for some time that the hippocampus plays a crucial role in the processing of experience for later retrieval. Damage to the hippocampus causes difficulty in mentally travelling back in subjective time, documented in patients who have undergone resection for the relief of intractable epilepsy (Noulhiane et al., 2007). The investigation of autobiographical memory complaints in TLE has recently led researchers to describe clinical features of “non-standard” memory disorders. One such disorder has been termed accelerated long-term forgetting (ALF).

2.1 Accelerated long-term forgetting

In ALF individuals learn and initially retain information normally, but forget it at an unusually rapid rate over the following days or weeks (Butler & Zeman, 2008).

People with ALF report an inability to remember salient experiences such as family holidays or weddings, resulting in considerable distress for the individual. Memory complaints are associated with emotional problems such as low self esteem and co-morbid anxiety or depression (Ponds & Hendriks, 2006).

ALF poses a challenge to standard clinical measures. ALF is most convincingly demonstrated when patients exhibit normal retention at a 30 minute delay but clear impairment over longer intervals (Butler & Zeman, 2008). Currently, disturbances such as ALF are not picked up in routine clinical settings as standard

neuropsychological tests only assess long term memory at delays of up to 30 minutes (Blake et al., 2000). Consequently, little is known about the aetiology and treatment of vulnerable personal memories (Manes et al., 2004).

Traditional models of long term memory posit that information has been encoded into long term memory if it can be accurately retrieved after an interval.

Consolidation, the progressive postacquisition stabilisation of long term memory, is the process through which memories are cemented in our minds (Dudai, 2004). This process is, as yet, poorly understood (Zeman, 2009). ALF is important as it touches on a current controversy in memory research.

The standard and widely accepted theory argues for the existence of two long term memory consolidation processes: a fast process mediated by the hippocampus and a slower process arising in neocortical structures (Squire & Alvarez, 1995). During slow consolidation neocortical sites gradually form connections between each other as a consequence of repeated firing of hippocampal-neocortical connections. Embedding memories in the neocortex results in a deeper and sturdier memory file. Recently, a competing theory has challenged this model. Multiple trace theory (MTT) posits that autobiographical memories remain dependent on hippocampal traces throughout our lives (Nadel & Moscovitch, 1997). According to MTT, no long-term consolidation process occurs in which the hippocampal contribution is relinquished. There is some debate concerning which theory provides the best explanation for ALF.

In line with the standard theory of memory consolidation it has been postulated that epileptic activity may disrupt or produce a functional disconnection between cortical and hippocampal systems indicated by ALF (Blake et al., 2000). Whilst, the exact mechanisms of slow consolidation are yet to be determined, the findings that a reduction in seizures can lead to improved performance on memory tests (Zeman et al., 1998) and that ALF can be prevented by anticonvulsant medication (Midorikawa & Kawamura, 2007) suggest that any disconnection syndrome is potentially reversible (Blake et al., 2000). However, reports are conflicting as many patients describe that their memory difficulties persist after pharmacotherapy has resolved seizures (Butler et al., 2007).

It has been suggested that resilience to disruption can be developed by patients through rehearsal and relearning of material, particularly of critical information (Blake et al., 2010). Recently a case was reported where repeated recall of material provided a patient with ALF with relative immunity from abnormal forgetting of verbal material (Jansari et al., 2010). Memory reinforcement of a story presented in laboratory conditions, highlighted the potential benefits on long term memory of repeated, spaced review of material. The author recommended pursuing further investigations into the effects of various forms of rehearsal on memory for different types of material as the basis of a protective strategy. However, whilst repetition may be useful for learning information that can be represented (e.g. short stories), it is less easily applied to memory for events in general life, unless these have been recorded in some way (Jansari et al., 2010). Despite the strong theoretical

argument for rehearsal attenuating forgetting, to date no studies have been published using this strategy to enhance personal memories.

2.2. Rationale for this study

Preliminary evidence that recording personal events to facilitate rehearsal can form the basis of a clinical intervention has been demonstrated by Reynders (2002).

Repeated rehearsal of diary material was employed by a client with ALF associated with TLE who reported significant gaps in her memory for four to five years previous. This diary intervention was shown to have a moderate effect on long term retention of memories during the treatment phase but recall reverted to pre-intervention levels once the client ceased to rehearse events.

A possible alternative to the diary is a wearable camera, SenseCam, proven to be helpful in individuals with classic amnesia. The camera captures several hundred images a day automatically which can later be reviewed and replayed as a video on a computer. Rehearsal by reviewing the camera recordings improved autobiographical memory in patients with acquired brain injury (Berry et al., 2007; Brindley et al., 2011). The method of using SenseCam to aid repeated recall of personal memories has not been studied in patients who present with ALF and a call has been made for this research to be undertaken (Jansari et al., 2010).

Finally, since ALF is invisible to standard memory tests, this disorder is seldom suspected by clinicians. Consequently, there is often a long delay before clients get an appropriate diagnosis (Butler et al., 2007). Furthermore, there is little incentive for clinicians to pursue investigations of atypical memory difficulties, when no

treatment is available. Finding a means to rehabilitate ALF is imperative for developing new services which can assess and address abnormal forgetting.

2.3. Aims

The primary aims of this study are to investigate whether portable external memory aids assist people with ALF to retain recently acquired personal memories over a two week period and whether any observable improvement in memory retention can be sustained over a month. A secondary aim is to investigate whether memory intervention can improve mood and quality of life. Specifically the study tested the following hypotheses:

- External memory aids can increase the number of personal memories retained in people with ALF.
- Rehearsal will enable memories to be retained at one month following withdrawal of the memory aid.
- Rehearsal of recorded material can increase the vividness of memories for important personal events.
- Engaging in memory rehabilitation will improve mood and quality of life in people with ALF.

3. Method

3.1. Rationale for study design

As the field is in its infancy, a case series design was chosen as it is ideally suited to exploratory work. Single case methodology enables the clinician to focus on issues using individualised strategies, adapted to the setting in which they need to function. A cross over ABAC design was employed so that each participant utilised two different types of memory aid (camera and diary).

3.2. Research development

3.2.1. Service user review

Prior to submission for scientific review, the protocol was reviewed by the Epilepsy Action Research Network (Appendix B).

3.2.2. Ethical approval

Scientific approval was granted by the University of Sheffield (Appendix C) Ethical approval was granted by Sheffield Research Ethics Committee (Appendix D) and governance approval was granted by Sheffield Teaching Hospitals NHS Foundation Trust (Appendix E).

3.3. Participants

3.3.1. Selection Criteria

Adults aged 18-65 with a diagnosis of TLE were invited to participate if they reported experience of forgetting personal events. Participants were excluded if they had a learning disability, severe cognitive impairment or a memory disorder other than ALF e.g. Alzheimer's disease.

3.3.2. Recruitment

Participants were recruited from adult out-patient epilepsy clinics at Sheffield Hallamshire Hospital and Epilepsy Action. Three individuals were approached by their neurologist and referred to the clinical neuropsychology department for help with ALF. Ten individuals responded to an announcement placed in the magazine Epilepsy Today (Appendix F). Potential participants were sent an information sheet (Appendix G) in the first instance. Five people decided not to take part in the research. An appointment was made with eight individuals to be seen either in the neuropsychology clinic or at the Epilepsy Action office to discuss the study further. All these individuals provided informed consent (Appendix H).

3.3.3. Neuropsychological assessment

At the initial appointment, the cognitive profile of participants was assessed using standardised neuropsychological tests: Weschler Test of Adult Reading (WTAR; Weschler, 2001; Appendix I) to estimate pre-morbid level of intellectual functioning, Repeatable Battery for the Assessment of Neuropsychological Status, (RBANS; Randolph, 1998; Appendix J) to obtain a sampling of important cognitive areas, Autobiographical Memory Interview (AMI; Kopelman, Wilson & Baddeley, 1990; Appendix K) to measure recall of personal facts and specific events across the lifespan and the Adult Memory and Information Processing Battery (AMIPB) word list (Coughlan & Hollows, 1985; Appendix L) to assess long term verbal memory.

3.3.4. Assessment of ALF

For the purpose of this study, the presence of ALF was confirmed if participants recalled seven words or less from a total of 15 words from the AMIPB following a one week interval (i.e. performance fell within one standard deviation of the patient sample reported by Butler et al. (2007)). The list was presented orally over a minimum of five and a maximum of 10 trials until the participant attained at least 87% accuracy at free recall (i.e. learned at least 13 words). To avoid rehearsal, participants were not informed that they would be asked to recall the list later, rather it was explained that the researcher was assessing the number of trials it took for participants to learn the list. Seven days later, participants were asked to recall the word list by telephone.

Three out of eight participants did not demonstrate ALF i.e. they recalled eight or more words after a one week delay. One participant who did not demonstrate ALF was included as a control (Case1) to assess the impact of the intervention in an individual who complained of poor autobiographical memory but did not demonstrate ALF. The remaining two participants who did not demonstrate ALF were excluded from the study. Six participants were invited to attend the clinic to receive intervention.

3.3.5. Participant characteristics

One male and five females of ages ranging from 30 - 59 years took part in the study. Two participants were in paid employment. The participants' performances on neuropsychological tests are presented in Table 1 overleaf.

Table 1: Performance of participants on neuropsychological test batteries

| TEST | CASE 1 JO | CASE 2 AD | CASE 3 EV | CASE 4 KC | CASE 5 AL | CASE 6 SU |
|--------------------------------|--------------|--------------|--------------|--------------|--------------|--------------|
| AMIPB | | | | | | |
| No. trials for learning | 5 | 10 | 8 | 9 | 8 | 7 |
| Total words recalled | 9 | 0 | 3 | 1 | 5 | 7 |
| Retention % | 60 | 0 | 20 | 7 | 30 | 47 |
| WTAR Raw score | 42 | 26 | 38 | 43 | 43 | 41 |
| Estimated FSIQ | 110 | 86 | 104 | 109 | 109 | 108 |
| AMI Personal semantic | | | | | | |
| Childhood | 17 | 14 | 19 | 17.5 | 20 | 20.5 |
| Early adult life | 17.5 | 10.5 | 19.5 | 15 | 19.5 | 18.5 |
| Recent life | 21 | 15 | 15.5 | 18 | 14.5 | 18 |
| AMI Autobiog. Incidents | | | | | | |
| Childhood | 7 | 5 | 5 | 4 | 6.5 | 8 |
| Early adult life | 9 | 2 | 4 | 6 | 6 | 2 |
| Recent life | 8 | 0 | 3 | 7 | 6 | 8 |
| RBANS | Index score | | | | | |
| Immediate Memory | 129 | 83 | 97 | 106 | 100 | 100 |
| Visuospatial | 116 | 75 | 87 | 96 | 96 | 105 |
| Language | 97 | 74 | 103 | 102 | 97 | 116 |
| Attention | 79 | 46 | 109 | 103 | 79 | 91 |
| Delayed Memory | 98 | 52 | 100 | 101 | 99 | 97 |

| | | | | | | |
|--------------|-----|----|----|-----|----|-----|
| Total | 104 | 56 | 98 | 101 | 91 | 101 |
|--------------|-----|----|----|-----|----|-----|

3.4. Materials

3.4.1. Diary

Participants were provided with 28 A4 page per day diary record sheets (Appendix M) in a ring binder. Four participants decided to use their own diaries which were more portable. They followed the same structure as the diary record sheet to make daily entries. The following information was recorded daily: details of up to 3 activities, an importance rating for each event, and a description of emotions experienced during significant events. Researchers have found that felt emotion strengthens the subjective experience of recollection (Rimmele et al., 2011). However, it was not an aim of this study to investigate the relationships between felt emotion at the time of the event and later recall or the objective accuracy of memories. Such an analysis would require the researcher to keep duplicates of the participant's diary records. In this study, it was made clear to participants that their diaries were their own personal property.

