



The everyday functioning of individuals with
cognitive difficulties and their families:
going beyond neuropsychological assessment

being a thesis submitted for the Degree of Doctor of Clinical
Psychology at the University of Hull

by

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Overview

The portfolio has three parts:

Part One is a systematic literature review, in which the theoretical, conceptual and empirical literature relating to the active involvement of family members in interventions for adults with memory impairment is reviewed.

Part Two is an empirical paper, which explores how objective cognitive performance translates into self-reported cognitive skills and diabetes self-management in individual with Type 1 Diabetes.

Part Three comprises the appendices.

PART ONE

SYSTEMATIC LITERATURE REVIEW

Family members actively involved in interventions for adults with memory impairment: a systematic review

This paper is written with the intention of submission to the journal *Neuropsychological Rehabilitation*¹

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¹ Appendix B: Neuropsychological Rehabilitation 'Information for Authors'

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Family members actively involved in interventions for adults with memory impairment: a systematic review

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Abstract

Memory impairment occurs in a wide range of neurological populations and influences patient functioning and family coping. The healthcare system depends upon families to provide care for these individuals. However, recommendations for the optimal methods of actively involving families in memory interventions are not clearly documented. This systematic review aimed to describe and evaluate the range of memory interventions that feature active family involvement for adults with memory impairment of any severity and cause. Twenty studies featuring seven broad intervention designs for family involvement were included. It was found that at-home memory aid practice with family involvement could positively influence patient cognitive outcomes and interaction and communication within the dyad was shown to increase. Results also showed improved family member mood and reduced perceived burden, though not reliably. This review highlighted a need for methodologically rigorous studies involving family members as a defined component of cognitive rehabilitation, with valid evaluation of useful patient and family outcome data. This is needed to provide the evidence underlying care quality guidelines that recommend family member involvement in patient populations with memory impairment and to catch up with real world practice.

Key words: memory, rehabilitation, family, systematic review

Introduction

Memory impairment is a significant cause of difficulty for individual sufferers and their families. Memory impairment occurs when the complex systems involved in encoding, storing and retrieving information are disrupted. Largely this disruption occurs when the neuroanatomical structures involved in memory are damaged (Wilson, 2009). The populations affected by memory impairment include people with dementia (Clare et al. 2000; Camp, Foss, O'Hanlon & Stevens, 1996; American Psychiatric Association, 2004; Farran, Loukissa, Perraud & Paun, 2003), brain injury (Corrigan, Whiteneck & Mellick, 2004; Kreutzer et al. 2009; Jennekens, de Casterle & Dobbels, 2010), history of stroke (King, Ainsworth, Ronen & Hartke, 2010), people with HIV infection (Woods et al. 2008) and cerebral hypoxia (Grubb, O'Carroll, Cobbe, Sirel & Fox, 1996).

Memory impairment has been clearly documented as having a disruptive effect on the everyday functioning of individuals, contributing to a variety of cognitive and behavioural problems (Howieson & Lezak, 2004). Its impact has been identified as one of the most common areas of difficulty for family caregivers across a range of neurological conditions (Junque, Bruna & Mataro, 1997; Low, Payne & Roderick, 1999; Sinnakaruppan & Williams, 2001; Sinnakaruppan & Williams, 2001; National Institute of Health and Clinical Excellence, NICE, 2006; Grant, Glandon, Elliot, Giger & Weaver, 2004; Haley et al. 2009; Jennekens et al. 2010). The adverse effects of neurological conditions on the patient's family and family relationships are consistently recognised in healthcare quality standards (NICE, 2006; 2008) and well documented in the clinical literature (e.g. Vitaliano, Young & Zhang, 2004).