3.4.2. Wearable automatic camera

Participants were provided with a digital automatic camera on a lanyard, a CD containing software and manual (Appendix N). All participants received a demonstration of how to use the device and review an album of images taken by the researcher. A laptop computer was available for participants to use, but all participants preferred to use their own personal computer. As with the diary, participants kept their own data recordings.

3.4.3. Primary outcome measures

The dependent variable was the number of personal events participants could freely recall over the past two weeks. To assess this a template for eliciting personal memories via thematic cueing was implemented (Kemp et al., 2007). The researcher developed a form to record participant's memories for recent personal experiences (Appendix O). The researcher completed the record by asking the participant 'what did you do yesterday?' followed by 'what did you do the day before yesterday?' and so forth for the preceding two weeks. A fortnightly interval was selected to capture the forgetting that participants demonstrated after one week. Recall for events experienced in the previous two weeks was assessed every two weeks throughout the study. The events discussed were selected by the participants, based on what they chose to tell the researcher.

A novel method of assessing the subjective quality of elicited autobiographical memories by eliciting vividness ratings has been reported (Kemp et al, 2007). Using this as a template, an idiographic measure of subjective vividness was included on the record form. Participants were asked to assign a memory vividness rating, on a scale of zero to ten, for their daily recollections.

3.4.4. Long term evaluation

In order to assess the long term effects of rehearsing memories recorded using a diary or camera, one salient personal event (e.g. a birthday, family outing) from

each intervention phase was selected to discuss in more depth. One method for doing this, outlined by Berry et al. (2007) expresses recall as a percentage calculated by the number of themes recalled from an event compared to the number of themes that actually occurred. An example given is for a trip to hospital: “Drive to East Cowes, walk to ferry, ferry to Southampton, taxi to hospital, taxi back to shopping centre, shopping, light lunch, walk to ferry, walk to car, drive home” (Berry et al., 2007). In this example, if the client remembered 7 out of 10 key events, they achieved a score of 70%. This procedure was followed to assess long term recall for a salient event that occurred during each intervention period at a one month follow up appointment. A template was developed to record participants’ responses to questions e.g. Do you remember what happened on your birthday? (Appendix P).

3.4.5. Pre and post intervention outcome measures

Participants completed the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983, Appendix Q) and the Quality of Life in Epilepsy-31 (QOLIE-31, Cramer et al., 1998, Appendix R) during the initial consultation. These measures were also administered at the end of each intervention phase. The HADS is a self-report measure of anxiety and depression developed for use in a hospital out-patient setting. This scale has good internal consistency in people with epilepsy and has been used as both a continuous and categoric measure in seizure clinics (Panelli et al., 2007). The QOLIE-31 is a 31-item questionnaire developed to assess health-related quality of life in people with epilepsy (Cramer et al., 1998). The questionnaire contains 7 subscales that focus on specific areas of concern for

people with epilepsy: seizure worry, overall QOL, emotional well-being, energy-fatigue, cognitive functioning, medication effects and social functioning. Test-retest data demonstrates good reliability (range $r = 0.64-0.85$).

3.5 Procedure

Condition A was a repeated baseline of the total number of personal events (NPE) recalled without use of a memory aid. The first baseline was taken at the initial appointment. One week later participants were asked to recall items from AMIPB word list to confirm the presence of ALF. Participants were invited back to clinic the following week to administer the second baseline NPE measure and start the first intervention (diary or camera).

Condition B was the first intervention. Three individuals received the camera first and three individuals received the diary. The memory aids were used for four weeks. Between weeks 7 and 11, following completion of the first intervention, no clinic appointments were made to build in a third baseline. This was taken at week 11, when participants returned to clinic to receive the second intervention.

Condition C was the second intervention. The interventions were crossed over in the third phase of the study so that those who received the diary as their initial memory aid were provided with the camera and vice versa. Long term recall of an important event recorded with each memory aid (diary or camera), was taken four weeks after the intervention was terminated. Table 2 (overleaf) outlines the schedule for the assessments used in the study. Participants were met every two weeks to test their recently acquired memories for preceding two weeks.

Table 2: Summary of measures administered over time

| Phase | Condition A Baseline | | Condition B First intervention Diary or Camera | | | Condition A No intervention | Condition C Second intervention Diary or Camera | | | Study end |
|---------|---|---------------------------|--|-----|----------------------|---|---|---|----------------------|--|
| Week | 1 | 2 | 3 | 5 | 7 | 9 | 11 | 13 | 15 | 19 |
| Measure | NPE AMI RBANS WTAR AMIPB HADS QOLIE | AMIPB 1 week Recall | NPE | NPE | NPE HADS QOLIE | No measures | NPE | NPE <i>1 month Follow up Condition B</i> | NPE HADS QOLIE | 1 month Follow up Condition C |

NPE= Number of personal events recalled, AMI= Autobiographical Memory Inventory, RBANS= Repeatable Battery of Neuropsychological Status, WTAR= Weschler Test of Adult Reading, AMIPB = Adult Memory and Information Processing Battery, HADS= Hospital Anxiety and Depression Scale, QOLIE = Quality of Life in Epilepsy Inventory-31

3.6. Intervention

3.6.1. Diary Intervention

Instructions for using the diary emphasised that participants should rehearse the information five times every day (Appendix S). This included the information in the new diary record and information in the records for the preceding weeks. Particular attention was paid to important events highlighted in the diary. Participants were asked to bring their diaries to appointments to check that they were being completed appropriately and that salient days were marked.

3.6.2. Camera Intervention

Clients were asked to wear the camera at interesting or non-routine events (Appendix T). At the end of each day participants were instructed to upload the images on to a computer and view their 'albums' five times. During this phase of the study technical support was available from the manufacturer.

4. Results

Each participant is presented individually with relevant background information. The daily number of personal events recalled (ranging from zero to three) was aggregated for each week and presented as a graph for visual interpretation. Subjective vividness ratings for memories recalled for each day in the preceding two weeks is presented so that fluctuations in the baseline and intervention phases can be observed. Statistical analysis was conducted

on daily number of personal events and memory vividness. Finally a brief account of each participant's evaluation of the memory aids is given.

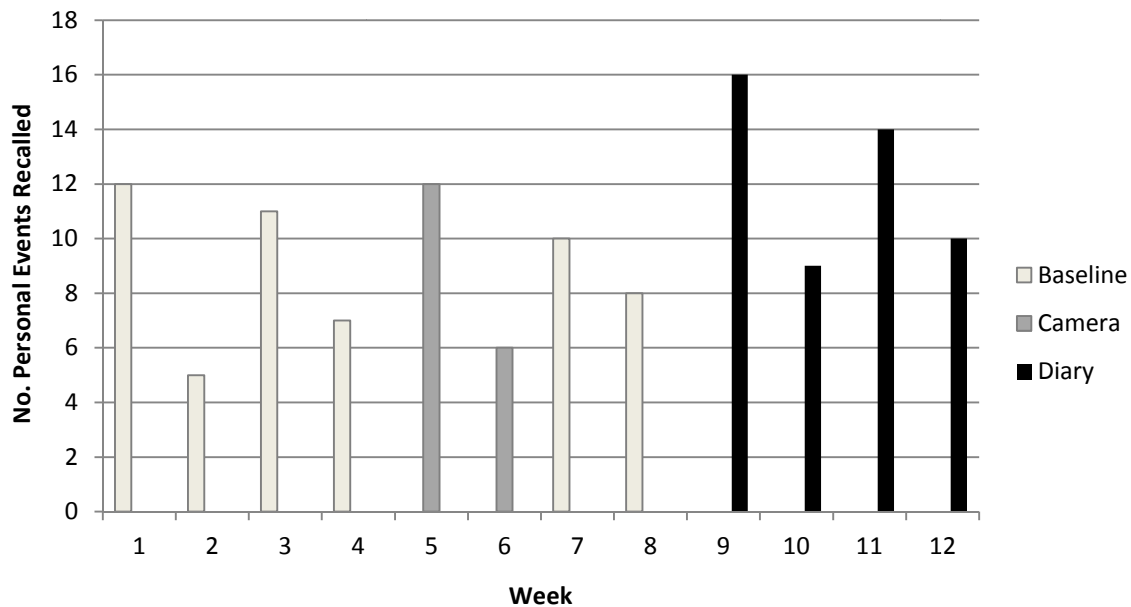
4.1. Case 1 (Control participant)

J.O. is a 44 year old female who had a right temporal lobectomy for refractory epilepsy in 2005. Although the surgery was successful in reducing her seizures, she still experiences around one seizure a month. J.O. works full time and lives independently. Assessment on WTAR estimated her general intelligence level to be in the superior range. Her performance on RBANS was in the superior range for visuospatial skills and immediate memory, average range for language and delayed memory and below average for attention. J.O. reported that she experiences difficulty with her autobiographical memory but her retention of 60% of word list indicated that she did not experience ALF. No abnormality in autobiographical memory was found on the AMI. J.O. was recruited to act as a control in the study to assess the effectiveness of the interventions in an individual who experienced autobiographical memory problems but not ALF. J.O. used the camera twice, but reported that she felt uncomfortable using the device and was reluctant to use it again. The camera intervention was discontinued after two weeks.

4.1.1. Visual analysis

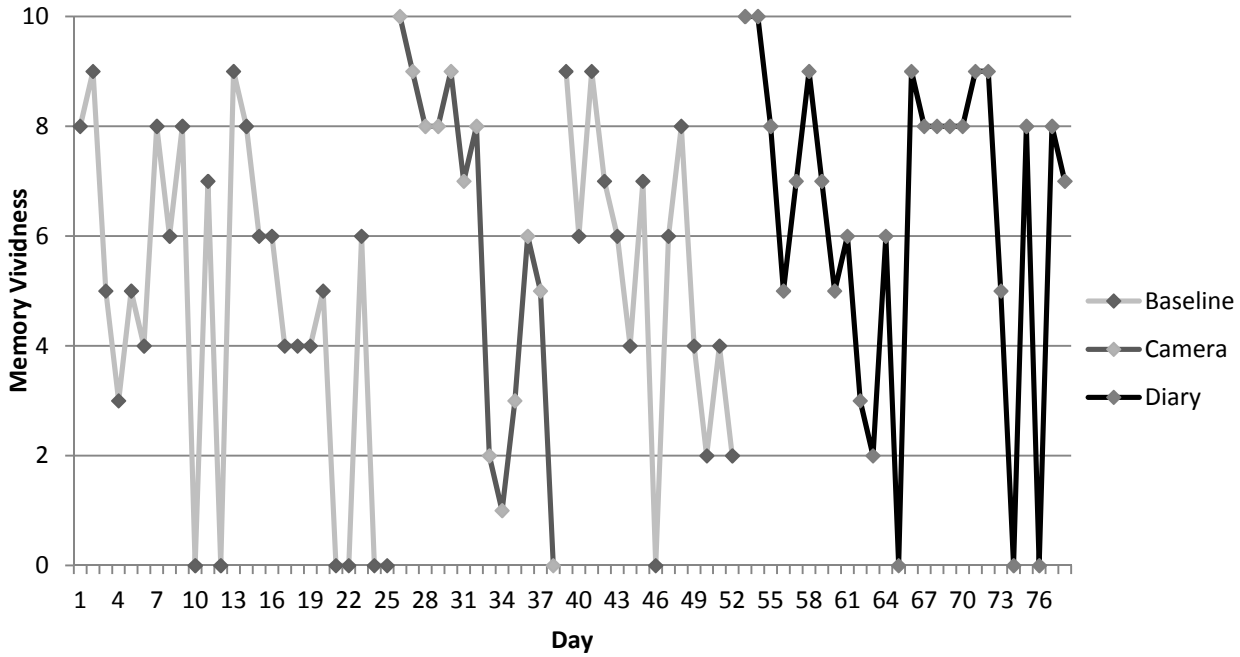
The total number of personal events recalled each week by J.O. is presented in figure 1.

Figure 1. Weekly number of personal events recalled by J.O.



The bars represent the total number of events recalled for that week. Recall was assessed in weeks one, three, five, seven, nine and eleven for the preceding two weeks. Even number weeks represent the week prior to recall i.e. the week in which memories fade in ALF patients. Visual analysis indicates that a consistent and stable pattern of total number of events recalled every fortnight was yielded in the baseline. As expected J.O. could recall more events in the present week than from the previous. The graph indicates improvement of recall for personal events during the diary phase. J.O. experienced one seizure in week 12 of the study. Figure 2 illustrates a plot of the daily vividness scores for data yielded in the baseline and diary phases.

Figure 2: Daily vividness ratings for J.O.'s personal memories



Daily vividness scores fluctuated markedly ranging between zero and nine during the baseline and zero and ten for the memory aid conditions. The graph illustrates that vividness ratings were generally higher in the diary phase.

4.1.2. Statistical analysis

Due to the effects of serial dependency, it was not appropriate to autocorrelate the data. Even though J.O. did not demonstrate ALF, memories for events that occurred in days immediately prior to recall were preserved relative memories for events that occurred in the previous week. Since the data set for the camera intervention was incomplete due to the intervention being terminated early, this was excluded from the statistical analysis. Descriptive statistics for daily number of events recalled are presented in Table 3. ‘N’ represents the number of days in each phase of the study.

Table 3: Summary statistics for daily number of personal events recalled by J.O.

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|-----|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 40 | 0 | 3 | 0.75 | 1.0 | 2.0 |
| Diary | 25 | 0 | 3 | 1.0 | 2.0 | 3.0 |

A Wilcoxon signed rank test was conducted between the baseline and diary totals for the number of personal events recalled. i.e. yesterday in the baseline recall was paired with yesterday in the intervention phase. The day before yesterday (2 days ago) was paired with recall for 2 days ago for the intervention phase and so forth. The median daily number of events recalled was significantly greater in the diary phase (Mdn =2) of the study than at baseline (Mdn =1), $Z = -2.638, p = .008$.

Descriptive statistics for daily vividness ratings are presented in Table 4.

Table 4: Summary statistics for J.O.'s memory vividness

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|------|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 40 | 0 | 9 | 0.0 | 4.5 | 6.25 |
| Diary | 25 | 0 | 10 | 5 | 7.5 | 8.25 |

A Wilcoxon signed rank test indicated that daily vividness ratings were significantly greater in the diary phase (Mdn = 7.5) than during the baseline (Mdn =4.5)

$Z = -2.545, p = 0.01$.

4.1.3. Long-term follow up

Recall for a significant event that occurred during diary phase was assessed four weeks later. J.O. had enjoyed a day walking, meeting other friends for a meal before going to a sporting event. She recalled all elements of the day (100%) compared with the researcher’s notes made one month earlier. Her subjective rating of memory vividness increased from six to seven over the four week interval.

4.1.4. Standardised outcome measures

The Reliable Change Indices (RCI) for the QOLIE-31 and HADS subscales were calculated using the Leeds Reliable Change Index Calculator (Agostinis et al., 2008) (Appendix U). Table 5 presents J.O.’s scores obtained on the standardized measures (HADS and QOLIE-31) pre and post each intervention.

Table 5: Questionnaire measures taken pre and post each intervention

| Measure | Baseline | Post Camera | Post Diary | RCI |
|--------------------------------|----------|-------------|------------|-------|
| QOLIE-31 Scale | | | | |
| Seizure worry | 81 | 70 | 95 | 32.72 |
| Overall quality of life | 78 | 60 | 83 | 23.35 |
| Emotional well-being | 72 | 72 | 80 | 22.03 |
| Energy/fatigue | 70 | 60 | 80 | 23.39 |
| Cognitive functioning | 83 | 85 | 94 | 24.43 |
| Medication effects | 83 | 72 | 72 | 39.68 |
| Social functioning | 46 | 53 | 80 | 35.73 |
| Overall Score | 71 | 67 | 84.6* | 11.96 |
| HADS | | | | |
| Anxiety | 4 | 2 | 1 | 5.2 |

| | | | | |
|-------------------|---|---|---|-----|
| Depression | 1 | 3 | 0 | 5.2 |
|-------------------|---|---|---|-----|

* denotes reliable clinical improvement

J.O.'s scores at baseline were above the mean of the general epilepsy population in line with her high level of social and occupational functioning. No clinically significant change was observed in her scores following the camera intervention. Improvement was noted on all domains of the QUOLIE-31 following the diary intervention except for medication effects. Clinically significant and reliable change, exceeding that which may be attributable to measurement error, was observed in her overall score which increased from 71 (T=55) at baseline to 84.6 (T=64) following the diary intervention. No observable difference was noted in her reported levels of anxiety or depression which were in the normal range during each phase of the study.

4.1.6. Anecdotal report

At the end of the study, J.O. reported that she used her diary all the time. She was used to recording information that she was prone to forgetting e.g. names but said she was now writing down her personal experiences in detail. She found it easy to incorporate into her life, developing a routine of writing her diary in the evening. She placed stickers in her diary to highlight important days and included mementos of things she had enjoyed e.g. cinema and theatre tickets. She found the diary prompted her memory with little effort. In contrast, she felt the camera was "intrusive". Feeling uncomfortable with having her own photograph taken, J.O. was reluctant to capture images of other people. She used the camera when she was entertaining her family in her home but did not wish to use the camera outside. J.O. acknowledged that she has a heightened awareness of consent and privacy due to her professional role. Having demonstrated that rehearsal enhanced both

the quality and quantity of personal memories in an individual who complained of autobiographical memory problems, the intervention was then offered to participants with ALF.

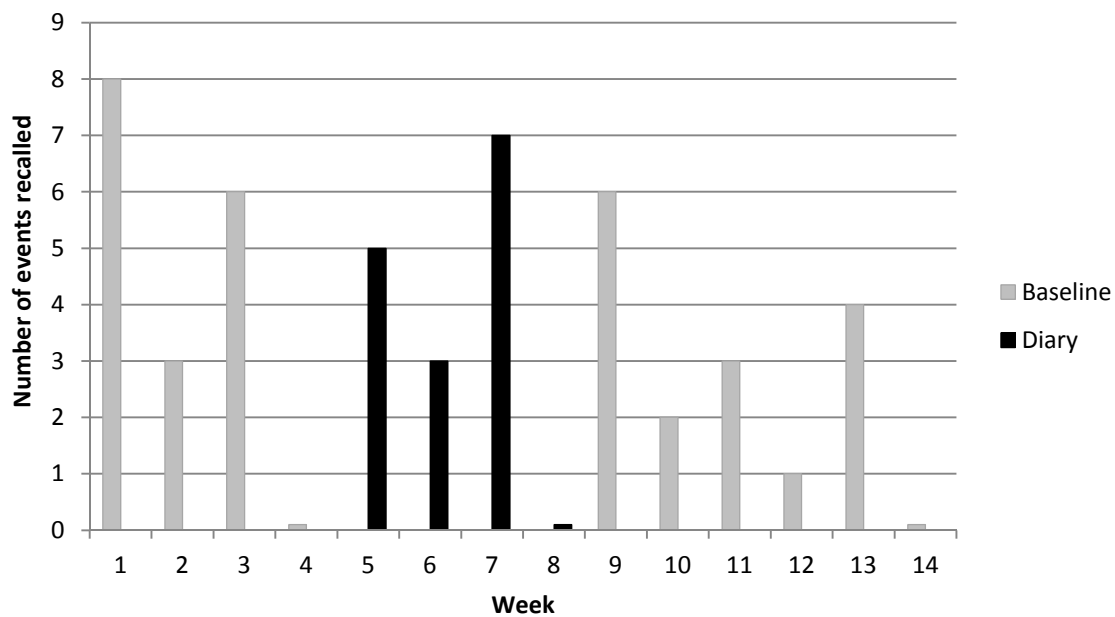
4.2. Case 2

A.D. is a 35 year old male with medically intractable TLE. In 2005, he was assessed for epilepsy surgery but intracranial EEG found that his seizures were of bilateral origin. He has frequent seizures which occasionally result in hospitalisation with status epilepticus. In 2010 he had a Vagus Nerve Stimulator implanted. He lives with his father, and has not worked since the onset of his epilepsy aged 24. He visits his local pub every night with his father, consuming 5 pints on a week day and more at weekends. He considers this intake to be moderate. The presence of ALF was confirmed as he could not recall any words from the list learned one week earlier. His descriptions of his forgetting were striking: he once forgot that a friend had died even though he had attended the funeral only one week before, he couldn't remember participating in a television show and he fails to recognize people that he sees on a regular basis, including the researcher. His scores on AMI were in the 'definitely abnormal' range for both semantic and autobiographical incidents and revealed a marked temporal gradient, whereby disruption of retrograde memory showed relative sparing of the most distant childhood memories. In addition to significant memory impairment, assessment on RBANS revealed that he experienced difficulties with attention and verbal fluency. A.D. declined to use the camera for social reasons. Data gathered during the 'camera' phase thus provided an extended baseline.

4.2.1. Visual analysis

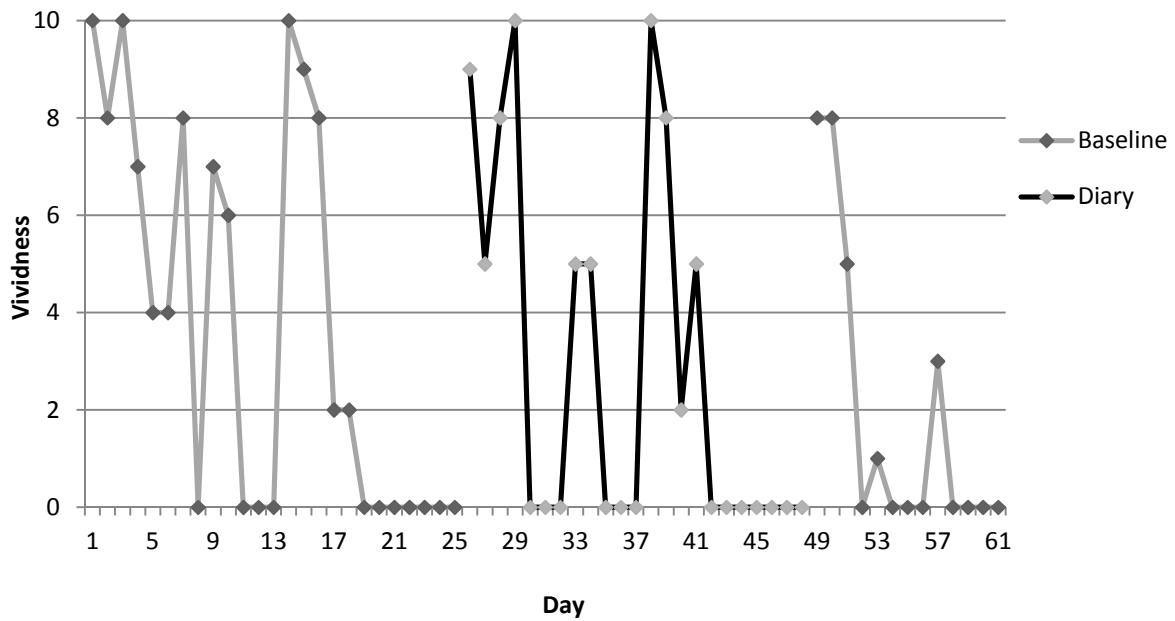
The total number of personal events recalled each week by A.D. is presented in Figure 3. A.D. experienced four seizures during the study (weeks 4, 8, 10, 11). He was hospitalized with status epilepticus for two days during week 11. Following this episode he experienced significant post-ictal amnesia. There was no observable difference between the number of events recalled during each phase of the study.