The healthcare system in the UK is dependent upon family caregivers to care for the majority of individuals with neurological illness or injury in their own home (Harrison-Felix, Newton, Hall & Kreutzer, 1996; Sinnakaruppan & Williams, 2001; Vitaliano et al. 2004; Kreutzer et al. 2009; Opara & Jaracz, 2010). This resourcefulness is well established (Department of Health, DH, 2008). For example, it is estimated that 670,000 family and friends act as primary caregivers for 800,000 individuals with dementia in the UK (Alzheimer's Society, 2012). Familial care is often provided over prolonged periods of time, increasing with the degree of disability and at vital transition points to and from healthcare services (Oddy & Herbert, 2003; Kreutzer et al. 2009; Wilson, 2009; Commission on Accreditation of Rehabilitation Facilities, CARF, 2011; Brain Injury Rehabilitation Trust, BIRT, 2012). Informal caregivers provide support in a way that is invisible to healthcare services and to the patient (Vikström, 2008), adapting the home environment, sharing tasks and providing comfort and support in a way that is tailored to individual needs. Benefits can also exist for families, with active caregiver involvement protecting against caregiver strain and depression (Tarlow et al. 2004;

Hilgeman, Allen, DeCoster & Burgio, 2007) and meeting caregiver needs for a meaningful role (Camp et al, 1996; Farran, Miller, Kaufman, Donner & Fogg, 1999; Oddy & Herbert, 2003; Roff et al. 2004).

Therefore, given the marked difficulties for patients and families caused by memory impairment in a broad range of neurological conditions, and the prevalence of family caregiving, it logically follows that family members could be collaboratively involved in memory rehabilitation.

It is worth taking a moment to consider how this might look: collaborative memory interventions engage the patient and family member together to reach a shared goal (Vikström, 2008; Neely, Vikström & Josephsson, 2009), ultimately to increase the functioning and quality of life of both the patient and family (CARF, 2011). In this respect, the unique role and the needs of the caregiver are recognized in addition to the needs of the patient (Elliott & Pezent, 2008; Clare, 2009). However, the notion of collaborative cognitive rehabilitation is recent to the literature, having historically focused on either the patient or the caregiver (Judge et al. 2010). Despite a growing literature base for multi-component and psycho-social interventions for conditions of memory impairment (Moniz-Cook & Manthorpe, 2009; Moniz-Cook, Vernooij-Dassen, Woods, Orrell & Interdem Network, 2011), memory interventions are largely delivered by healthcare providers (Wilson, 2009) without active input from family members.

This research context is consistent with the limited guidance from care quality standards of how to utilize family members in conditions resulting in memory impairment (British Society of Rehabilitation Medicine, BSRM, 2003; NICE 2006; 2007; 2008; DH, 2007; Intercollegiate Stroke Working Party, ICSWP, 2008). This guidance recommends that family members help to determine patient rehabilitation goals and are provided with information (i.e. from leaflets and voluntary sector services). The importance of locating rehabilitation within the home environment following stroke has also been recognized (DH, 2007; ICSWP, 2008) yet multi-disciplinary professional input is recommended to achieve this. There is no guidance for actively involving family members in memory interventions, although this has been recommended in mood disorders and activities of daily living with “active participation” of carers (NICE, 2006, pp.40; ISWP, 2008).

Research aims

To the authors' knowledge this is the first systematic literature review aiming to document the ways that memory interventions for adults have utilized family members as a component of the intervention. The review also evaluates the impact of family

involvement on outcome, where any evaluated outcome was considered, including patient and caregiver variables.

This provides an attempt to synthesize an evidence base to inform guidelines on how to best utilize family members in memory interventions, with an aim to improve patient and family outcomes and increase resourcefulness in healthcare (Lavis, Posada, Haines & Osei, 2004).

Method

Search protocol

Psycinfo, Scopus, The Cochrane Library and CINAHL databases were searched. Search terms were: couple, partner, spouse, dyad, wife, husband, family, caregiver, memory, intervention, training, and technology. Wild cards and truncations were used to maximize the number of articles retrieved. Search terms were generated by listing alternate words for 'family' and 'intervention'. Preliminary database searches using these search terms along with 'memory' and manual searches of reference sections and 'key words' of returned articles were used to expand the search terms. All terms were applied to 'topic, 'title' and 'abstract'. Retrieved articles and relevant reviews were searched manually for additional references. Key authors were contacted to capture further articles not retrieved in the database search. The search continued until 1 September, 2012³.

Inclusion criteria

Studies were required to meet seven criteria:

- (1) Published in the English language.
- (2) From peer-reviewed and non-peer reviewed and unpublished sources.
- (3) Featured the implementation and evaluation of a memory intervention of any kind (e.g. internal or external memory aids). Studies that implemented a memory intervention as one component of a wider intervention were included.
- (4) Featured family involvement as a defined component of the intervention protocol.
- (5) Participants with memory impairment of any severity, of any cause.
- (6) Adult participants (≥ 18 years).
- (7) Had primary source quantitative or qualitative data, with any outcome aims.