Figure 3: Weekly number of personal events recalled by A.D.



A.D. could remember very little from the week preceding recall (on three occasions remembering nothing at all for the whole week). Daily vividness scores yielded during the baseline and diary intervention are presented in Figure 4.

Figure 4: Daily vividness ratings for A.D.’s personal memories



A.D.'s subjective ratings of vividness fluctuated markedly. However, the pattern of vividness is similar in both conditions, being reasonable for five days prior to recall before falling to zero for events that occurred in the week prior to recall.

4.2.2. Statistical analysis

Descriptive statistics for number of events recalled by A.D. for each day in the fortnight prior to recall are presented in Table 6.

Table 6: Summary statistics for daily number of personal events recalled

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|-----|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 40 | 0 | 3 | 0.0 | 0.0 | 1.0 |
| Diary | 25 | 0 | 3 | 0.0 | 0.0 | 1.0 |

In both conditions his forgetting was marked. A Wilcoxon signed rank test performed on the data revealed no significant difference between the median daily number of events recalled in the diary phase (Mdn =0) to that of the baseline (Mdn =0), $Z = -0.494, p = 0.621$.

Descriptive statistics for daily vividness ratings are presented in Table 7.

Table 7: Summary statistics for A.D.'s ratings of memory vividness

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|-----|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 40 | 0 | 10 | 0.0 | 2.0 | 8.0 |
| Diary | 25 | 0 | 10 | 0.0 | 0.0 | 5.0 |

A Wilcoxon signed rank test indicated that there was no significant difference between subjective vividness ratings in the diary phase (Mdn = 0.0) than during the baseline (Mdn =2.0), $z = -1.4, p = 0.161$.

4.2.3. Long-term follow up

A.D. was asked to recall his birthday which occurred during diary phase, four weeks later. He reported that he had very poor memory of the day and rated his vividness of the event to be two, compared to the original rating of five given the week of the event. He was able to recall 60% of the elements that were recorded in the researcher's notes.

4.2.4. Standardised outcome measures

Table 8 presents A.D.'s scores obtained on the standardized measures (HADS and QOLIE-31) pre and post each intervention. A.D.'s scores on psychometric measures were consistent throughout the study. At baseline, his perception of his quality of life was around the mean of the clinical population ($T = 48$). Despite severe epilepsy, he enjoys an active social life. No

clinically significant change was observed in his quality of life or mood throughout the study as assessed by the QOLIE-31 and HADS.

Table 8: Questionnaire measures taken pre and post each intervention

| Measure | Baseline | Post diary | Study end | RCI |
|--------------------------------|----------|------------|-----------|-------|
| QOLIE-31 Scale | | | | |
| Seizure worry | 36.32 | 26.32 | 40.32 | 32.72 |
| Overall quality of life | 72.5 | 68 | 73 | 23.35 |
| Emotional well-being | 80 | 76 | 80 | 22.03 |
| Energy/fatigue | 80 | 65 | 75 | 23.39 |
| Cognitive functioning | 40 | 43 | 41 | 24.43 |
| Medication effects | 53 | 72 | 72 | 39.68 |
| Social functioning | 58 | 67 | 76 | 35.73 |
| Overall Score | 59.23 | 58.63 | 63.36 | 11.96 |
| HADS | | | | |
| Anxiety | 8 | 6 | 7 | 5.2 |
| Depression | 6 | 4 | 4 | 5.2 |

4.2.5. Anecdotal report

A.D. reported that he felt at ease with the diary intervention though he had difficulties with writing and spelling. Entries were sparse for each day e.g. 'went to football match'. He reported that he did not rehearse material as instructed. He did review his notes after a seizure, but this apparently did not cue recall in the post-ictal period. A.D. had been requested to keep a seizure diary for his epilepsy specialist nurse but had declined to do so. A.D. was happy to complete the diary for purposes of research but he did not use it once the study had finished. A.D. explained that he could not wear the camera as he felt he would be

humiliated by his friends, who teased him about his VNS. He could not use it in his local pub, as he was aware that drug users frequented the premises. He was counseled against drinking alcohol by his healthcare professionals, but he made an informed decision to continue with his lifestyle as this was his main source of social support.

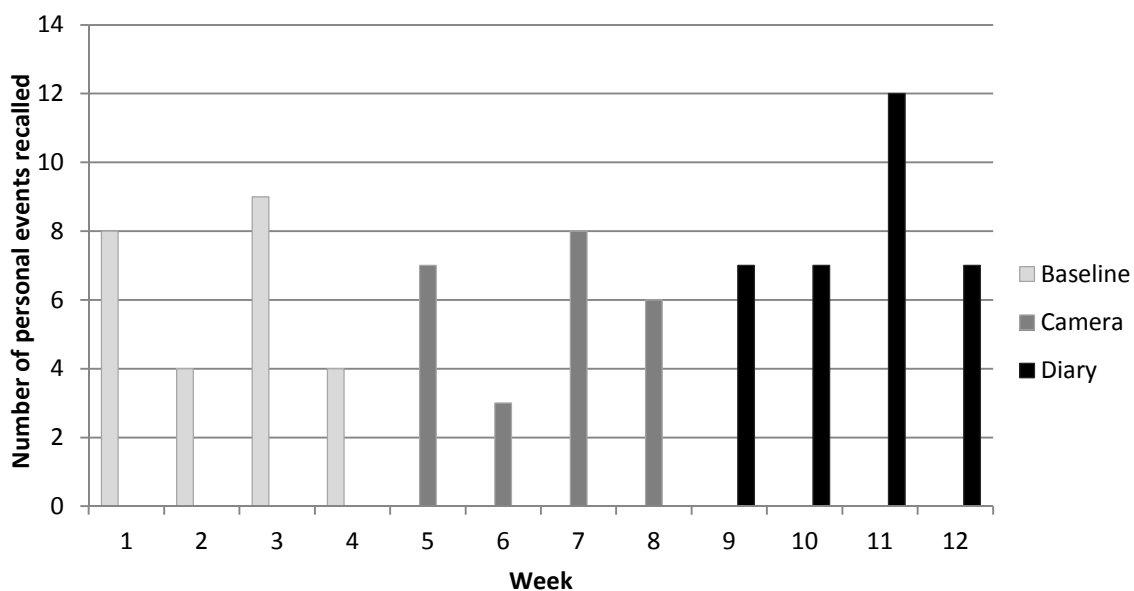
4.3. Case 3

E.V. a 49 year old female, was diagnosed with TLE when she was aged 35. She had a right temporal lobectomy in 2001, following which she apparently remained seizure free. She reported problems with forgetting conversations and significant aspects of her past, including her son's childhood. E.V. retained only three words after a one week delay from the AMIPB word list, showing a rapid rate of decay of her memories consistent with ALF. In addition she demonstrated a temporal gradient on the AMI for autobiographical incidents: her score was in the 'definitely abnormal' range for recent life and borderline for childhood. No other cognitive impairment was identified from assessment on RBANS and her estimated pre-morbid IQ was in the average range. On leaving school, she qualified as a nurse. She enjoyed her career, but stopped work when she was diagnosed with epilepsy. She works in a voluntary capacity for various charitable organisations and has an active social life. E.V. lives with her husband and son. She was being treated for depression and anxiety by her G.P. Following the camera intervention, E.V. reported symptoms of paranoia and disclosed suicidal ideation to the researcher. It was therefore decided not to conduct a second baseline. The diary intervention was commenced immediately and she was requested to consult her epilepsy specialist nurse for an urgent review.

4.3.1. Visual analysis

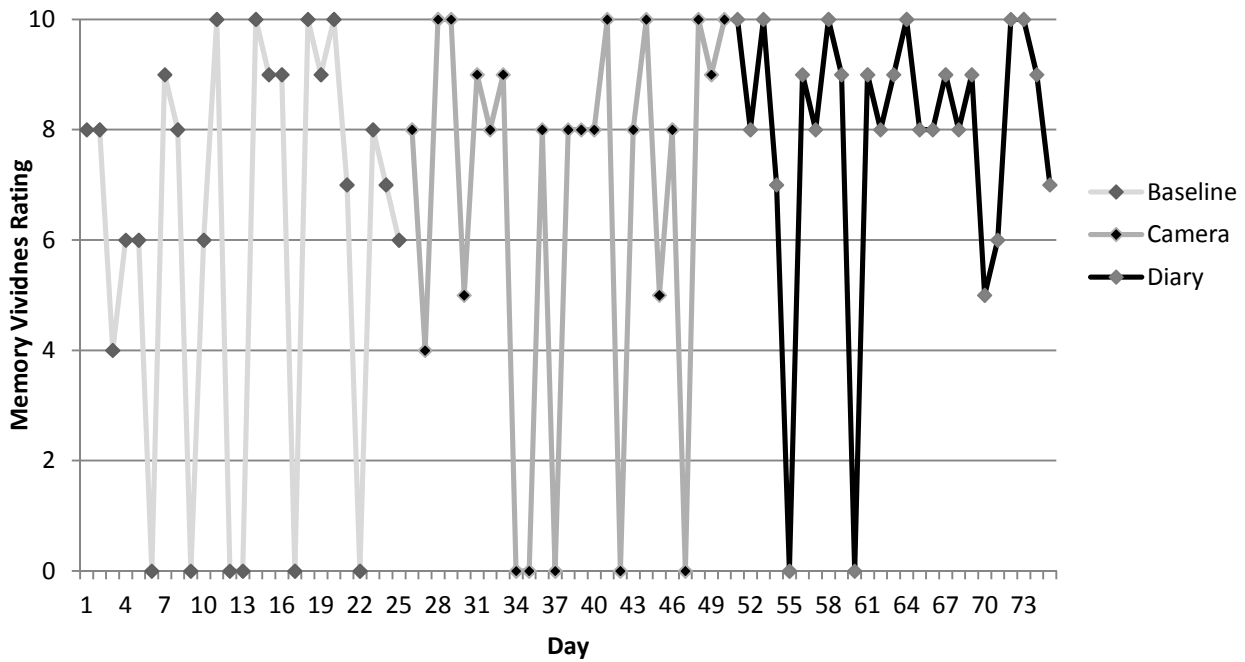
Figure 5 illustrates E.V.'s weekly total number of events recalled in each phase of the study. E.V.'s recall for personal events was similar throughout the baseline and camera phases of the study. The graph illustrates that when she was using a diary she could recall more events.

Figure 5: Weekly number of personal events recalled by E.V.



E.V.'s memory vividness scores are presented in Figure 6. Vividness ratings ranged from zero to 10 in all study conditions.

Figure 6: Daily vividness ratings for JB's personal memories



In the latter part of the diary condition E.V.'s vividness ratings did not fall below five. There were more days where ratings were zero in the baseline and camera conditions.

4.3.2. Statistical analysis

Descriptive statistics for number of events recalled for each day are presented in Table 9.

Table 9: Summary statistics for daily number of personal events recalled

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|-----|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 26 | 0 | 2 | 0.5 | 1.0 | 1.5 |
| Camera | 26 | 0 | 3 | 1.0 | 1.0 | 1.0 |
| Diary | 26 | 0 | 3 | 1.0 | 1.0 | 2.0 |

A Friedman test was performed on the data. There was no significant difference between the median daily number of events recalled in the diary (Mdn =1.0), camera (Mdn =1.0) and baseline phases (Mdn =1.0), $\chi^2 = 3.273, p = 0.195$

Descriptive statistics for daily vividness ratings are presented in Table 10.

Table 10: Summary statistics for E.V.'s memory vividness

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|-----|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 26 | 0 | 10 | 2.0 | 7.0 | 9.0 |
| Camera | 26 | 0 | 10 | 4.5 | 8.0 | 9.5 |
| Diary | 26 | 0 | 10 | 7.5 | 9.0 | 9.5 |

A Friedman Test conducted on the data found no significant differences between subjective memory vividness ratings yielded in the diary (Mdn = 9.0), camera (Mdn = 8.0) and baseline (Mdn =7.0) conditions ($\chi^2 = 1.788 (2), p = 0.534$).

4.3.3. Long-term follow up

E.V. was asked to recall a significant event she had recorded with the camera, one month after the event. She remembered seven out of eight elements (87.5%) originally recorded by the researcher. Her vividness for the event, nine the week the event occurred was eight one month later. E.V. said she was still able to visualise the images captured when she was walking down the street to visit her friend.

E.V. was able to provide a full account of a significant event recorded in her diary, one month later. She recounted 10 out of 10 elements (100%) in full detail, including aspects that were not actually recorded in her diary. E.V. said she had been rereading the day

frequently as it was important to her. Her vividness rating of 10 the week the event happened, remained at 10 four weeks later.

4.3.4 Standardised outcome measures

Table 11 presents E.V.'s scores obtained on the standardized measures (HADS and QOLIE-31) pre and post each intervention.

Table 11: Questionnaire measures taken pre and post each intervention

| Measure | Baseline | Post camera | Post diary | RCI |
|--------------------------------|----------|-------------|------------|-------|
| QOLIE-31 Scale | | | | |
| Seizure worry | 79 | 64 | 100* | 32.72 |
| Overall quality of life | 77.5 | 50 | 83 | 23.35 |
| Emotional well-being | 32 | 28 | 36 | 22.03 |
| Energy/fatigue | 30 | 20 | 50* | 23.39 |
| Cognitive functioning | 25.5 | 29 | 41 | 24.43 |
| Medication effects | 22 | 22.2 | 58 | 39.68 |
| Social functioning | 55 | 52.5 | 65 | 35.73 |
| Overall Score | 45.25 | 39 | 57.50* | 11.96 |
| HADS | | | | |
| Anxiety | 19 | 17 | 17 | 5.2 |
| Depression | 7 | 9 | 5 | 5.2 |

* denotes reliable clinical improvement

At baseline E.V.'s overall score was below the mean of the general epilepsy population (T = 39) for quality of life. E.V.'s scores on the item overall quality of life reduced following the camera intervention relative to the baseline. However, this change did not represent

significant deterioration. Following the diary intervention, E.V.'s scores increased across all items. This represented clinically significant and reliable improvement for seizure worry, overall quality life, energy and total QOLIE-31 score. Following the diary intervention, her perception of her quality of life was around the mean of the epilepsy population (T =46) indicating a more favourable quality of life. This improvement could not be attributed to a change in her emotional well-being. Despite pharmacological treatment, E.V. experienced clinically significant symptoms of anxiety throughout the study. No significant change was observed in her mood in different study phases as assessed by the HADS.

4.3.5. Anecdotal report

E.V. reported that she felt self conscious wearing the camera. She found that when she wore it on a shopping trip and to choir practice other people made comments. Whilst she was happy to disclose her epilepsy and memory problems to friends, she felt uncomfortable about discussing her difficulties with people she did not know and generally responded that she was using it for research purposes. E.V. felt the diary was more discreet and found writing things down at the end of day beneficial as it provided a goal for focusing on positive experiences. E.V. spontaneously started to use the diary when she was not feeling confident to challenge negative thoughts and cue pleasant memories. Following completion of the study E.V. informed the researcher that she had been diagnosed with inter-ictal psychosis and had commenced treatment with antipsychotic medication.

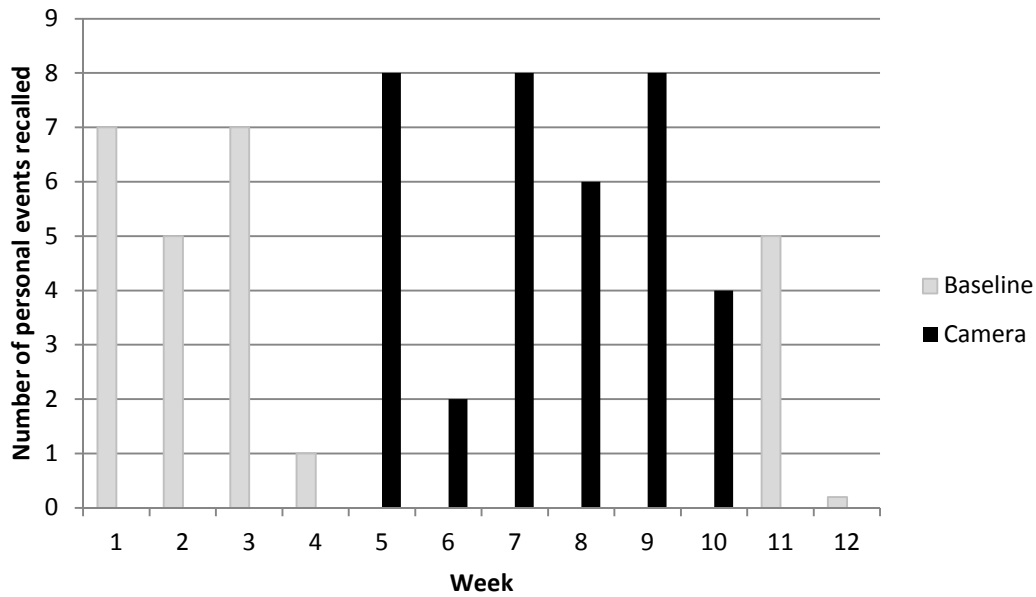
4.4. Case 4

K.C. is a 51 year old female with TLE of no clear focal origin. She has frequent seizures, which reportedly occur in clusters around every four weeks. She is currently studying for a degree in graphic design and lives with her husband and 11 year old son. She described severe autobiographical memory loss and topographical amnesia, particularly when recovering from a seizure. Her vivid descriptions included not recognising herself in the mirror, her own home or clothes or expecting to see her son as a toddler and being surprised to see an 11 year old boy. The presence of ALF was confirmed as she only retained 1 word from the list at one week delay. Her scores on the AMI were in the borderline range for both personal semantic and autobiographical incidents. Although her sensations were frightening at times, she also described that with a feeling of *jamais vu* 'things have a freshness'. K.C. has a complex history including two admissions to a psychiatric unit for treatment of post-ictal psychosis. K.C. was encouraged to try both interventions but she declined to use the diary.

4.4.1. Visual analysis

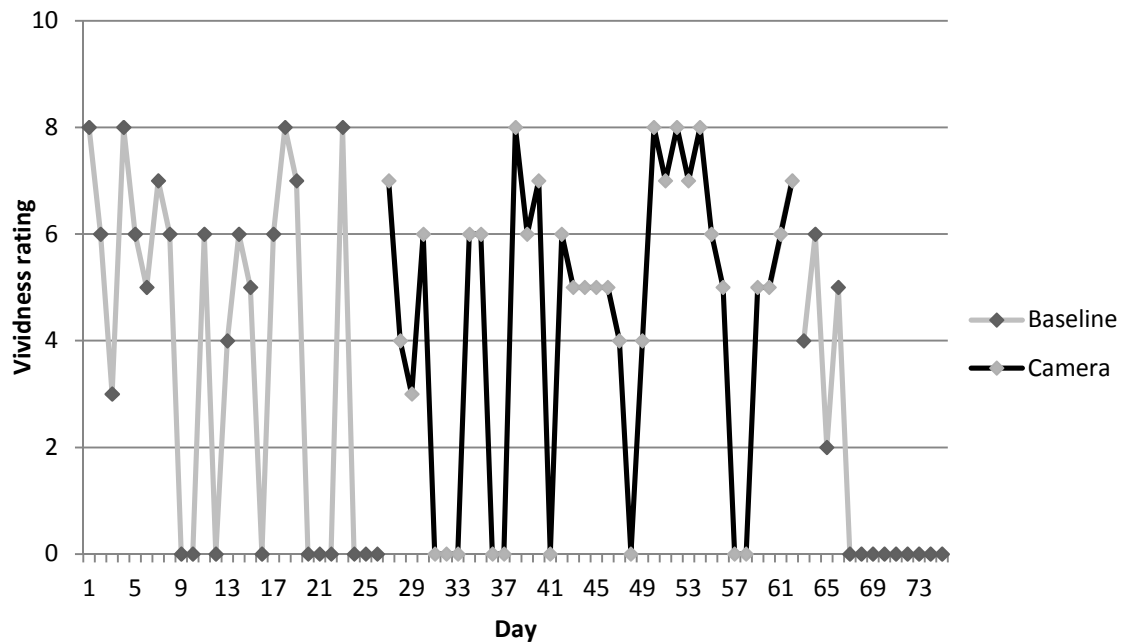
Figure 7 illustrates the total number of personal events recalled by K.C. across study phases. K.C. had six seizures throughout the study (during weeks 3, 4, 5, 8 and 12).

Figure 7: Weekly number of personal events recalled by K.C.



K.C. displayed a reasonable recall for events that occurred the week of the interview. However, in the baseline weeks she could recall little of what happened the week preceding recall. It is apparent that using the camera helped her retain more information about personal events that occurred more than one week previous. Subjective memory vividness scores yielded during the study are illustrated in Figure 8.

Figure 8: Daily vividness ratings for K.C.'s personal memories



Daily vividness ratings fluctuated between zero and eight in both study conditions. K.C.’s subjective vividness for recent memories in the third baseline was lower than 1st baseline and camera phase, as she reported her seizures were particularly severe. Visual analysis did not reveal clear differences between the different study phases.

4.4.2. Statistical Analysis

Descriptive statistics for number of events recalled for each day are presented in Table 12.

Table 12: Summary statistics for daily number of personal events recalled

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|-----|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 38 | 0 | 3 | 0.0 | 1.0 | 1.0 |
| Camera | 38 | 0 | 3 | 0.0 | 1.0 | 1.0 |

A Wilcoxon Signed Rank Test performed on the data confirmed there was no significant difference between the median daily number of events recalled in the baseline (Mdn =1.0)

and camera (Mdn =1.0) phase ($Z = 1.255, p =0.210$). Descriptive statistics for daily vividness ratings are presented in Table 13.

Table 13: Summary statistics for K.C.'s memory vividness

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|------|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 38 | 0 | 8 | 0.0 | 0.0 | 5.0 |
| Camera | 38 | 0 | 8 | 0.0 | 5.0 | 6.25 |

A Wilcoxon signed rank test confirmed that the difference between subjective vividness ratings yielded in the baseline (Mdn = 0.0), and camera phases (Mdn = 5.0) was not significant, $z=-1.625, p=0.104$.