³The review was submitted to the journal *Neuropsychological Rehabilitation* for peer review on 11 January 2013.

Exclusion criteria

- (1) Non-English studies.
- (2) Review or discussion papers.
- (3) Only featured psycho-education as an intervention.
- (4) Featured family involvement for evaluation purposes only.

Study selection summary

From the total studies identified from the database search (676 from Psycinfo, 720 from Scopus, three from Cochrane and 169 from CINAHL), 31 full articles were selected to be retrieved using the information available in abstracts. A further 22 articles were identified from the manual search and were retrieved in full. One article was identified following personal contact with key authors. A total of 54 articles were considered for review. Thirty-four articles were excluded for the following reasons: not an intervention study (n=6), no memory intervention or psycho-education only (n=20), no reported family involvement in the intervention (n=5), abstract only (n=2), unable to obtain the study in full (n=1). For details of the excluded articles see Appendix D.

A final sample of 20 studies met the inclusion criteria. A flow diagram documenting the selection of studies for the review is presented in Figure 1.

Data Extraction

A template was created for the systematic extraction of key information from each study, guided by NICE (2007), presented as an evidence table (Appendix E). Data extracted included *general study information*: title, authors and year of publication; *participant characteristics*: sample size, diagnosis, age and gender; *caregiver characteristics*: age, relationship to patient and living arrangement; *study characteristics*: research aims, caregiver involvement, methodological design, intervention description and methodological quality; *outcome*: outcome measures, statistical analysis and results; *study conclusions*.

Methodological Quality Assessment

A quality checklist was developed using existing templates (Downs & Black, 1998; Scottish Intercollegiate Guidelines Network, 2002) to ensure that study information was analysed in a comprehensive and objective way (Appendix F). Quality was reviewed in terms of the ability to answer the research question whilst accounting for different factors of study design. It comprised 19 items, each rated 0, 1 or 'not applicable'.

The checklist was used to provide a summary score of study quality. Information of all