4.4.3. Long-term follow up

K.C. was asked to recall a trip she had taken with her husband on a motorbike, recorded with the camera, after a one month delay. She remembered all elements (100%) that were originally recorded by the researcher. Her vividness for the event, rated seven the week the event occurred, remained at seven one month later.

4.4.4. Standardised outcome measures

Table 14 presents K.C.'s scores obtained on the standardized measures (HADS and QOLIE-31) pre and post the camera intervention.

Table 8: Questionnaire measures taken pre and post intervention

| Measure | Baseline | Post camera | RCI |
|---------|----------|-------------|-----|
| | | | |

| | | | |
|--------------------------------|-------|-------|-------|
| QOLIE-31 Scale | | | |
| Seizure worry | 60 | 69.34 | 32.72 |
| Overall quality of life | 67.5 | 50 | 42.50 |
| Emotional well-being | 56 | 56 | 22.03 |
| Energy/fatigue | 55 | 50 | 23.39 |
| Cognitive functioning | 37.50 | 57.21 | 24.43 |
| Medication effects | 0 | 25 | 39.68 |
| Social functioning | 65 | 61 | 35.73 |
| Overall Score | 53 | 55 | 11.96 |
| HADS | | | |
| Anxiety | 14 | 12 | 5.2 |
| Depression | 2 | 2 | 5.2 |

K.C.'s scores on the QOLIE-31 and HADS did not alter significantly following memory aid intervention. It is notable that she reported symptoms of anxiety that were of clinical significance. As indicated by her very low score on medication effects, she experienced considerable anxiety regarding her pharmacotherapy, which impacted adversely on her compliance with medical treatment. Using the camera had a beneficial effect on her perceived cognitive functioning, but the increase in her score on these items did not exceed the reliable change index.

4.4.5. Anecdotal report

K.C. reported that she hated writing and that she had never been able to keep written records even for her university course. She described the camera as 'brilliant' and felt that it wasn't intrusive. She found reviewing the images therapeutic and described this process as feeling like a 'brain massage'. She considered the recordings to have an ethereal quality, due to the lack of sound. Following a seizure, she felt as if she had to do everything again for the

first time and used her recordings to refamiliarise herself with her routines e.g. of her train journey to the university. K.C. found that others did enquire about the device but in contrast to E.V., she was pleased when this happened as it allowed her to talk about her epilepsy and bring up a difficult subject. K.C. used the camera regularly to capture moments such as birthday celebrations, trips to seaside and meetings with fellow artists. She put it on a shelf in the kitchen when her family visited and on another occasion asked someone else to wear it so that she could see herself in the images. However, K.C. did not rehearse the images taken with the camera; rather she used the device to store pictures of her experiences. In this sense she was creating a digital back up rather than consolidating her own memories.

4.5. Case 5

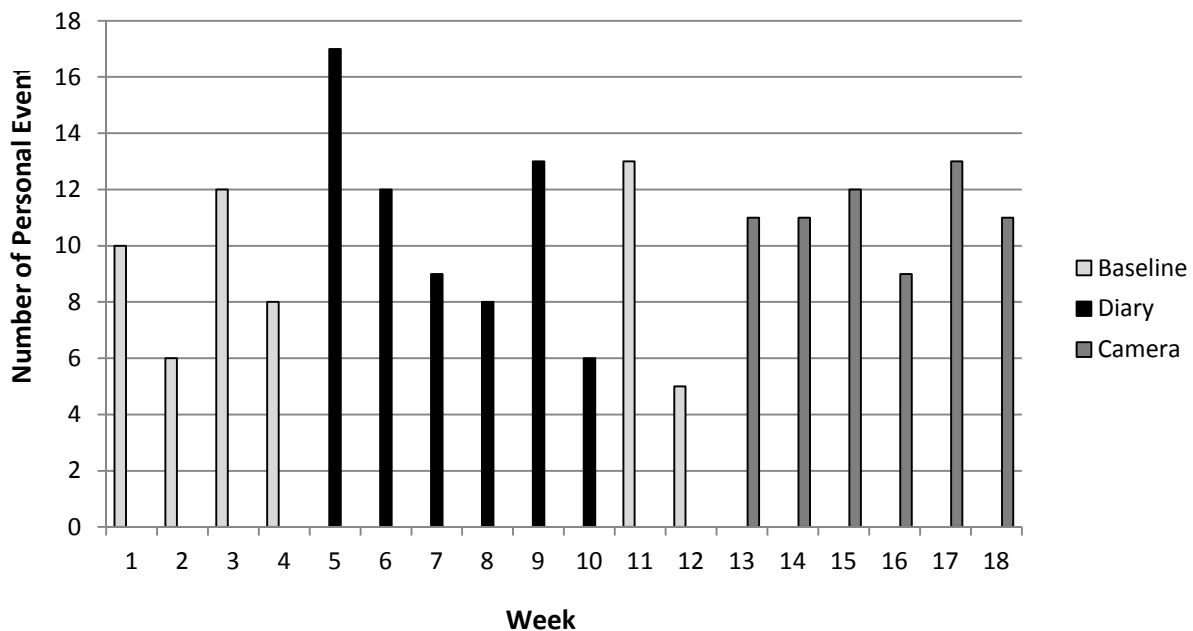
A.L., a 59 year old female of French origin, was diagnosed with TLE in 2001. She reported that her memory difficulties were of recent onset and noticed in the last year she frequently forgot conversations she had with others. Assessment using the RBANS found no impairment in memory, visuospatial skills or language. However, her scores for attention, were relatively poor placing her at the 8th percentile. She described incidents such as putting petrol in her diesel car. Her performance on the AMI produced a temporal gradient for both semantic and autobiographical incidents, with relative sparing of the most distant memories. She retained only five words from the list of 15 learned one week earlier. Her forgetting caused her considerable anxiety, since she worked as a foreign language teacher and translator. She lives with her husband and has two adult children. At study enrolment A.L.'s seizures were apparently well controlled. However, she reported that she had an

'absence' attack whilst on holiday and recognised this as the first seizure she had in two years.

4.5.1. Visual analysis

Figure 8 illustrates the number of personal events that A.L. recalled during the different study phases.

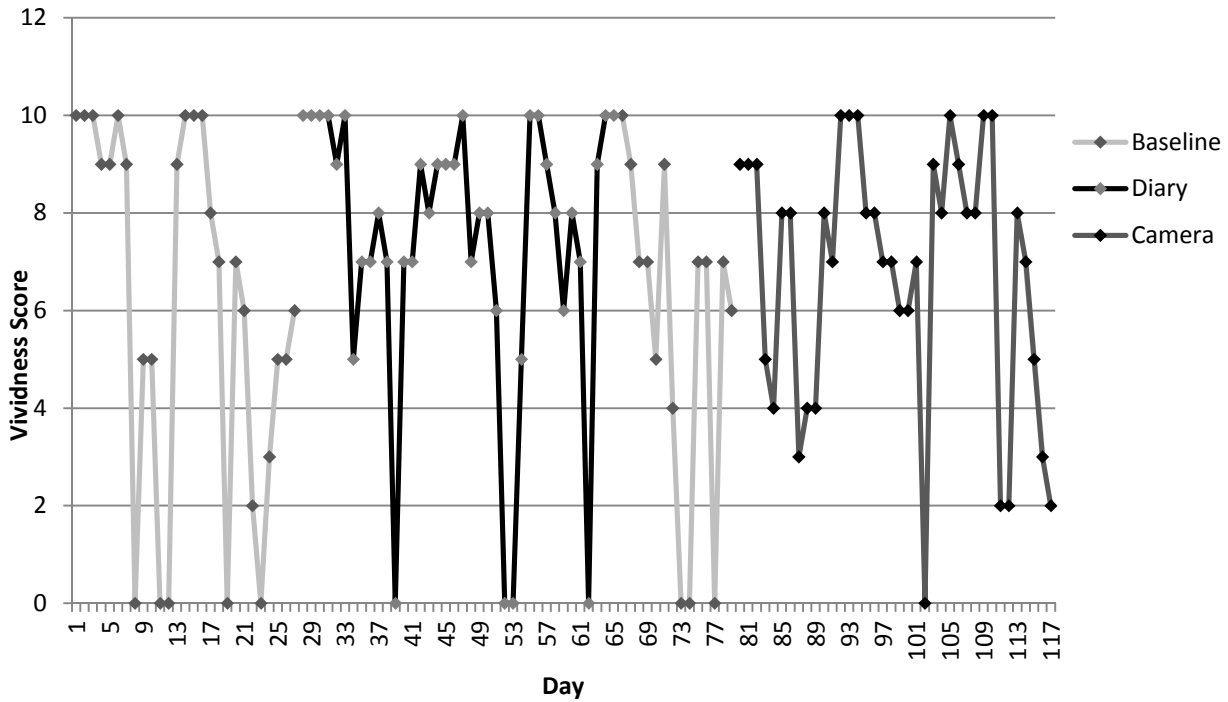
Figure 8: Number of personal events recalled by A.L. across study phases



The graph illustrates that the number of events recalled increased during the initial application of the diary relative to the baseline. However, this fell to baseline levels in subsequent weeks. It is notable that during the camera phase of the study the number of events recalled for the week previous was as good as recall for events in the current week. Figure 10 illustrates A.L.'s subjective vividness ratings in the different phases of the study. A.L.'s subjective vividness ranged from 0 to 10 in all phases of the study. The graph depicts

that there were fewer zero ratings in the camera phase of the study than in the baseline and diary phase.

Figure 10: Daily vividness ratings for A.L.’s personal memories



4.5.2. Statistical analysis

Descriptive statistics for number of events recalled by A.L. for each day are presented in Table 15.

Table 15: Summary statistics for daily number of personal events recalled

| Phase | N | Range | | Quartiles | | |
|-------|---|-------|-----|-----------|----|----|
| | | Min | Max | 25 | 50 | 75 |
| | | | | | | |

| | | | | | | |
|----------|----|---|---|-----|-----|-----|
| Baseline | 26 | 0 | 3 | 1.0 | 1.0 | 2.0 |
| Diary | 26 | 0 | 3 | 1.0 | 2.0 | 2.0 |
| Camera | 26 | 0 | 3 | 1.0 | 2.0 | 2.0 |

A Friedman test performed on the data found no significant difference between the median daily number of events recalled in the diary (Mdn =2.0), camera (Mdn =2.0) and baseline (Mdn =1.0) phases, $\chi^2 = 3.722, p = 0.155$. Descriptive statistics for daily vividness ratings are presented in Table 16.

Table 16: Summary statistics for memory vividness across study phases

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|------|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 26 | 0 | 10 | 4.75 | 7.0 | 9.0 |
| Diary | 26 | 0 | 10 | 7.0 | 8.0 | 10.0 |
| Camera | 26 | 0 | 10 | 4.75 | 8.0 | 9.0 |

The Friedman Test demonstrated a significant difference in subjective vividness ratings yielded in the diary (Mdn = 8.0), camera (Mdn = 8.0) and baseline (Mdn = 7.0) conditions ($\chi^2 = 9.232, df 2.0, p = 0.01$). There are no post-hoc tests following on from the Friedman, so pairwise comparisons were made between the diary - baseline and camera - baseline phases of the study. A Wilcoxon signed rank test revealed that the diary significantly increased daily vividness ratings relative to baseline ($z = -2.434, p = 0.015$) but that the camera did not ($z = -0.480, p = 0.63$).

4.5.3. Long-term follow up

A.L. was able to remember all elements (100%) of a significant event that occurred one month previously that had been recorded in her diary. Her vividness for the event was nine the week the event occurred and seven one month later. A.L. was able to recall very specific details including what she and her friend were wearing, what they discussed together and the route taken when she went on a country walk.