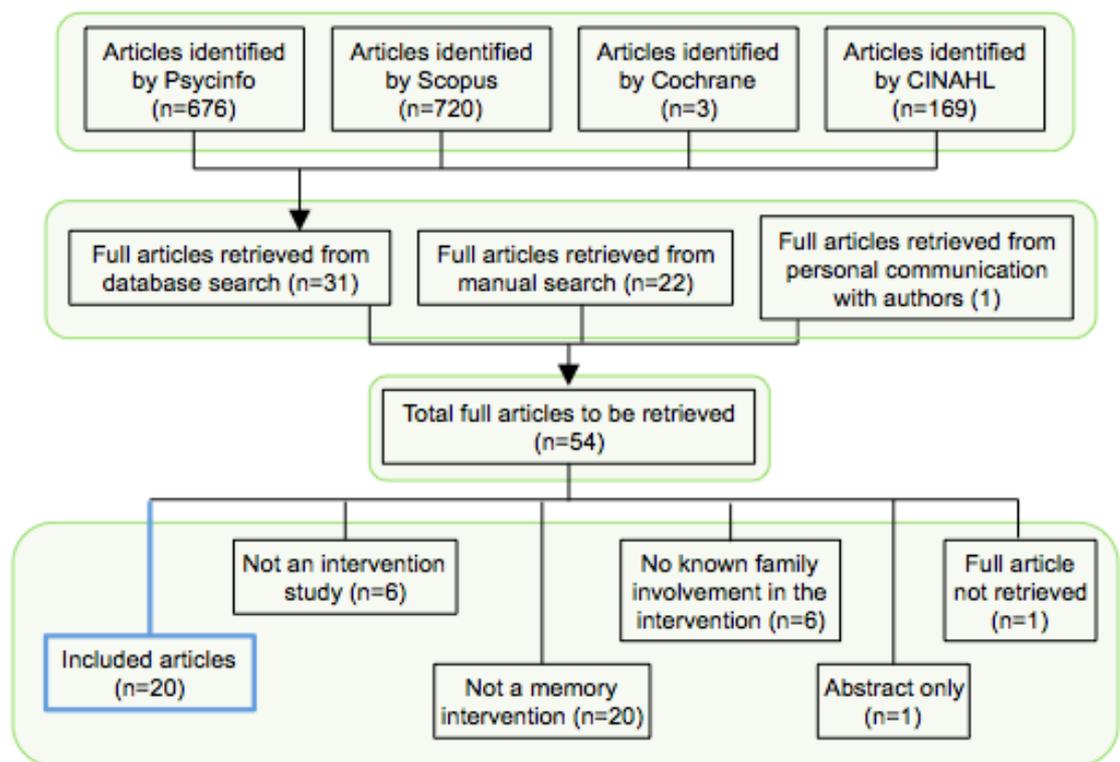


Figure 1. Full search results and the selection of studies for the current review

rated items is presented in Appendix F. A percentage of overall quality was used to account for items scored 'not applicable'. A second rater reviewed a sample of studies to assess the inter-rater reliability of the checklist. A good level of agreement was found: Kappa = 0.83 ($p < .001$), 95% CI (0.701, 0.951). Differences were discussed and a consensus quality rating agreed.

Data Analysis

Data was analysed using a narrative synthesis approach to provide the most meaningful results (Popay et al. 2006). This was appropriate given the heterogeneity of the designs and interventions featured.

Results

Details of the studies included in the review can be found in Table 1. Findings are first presented as an overview of featured study designs, interventions and neurological population followed by methodological quality across all studies. Descriptions of how families have been actively utilized in adult memory interventions (Part 1) and an evaluation of the outcomes of family involvement concerning either the patient or caregiver are then presented (Part 2).

Table 1. Summary of the main characteristics of included studies

Author(s)	Title of study and year of publication	Sample size	Participants characteristics Values = mean age in years, SD in parentheses unless stated otherwise.	Caregiver characteristics Values = mean age in years, SD in parentheses unless stated otherwise.	Caregiver involvement	Study design methodology	Intervention	Outcome measures	Main findings	Quality (% assessed by quality checklist)
Single case designs										
Berry, Kapur, Williams, Hodges, Watson, Smyth, Srinivasan, Smith, Wilson & Wood	The use of a wearable camera, SenseCam, as a pictorial diary to improve autobiographical memory in a participant with limbic encephalitis: A preliminary report (2007)	1 dyad	Limbic encephalitis. 63. Female.	Husband. 70.	Dyad was trained to use SenseCam. Decided the significant event to record and made written diaries. Recorded the participant's recall of the events, showed the participant the SenseCam images and written diaries and discussed the events.	Single case: experimental/comparative design.	1. SenseCam: The dyad were trained to use SenseCam. SenseCam images were viewed and tested every two days for two weeks. This was repeated for nine events. 2. Written diary: The husband made a written diary of an event and the same procedure for viewing and testing as for SenseCam was followed for three events. 3. No memory aids.	Throughout intervention and one, two and three months post-testing: Participant: 1. Autobiographical recall of predetermined events was tested by the family member every two days for two weeks followed by reviewing the SenseCam images or reading the written diary of the event. The family member decided a number of key points of the event and recorded the percentage remembered, was repeated for nine events in the SenseCam condition, three events in the written diary condition and one event in the no memory aid condition. Participant and family member: 2. Informal interview.	A significant increase in autobiographical recall occurred in the SenseCam condition only. The participant reported feeling less anxious about remembering when using SenseCam. The family member reported more readily sharing past experiences.	76.5
Bier, Provencher, Gagnon, Van Der Linden, Adam & Desrosiers	New learning in dementia: Transfer and spontaneous use of learning in everyday life functioning. Two case studies (2008)	1 dyad	An isolated progressive memory disorder or possible DAT+. 76. Male.	Wife. Age unknown.	Contributed to choosing the intervention. Wrote 'important information' on the calendar. Used a cuing technique to assist the participant in using the calendar. Completed the behaviour checklist outcome measure.	Single case: experimental/comparative design.	A one-day-per-page calendar was introduced over four months following an ABAB design. The dyad was taught spaced retrieval by the researcher at home.	Throughout intervention: Family member: 1. Behaviour checklist including a list of three behaviours (questions about the date, calls or time of day) and the seven days of the week. The family member noted each time the participant asked a question and consulted an external aid. Questions about the time of day served as a control and were not trained.	The participant significantly increased in calendar use. The calendar was used spontaneously, more specifically for the current date. There was a significant decrease in the number of questions asked about the date (and for the control behaviour of time of day). There was no significant overall decrease in questions about calls made to the family.	64.7
de Fatima Alves Monteiro, Prado Bolognani, Strahler Rivero & Amodeo Bueno	Neuropsychological intervention in a case of Korsakoff's amnesia (2011)	1 family	Korsakoff's amnesia. 42. Female.	Family. No further details.	Contributed to choosing the intervention. Received two hours of orientation with the researcher every two months.	Non-comparative: case study.	Over 25 weeks the participant received weekly one-hour individual sessions to complete activities for insight, orientation, compensatory memory strategies, decision making and emotional issues. The family received two-hours of orientation every two months. Two non-family caregivers were trained to carry out weekly activities at home including writing in a	Throughout the intervention: Non-family caregivers: 1. Observations of the participant's attitudes throughout the intervention. Pre and post-testing: Family member: 2. Everyday Memory Questionnaire (EMQ).	The participant engaged in the scheduled activities, established a daily routine and self-care habits, understood the need to ask for help and applied the external memory aids. Orientation and autobiographical memory improved. Autonomy increased in social activities outside of the house. EMQ scores reduced.	25.0