One month after the event, A.L. was able to describe a day that was recorded by her camera. She had used the camera on a long journey she took in Argentina. However, she found that the camera recorded many images that were not important to her, such as the interior of the train. She had used her own camera to take higher resolution images of moments and scenery that she wished to remember.

4.5.4. Standardised outcome measures

Table 17 presents A.L.'s scores obtained on the standardized measures (HADS and QOLIE-31) pre and post each intervention. A.L.'s scores on the QOLIE-31 were consistent following each study phase. Her overall quality of life score was above the mean of the general epilepsy population (T = 67-68) reflecting her engagement in multiple family, social and work activities. Her anxiety levels remained above clinical cut off throughout the duration of the study. A.L. recognized that her mood was labile and attributed her symptoms to her antiepileptic medication. At the end of the study she consulted her GP who referred her to a specialist epilepsy centre for further management.

Table 17: Questionnaire measures taken pre and post each intervention

| Measure | Baseline | Post diary | Post camera | RCI |
|----------------------|----------|------------|-------------|-------|
| QOLIE-31 Scale | | | | |
| Seizure worry | 96 | 80 | 93 | 32.72 |

| | | | | |
|--------------------------------|----|----|----|-------|
| Overall quality of life | 65 | 60 | 53 | 23.35 |
| Emotional well-being | 60 | 60 | 40 | 22.03 |
| Energy/fatigue | 40 | 55 | 45 | 23.39 |
| Cognitive functioning | 20 | 23 | 42 | 24.43 |
| Medication effects | 36 | 31 | 58 | 39.68 |
| Social functioning | 77 | 81 | 76 | 35.73 |
| Overall Score | 53 | 55 | 55 | 11.96 |
| HADS | | | | |
| Anxiety | 12 | 14 | 12 | 5.2 |
| Depression | 5 | 6 | 7 | 5.2 |

4.5.5. Anecdotal report

A.L. reported that her husband had commented that her memory had improved when she was using the aids. She preferred to use the diary as she could not wear the camera when she was teaching. Her participation in the study was extended in order to give her the opportunity of using the device during school holidays. However, A.L. found that she was not at ease using the camera as she felt uncomfortable using a computer. She had difficulty installing the software and the camera went into a 'deep sleep' mode. She experienced some distress with these negative experiences which reduced her self esteem. She reported that her memories were more vivid for non routine events and felt these did not warrant recording. Although she took the camera when she travelled she rarely used it as she did not have her computer with her. At the follow up interview, one month after the study ended she had ceased using both aids.

4.6. Case 6

J.S. is a 30 year old female, newly diagnosed with TLE. She lives with her husband and two young children. She suffered complications during the birth of her eldest child in 2005, following which she was diagnosed with post traumatic stress disorder. She received counseling but continued to experience considerable anxiety concerning her health, which was exacerbated by her diagnosis of epilepsy. She complained of significant autobiographical memory problems including not being able to recall her honeymoon or her daughter's christening. When assessed using the AMI she was unable to recall incidents from early adulthood, including the years she spent studying at college.

4.6.1. Visual analysis

Figure 11 illustrates the number of personal events that J.S. recalled during the different study phases. Visual analysis reveals that J.S. remembered more events in the diary and camera phases of the study. However for week 6 she could only remember 2 events for the whole week. J.S.'s memory appeared to fluctuate over a 4 weekly cycle with less being remembered in the first two weeks compared to the last two weeks.

Figure 11: Weekly number of personal events recalled by J.S.

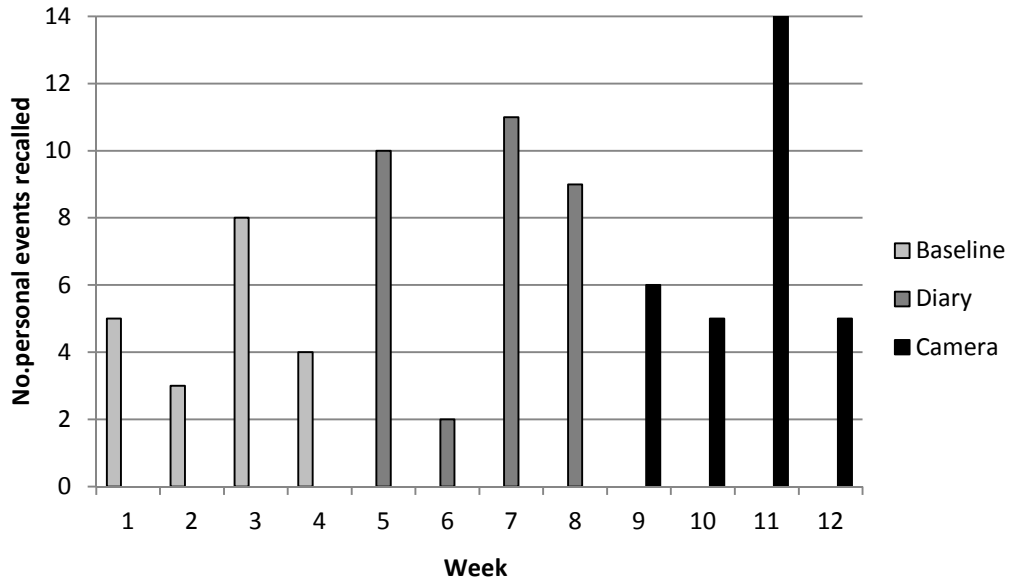
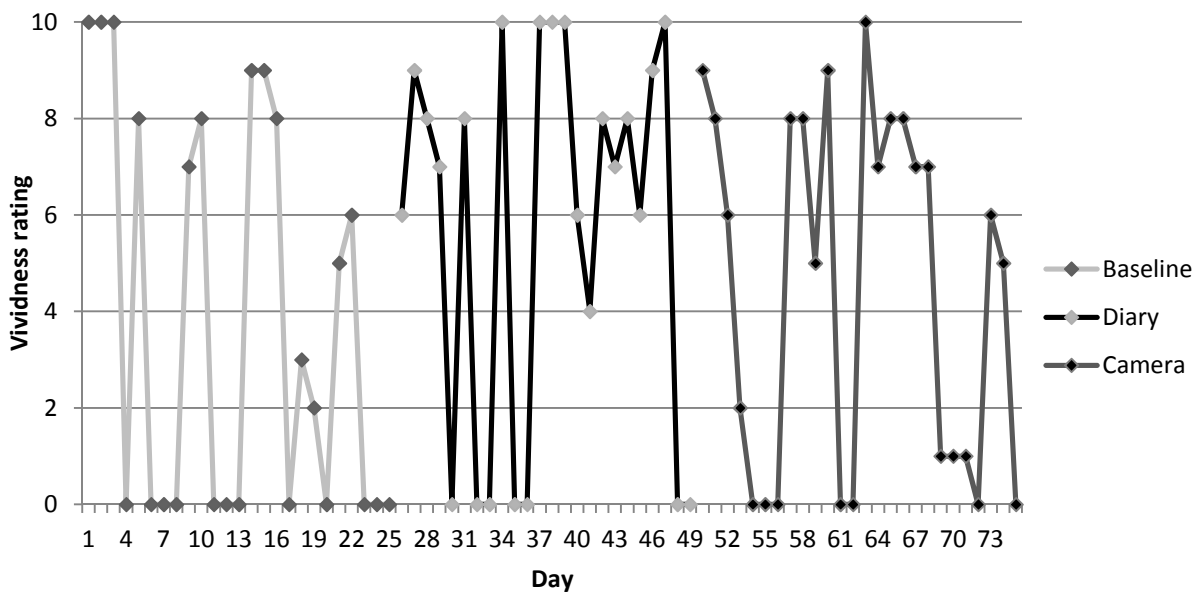


Figure 12 illustrates the daily vividness rating for her memories. J.S.'s subjective vividness fluctuated in all conditions from 0 to 10 for her personal experiences.

Figure 12: Daily vividness ratings for JT's personal memories



In the latter two weeks of the diary phase, her vividness ratings were above zero for all but two days of the fortnight recalled.

4.6.2. Statistical analysis

Table 18 presents summary statistics for the number of events recalled each day over a two week period.

Table 18: Summary statistics for daily number of personal events recalled

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|----|----|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 26 | 0 | 3 | 0 | 1 | 1 |
| Diary | 26 | 0 | 3 | 0 | 1 | 2 |
| Camera | 26 | 0 | 3 | 0 | 1 | 2 |

A Friedman test conducted on the data revealed a significant difference between the number of personal events recalled in the baseline (Mdn =1), diary (Mdn = 1) and camera phases of the study (Mdn =1), $\chi^2 = 5.945$, $p = 0.05$. A Wilcoxon signed rank test confirmed that the number of events recalled in the diary phase was significantly greater than in the baseline phase $z = -2.206$, $p = 0.027$. There was no significant difference between the number of events recalled in the camera phase of the study compared to baseline $z = -1.727$, $p = 0.084$. Summary statistics for daily vividness scores are presented in Table 19 .

Table 19: Summary statistics for J.S.'s memory vividness across study phases

| Phase | N | Range | | Quartiles | | |
|----------|----|-------|-----|-----------|-----|----|
| | | Min | Max | 25 | 50 | 75 |
| Baseline | 26 | 0 | 10 | 0 | 1.5 | 8 |
| Diary | 26 | 0 | 10 | 0 | 7 | 9 |
| Camera | 26 | 0 | 10 | 0 | 5.5 | 8 |

A Friedman test revealed no significant difference in J.S.'s subjective vividness ratings yielded in the baseline (Mdn = 1.5), diary (Mdn = 7) and camera (Mdn = 5.5) phases of the study $\chi^2 = 3.852, p=0.146$.

4.6.3. Long-term follow up

J.S. recorded details of her son's christening in her diary. She was keen to rehearse this information as she could not recall her daughter's christening. J.S. found that one month later she was still able to recall all key details (100%) of the day. However, in addition to the diary she had made up a photograph album. Her memory vividness rating for the event was nine the week of the event and eight one month later.

J.S. was able to remember all elements (100%) of a seaside trip recorded by the camera, one month later. J.S. was able to recall special moments she shared with her family including memories that made her laugh, such as when seagulls targeted their car. Her vividness rating for the event was eight the week the event occurred, and seven one month later.

4.6.4. Standardised outcome measures

Table 20 presents J.S.'s scores obtained on the standardized measures (HADS and QOLIE-31) pre and post each intervention.

Table 20: Questionnaire measures taken pre and post each intervention

| Measure | Baseline | Post diary | Post camera | RCI |
|--------------------------------|----------|------------|-------------|-------|
| QOLIE-31 Scale | | | | |
| Seizure worry | 73 | 83 | 100 | 32.72 |
| Overall quality of life | 65 | 83 | 95* | 23.35 |
| Emotional well-being | 32 | 64* | 72* | 22.03 |
| Energy/fatigue | 40 | 60 | 70* | 23.39 |
| Cognitive functioning | 13 | 42* | 59* | 24.43 |
| Medication effects | 0 | 41* | 53* | 39.68 |
| Social functioning | 0 | 54* | 18 | 35.73 |
| Overall Score | 28 | 59* | 62* | 11.96 |
| HADS | | | | |
| Anxiety | 10 | 7 | 8 | 5.2 |
| Depression | 5 | 3 | 4 | 5.2 |

*denotes reliable

clinical improvement

At baseline, J.S.'s perception of her quality of life was below the mean of the epilepsy population (T = 38) indicating the difficulty she had in coming to terms with her diagnosis. Using a diary increased J.S.'s quality of life across all domains. This improvement represented clinically significant and reliable change for emotional wellbeing, cognitive functioning, medication effects, social functioning and her overall score. Whilst some improvement could be attributed to better adjustment, her responses on the questions of cognitive functioning indicated that she experienced fewer memory failures. Further gains were made following intervention with the camera which also showed reliable improvement in energy and overall quality of life relative to baseline measurement. J.S.'s reported symptoms of anxiety were in the borderline range at baseline and these reduced following intervention so that she was no longer in the clinical range.