							journal, repetition of daily routine and increased social activities.			
De Leo, Brivio & Sautter	Supporting autobiographical memory in participants with Alzheimer's disease using smart phones (2011)	1 dyad	Mild dementia. 80. Male.	Spouse. 73. Female. Dyad living together.	Dyads were trained to use the smart phone. Received one hour of training on how to select significant events from the image slideshow for testing. Designed and administered the weekly recent events memory recall test.	Non-comparative: case study.	The participant carried a smart phone for 12 hours daily for four weeks that took pictures every five minutes. Pictures were mailed to the participant as a DVD each week. The participant's memory was assessed and the participant viewed the slideshow weekly.	Weekly throughout the intervention: Participant: 1. A recent events memory recall test comprised of a list of events selected by the family member from a weekly slideshow of images taken by the smartphone. Administered by the family member weekly pre and post slideshow viewing. Participant and family member: 2. Intervention satisfaction questionnaire. Pre and immediate post-testing: Participant: 3. Repeatable Battery for the Assessment of Neuropsychological Status (RBANS).	The participant remembered more events after watching the slideshow. Raw scores showed improvement on the majority of RBANS subtests excluding delayed recall. Satisfaction decreased over the four weeks.	50.0
Del Grosso Destrieri, Farina, Calabrese, Pinardi, Imbornone & Mariani	Frontal impairment and confabulation after herpes simplex encephalitis: a case report (2002)	1 family	Herpes simplex encephalitis. 53. Female.	Husband and children. No further details.	Received psycho-education. Instructed to contrast confabulation, talk about salient events and provide cognitive stimulation for the participant.	Non-comparative: case study.	Inpatient, one month: Twice-daily cognitive rehabilitation training. Discharged, one month: continued training two days per week. The participant followed a rigid weekly routine written in a memory book and completed a diary. On weekend home visits, family members were asked to contrast confabulation, practice orientating tasks and discuss autobiographic history. Following discharge, family members continued the rehabilitation program independently.	Pre and two, five and ten month post-testing: Participant: 1. Mini-Mental State Examination. 2. Corsi tapping test. 3. Digit span forwards and backwards. 4. Serial position curve primary and recency effect. 5. Logical memory test. 6. Paired associated words test. 7. Corsi Supra Span Tapping Test. 8. Verbal Fluency task phonemic and semantic cues. 9. Attentional matrices. 10. Raven Coloured Matrices (A, AB, B). 11. Battery for verbal judgments. 12. Wisconsin Card Sorting Test. 13. Rey complex figure.	Following inpatient rehabilitation observed results were reduced confabulation, improved orientation, amnesia disappeared and less perseverations. At two-months improvements were observed in orientation, attention and autobiographical memory. Psychometric assessment showed improved frontal skills to within the normal range. At five-months assessment showed improvement in frontal tasks. At ten-months improvement in frontal skills were maintained and verbal fluency had improved to within the normal range.	56.3
Multiple participant designs										
Corbeil, Quayhagen & Quayhagen	Intervention effects on dementia caregiving interaction. A stress- adaptation modeling approach (1999)	87 dyads	Possible or probable DAT†. 74.2 (7.9). 31 female.	Primary caregiver. 67.1 (11.0). 67 female. Dyad living together.	Dyads taught weekly modules addressing specific mental abilities. Caregivers trained in activities to cognitively stimulate the participant, with instructions for practicing throughout the week.	Randomised control trial.	12-weeks. Dyads attended weekly module training and implemented one hour of at-home active cognitive stimulation daily for six days each week. 1. Intervention: Caregivers were trained in activities to cognitively stimulate the participant. 2. Placebo: trained activities were passive (e.g. watching television). 3. Control condition: no intervention. Two booster contacts were	Pre- and three and nine months post-testing: Family member: 1. Memory and Behavior Problems Checklist- Part A. 2. Part B. 3. Ways of Coping Scale-Revised. 4. Social Support Questionnaire. 5. Marital Needs Satisfaction Scale.	At three months: Participant deterioration paralleled increased stress in the family member for all treatment groups. The effect of stress on dyadic interaction was attenuated in the experimental group. The coping strategy of 'positive reappraisal' had a positive effect on dyadic interaction in the experimental group. At nine months: Family member stress remained higher than at pre-assessment and its impact on the dyadic interaction remained negative.	63.2