4.6.5. Anecdotal report

J.S. considered that she benefited from using both memory aids. However, she preferred to use the diary as it was more convenient. She elaborated that using the camera needed more planning to ensure it was charged in advance. She missed the opportunity of recording a surprise birthday party held for her by her family, as by not anticipating this special event, she had not worn the camera. However, spontaneous events could be written in her diary. She also felt it was inappropriate to use the camera for much of her daily routine which involved attending school and play groups with other children.

5. Discussion

The results of this study provide some support for the four hypotheses tested. One participant with ALF yielded a significant increase in the number of personal memories recalled following use of a diary. Another participant with ALF reported significantly higher subjective vividness ratings with the diary intervention. No significant gains in quantity or quality of personal memories were observed for participants when using the camera. However, all participants reported being able to retain memories that were important to them at one month follow up, after rehearsal of the diary or camera recordings had ceased.

In two individuals with ALF memory intervention was associated with a clinically significant and reliable improvement in their perceived quality of life. In one of these individuals this effect was observed despite her not achieving a significant increase in vividness or quality of recently acquired memories. In TLE patients self-reported memory, is an important predictor of quality of life, which correlates with performance on memory tests (Giovagnoli & Avanzini, 2000). Health related quality of life declines if memory declines as a result of

epilepsy surgery ([Langfitt et al., 2007](#)). This supports the assertion that compensating for memory problems is one of the best strategies for improving quality of life for people with memory impairment (Wilson, 2004). To our knowledge this is the only study to have demonstrated this effect in people with epilepsy.

Two participants (A.D. & K.C.) did not demonstrate significant gains in memory vividness, quantity or perceived quality of life. In addition to exhibiting profound ALF, both experienced frequent seizures. Unfortunately, A.D. was hospitalised during the diary intervention after experiencing status epilepticus. Prolonged complex partial status epilepticus causes severe episodic memory deficit (Jambaqué et al., 2006) which has been postulated to be permanent (Krumholz et al., 1995). However, epileptic amnesic syndrome is distinct from ALF which is an interictal memory disturbance. A.D. and K.C. experienced both epileptic amnesic attacks and ALF. These cases illustrate that even within a clinically distinct syndrome such as ALF, there is substantial heterogeneity in the population.

Both A.D. and K.C. reported that seizures prevented them from rehearsing recorded material. They also had difficulty following advice offered by their professional carers (A.D.'s intake of alcohol was high and K.C. did not wish to increase the dosage of her antiepileptic medication). People with epilepsy have weak perceptions of internal health locus of control and this has been linked to lower levels of engagement in beneficial health behaviours and active coping strategies (Asadi-Pooya et al., 2007). A.D. and K.C. may have benefited from an intervention aimed at reducing their seizures through achieving better compliance before introducing a memory aid. Other researchers have concluded that some individuals require self-awareness training before receiving memory intervention

(Ownsworth & McFarland, 1999). Poor adherence to prior professional intervention may indicate when this is necessary.

Issues of disclosure and privacy were commonly encountered by individuals when wearing the camera. In two individuals the potential adverse reaction of others, prevented them from wearing the device regularly. For many people with epilepsy, the continuing social reality of their condition is as a stigma (Jacoby & Austin, 2007). Once diagnosed, people with epilepsy may operate in expectation of negative reactions from others and develop an identity underpinned by these expectations (Scambler, 1989). Felt stigma may become a self-fulfilling prophecy, in that fear and shame about their epilepsy leads people to conceal it from others and denies the opportunity to test whether the enacted stigma they expect will materialise (Scambler, 1989).

Three individuals felt that the camera compromised confidentiality issues. It may be that the camera is unsuitable for individuals working in a profession which requires a high degree of confidentiality (e.g. health care or teaching). One participant felt that she could not record activities where she interacted with other people's children. Despite the early promise of SenseCam technology, this research indicates that there are several contexts where it is inappropriate to record events with a camera and this adversely affects the acceptability the device.

It has been suggested that the specific features of a memory aid should be matched to a client's neuropsychological profile (Kapur et al., 2002). Careful evaluation of the individual responses to the diary or camera in this study did not reveal a pattern based on clinical descriptions. In this study, participants elected to maintain the use of a diary, camera or a combination of both aids depending on their lifestyle. Research that places greater

emphasis on the client's social context may lead to a greater refinement in our understanding of which patients will benefit most from particular memory aids.

Four participants experienced clinically significant symptoms of anxiety. Patients with temporal lobe epilepsy have a higher incidence of affective disorders, often in comorbidity, than patients with other types of epilepsy and it has been suggested that this reflects a wider limbic dysfunction ([Perini et al., 1996](#)). Research has shown that people with anxiety disorders exhibit significant impairments in autobiographical memory and executive functioning (Airaksinen et al., 2005) and that individuals susceptible to stress, are more likely to report memory failures (Neuport et al., 2008). In a preliminary report on ALF, researchers identified that the patients' mean score on the anxiety scale of the HADS was in the borderline range but at an individual level, scores bore no relationship to performance on memory tests (Blake et al, 2000). Whilst the authors concluded that negative mood was insufficient to explain their results, the relationship between anxiety and forgetting in people with epilepsy warrants further elucidation.

5.1 Limitations

One consideration is that there is no standardised memory test available that can confirm the presence of ALF. This study used retention of recently learned words following a delay of one week described by researchers in the field (Butler et al., 2007). The ecological validity of using word list recall as a test of memory has been questioned as the task does not simulate real life behavior (Higginson et al., 2000). Whilst it can be acknowledged that such tests appear abstract, learning a word list in a clinic does constitute an "event", and the remembering of information from this event will involve some element of episodic autobiographical memory (Mayes & Roberts, 2001). In a study investigating ecological

validity of memory assessments, researchers found the memory measures that best correlated with functional status involved free recall after a delay (Higginson et al., 2000). The authors argued that this outcome was not surprising as having to recall information from the past is a relatively frequent event in an individual's daily life. Indeed performance on tests of long-term retention of verbal material does correlate with subjective experience of ALF and discriminates between people with ALF and controls (Butler et al., 2007). Patients who reported "real-world" ALF show significantly faster forgetting of word lists over longer intervals. However, identifying other valid tools that can be used to assess ALF in routine clinical practice remains a research priority.

It is recognised that the number of participants in this study is very small and does not allow for group statistical analysis. Moreover, given the differences in the emotional adjustment and cognitive profiles of the participants, it would not be appropriate to consider the data as being derived from a homogenous group. Even if more participants were recruited, interpretation of group statistics would be hindered by this heterogeneity. For this reason, a case series design was employed for the present study. Group studies involving larger numbers of participants whilst desirable, would need to control for the varying clinical and cognitive characteristics pertaining to patients with a diagnosis of ALF.

In this study, the researcher provided a consistent treatment and set of instructions to every participant. However, the literature suggests that in memory impaired individuals, learning to use an external aid may be protracted and require a longer period of training. This was particularly evident for completion of the diary entries and the rehearsal of material which was undertaken with varying degrees of success. It is recommended that future studies of

this nature provide more emphasis on the acquisition of the necessary skills to record and rehearse appropriate material.

Finally, each phase in this study may not have been conducted for sufficient duration to achieve statistical significance between conditions in ALF patients. This is because most people who experience ALF can retain memories over periods of days, but lose them over weeks. We would therefore not expect to see a difference in recall of events between baseline and intervention conditions for the quantity and quality of events that occurred during the first week of recall. We would however, anticipate that the intervention would have an impact on their ability to recall events from the week prior to recall. This trend was evident in the data. As each intervention lasted a month, this time frame only captured two weeks when forgetting occurred. Future studies could accommodate this by only considering recall for events that occurred more than 1 week ago or conducting the study over a longer duration. This has to be balanced with ethical and pragmatic considerations, as conducting a baseline over long periods without intervention may not be viable.

5.2. Clinical implications

Currently, it is the predominant view that only mildly impaired patients benefit from memory strategies as evidence for successful treatment of memory impairment is weak (Glisky, 2005). The findings of this study do provide some support for this rather pessimistic outlook, since the client (A.D.) that showed the poorest response to intervention had the most severe form of ALF. Unfortunately, it is recognised that the use of external memory aids involves memory and the very people who need them the most, have the greatest difficulty with using them (Wilson, 2002).

To date, research with groups of patients with ALF has not provided support for psychological explanations for this memory disorder. Systematic assessment conducted with seven ALF patients found no psychiatric abnormality (Manes et al, 2005). The findings on this study suggest that psychological factors should be excluded with caution. Four individuals with ALF had a previous episode of mental illness and two had a history of alcohol abuse. Significant trauma had been experienced by four participants including, parental abandonment, domestic violence, Sydenham's chorea in childhood resulting in one year spent in isolation and chronic pain. Such experiences are not usually captured by HADS, particularly if individuals have made an apparent recovery and this may explain the negative findings in previous studies. The hippocampus is vulnerable to the harmful physiological effects of stress, which can in turn lead to impairments in memory. Research has demonstrated that stress is associated with hippocampal reduction in children with post-traumatic stress disorder symptoms (Carrion et al., 2007). Future research could elucidate if exposure to chronic stress predisposes individuals to ALF.

5.3. Theoretical implications

ALF poses a theoretical challenge to our understanding of consolidation of memories and the role of medial temporal lobe structures. Research of autobiographical memory deficits in 25 patients with TLE revealed that there was no temporal gradient in remote memory loss for personal episodes as measured by the AMI. The authors concluded that the absence of a temporal gradient was not compatible with consolidation theory, which is founded on the principle of differential sparing of remote memories (Viskontas et al., 2000). The fact that the loss of autobiographical memories encompassed all time periods equally, provided support for MTT which posits that autobiographical episodic memories remain dependent

on hippocampal traces throughout our lives. However, we found a distinct temporal gradient in two individuals with ALF, which contradicts the findings of Viskontas et al. (2000) and is less easily explained by MTT. Another prediction of MTT is that rehearsal would differentially benefit semantic memory (which may relocate to the neocortex) and not improve autobiographical memory which is reliant on the hippocampus indefinitely (Jansari et al., 2010). The results of this study, which found beneficial effects of rehearsal in four out of five people with ALF, provides support for the traditional model proposed by Alvarez and Squire. MTT, as yet, does not provide a good account for the protective effect of active review of autobiographical memories. Further work is required to define the processes that may be involved in consolidation and their role in ALF.

6. Conclusion

Active rehearsal of recorded material using a diary can enable some individuals with ALF to improve their recall of recently acquired memories or enhance their subjective memory vividness. We were able to replicate the findings of Berry et al., (2007) who demonstrated that memories of important experiences are retained, even after rehearsal has ceased for at least one month. Finally, although rehabilitation did not confer a beneficial effect on mood, in two out of five individuals with ALF memory intervention had a positive impact on their perceived quality of life. This study demonstrates that intervention can resolve some of the problems faced by people with ALF and provides a compelling argument for assessment and treatment of this disorder to be more widely available. As advocated by Wilson (2009) 'Rehabilitation makes clinical and economic sense and should be widely available to all those who need it'.

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