							made with the Intervention and Placebo groups between 3 and 9-month assessments.			
Crete-Nishihata, Baecker, Massimi, Ptak, Campigotto, Kaufman, Brickman, Turner, Steinerman & Black	Reconstructing the past: Personal memory technologies are not just personal and not just for memory (2012)	5 dyads	Early DAT† or MCI†††. Age unknown. 4 female.	No details.	Attended events with participants. SenseCam remix: Edited SenseCam images and narrated the video.	Within subjects, comparative design.	Within a four-month period, participants wore SenseCam during three non-routine outings. Participants were interviewed about each event five times within two-and-a-half weeks. For two outings the SenseCam media was viewed following each interview. 1. SenseCam reexperience presented unprocessed SenseCam images. 2. SenseCam remix was composed of a selection of 24 SenseCam images edited and narrated by the partner. 3. The third outing acted as a control condition.	Throughout intervention and three months post-testing: Participant: 1. Customized version of the Autobiographical Interview (AI) conducted following each outing and five times during two-and-a-half weeks. Immediate and three months post-testing: Participant and family member: 2. Video-recorded screenings of the SenseCam media.	Episodic recall of events was significantly improved in both SenseCam conditions as compared with the control condition, but recollection did not improve significantly over time in any condition. Qualitative data showed that SenseCam Reexperience was thought to aid recall whereas Remix was thought to aid sharing of the outing.	38.9
Damianakis, Crete-Nishihata, Smith, Baecker & Marziali	The psychosocial impacts of multimedia biographies on persons with cognitive impairments (2010)	12 families	DAT† or MCI†††. 79.58 (9.69). 7 female.	Spouse, children and/or grandchildren. Three participants had no family members. Age and sex unknown.	Provided materials for multimedia biographies and contributed to its design. In some instances family members narrated biographies. Instructed to show the biography to the participant once or twice weekly and record reactions.	Non-comparative study, qualitative.	Participants and family members met with a research assistant four-to-10 times to collect and structure materials to create a video multimedia biography. Families showed the biography to the participant once/twice weekly for six months.	Pre- and three and six months post-testing: Participant: 1. Reactions to viewing the biography were videoed. Throughout the intervention: Family member: 2. Recorded participant reactions to viewing the biography. Three and six months: Participants and family members: 3. Semi-structured interviews including overall experience of developing and viewing the biography, the effect on mood and memory, impact on quality and quantity of communication within the family and attitude toward the participant.	Short-term benefits showed participants and families engaged in the process of telling stories. Early memories were triggered and families gained insights into their relatives' lives leading to enhanced communication.	52.9
McDonald, Haslam, Yates, Gurr, Leeder & Sayers	Google Calendar: a new memory aid to compensate for prospective memory deficits following acquired brain injury (2011)	12 dyads	ABI. 47 (11). 6 female.	Family member. No further details.	Contributed to choosing the intervention. Attended one training session and taught how to use the allocated memory aid. Completed daily monitoring forms.	Randomised control trial.	15 weeks. Participants and family members identified routine target activities (e.g. taking medication). Completion of these activities was assessed at baseline for five weeks. All participants and family members attended a training session (approximately 90 minutes) for either Google Calendar or a standard diary and implemented the strategy for five weeks. Crossover design.	Daily: Family member: 1. Individualised monitoring form listing participant prospective memory targets and the time to be completed. Post-testing: Participant and family member: 2. Questionnaire of the experience of using the memory aids.	Average prospective memory performance was significantly better during the intervention phases than at baseline and was significantly better using Google Calendar than the written diary. Participants with the most severe memory and executive dysfunction benefited least from use of both memory aids.	52.6

Moniz-Cook, Agar, Gibson, Win & Wang	A preliminary study of the effects of early intervention with people with dementia and their families in a memory clinic (1998)	30 individuals, 17 family members.	Probable DAT ⁺ , multi-infarct dementia or frontal lobe dementia. 78.87 (5.83), 78.33 (5.21): two groups determined by intervention design. 18 female.	15 spouses, 2 daughters. Age and sex unknown.	Dyads received psycho-education. All interventions were home-based. Caregivers assisted with individualized memory rehabilitation activities: e.g. asking questions, role-playing and encouraging strategy use. Caregivers as "therapists".	Non-randomised control trial.	All families received three advice pamphlets. 1. Experimental group: participants received six-to-12 hours, during four-to-14 weeks of home-based psycho-education, counselling and individualised memory rehabilitation. The GP and EMIT ⁺ key worker were asked to reinforce the advice during ongoing contact. At six-months use of advice pamphlets and key worker support were reinforced. 2. The control group used the advice pamphlets only.	Pre- and 18 months post-testing: Participant: 1. Rivermead Behavioural Memory Test (RBMT). Pre- and six months and 12 months post-testing: Family member: 2. General Health Questionnaire (GHQ-30), 3. Beck Depression Inventory (BDI). 4. Hospital Anxiety and Depression Scale (HADS). 18 months after diagnosis: Participants and family members: Semi-structured interview and self-report questionnaire including the value of the advice pamphlets, maintenance of rehabilitative goals, involvement of GP and perceptions of support received. Keyworkers were interviewed or case notes examined.	The intervention group showed a non-significant trend for improvement on the RBMT and stability for family members on the HADS, GHQ and BDI compared with decline in the control group. Significantly more control participants were admitted to permanent residential care. At 18 months post-testing in the intervention group, memory aid use had generalized to everyday routine.	68.4
Moore, Sandman, McGrady & Kesslak	Memory training improves cognitive ability in participants with dementia (2001)	25 dyads	Mild-moderate dementia. 72.5 (8.04). Sex unknown.	Spouse. 70.0 (10.5). Sex unknown.	Dyads participated in the memory training programme, completing exercises jointly. Provided with activities for home practice.	Non-comparative study. Test-intervention-test.	Dyads attended a five week Memory-Training Programme (MTP). Each weekly session began with memory psycho-education and strategies to increase effort, arousal and interest with a focus on recall of names, faces, places and events. Strategies could be individualized. Caregivers practiced recall of faces and names at home with the participant. Caregiver support interventions included education, emotional support and stress relief.	Weekly: Participant: 1. Task-specific tests with feedback. Pre- and immediate post-testing: Participant and family member: 2. Geriatric Depression Scale (GDS), 3. Memory Function Questionnaire (MFQ), 4. The Kendrick Digit Copy, 5. Activities of Daily Living (ADL) from the Blessed Dementia Scale (BDS), and 6. Relative Stress Scale (RSS) with family members rating the ADL, GDS and MFQ in reference to the participant. One month post-testing: Participant: 7. Recall of names and faces.	Recall of names and significant events significantly improved over time and was retained one-month post-testing. Participant scores on the Kendrick Digit Copy and GDS significantly improved between the first and last week of the memory training but not on the MFQ, BDS or RSS. Family members indicated that the participants significantly improved in their perceived functional ability as rated on the MFQ. No changes for controls.	52.6
Moro, Condoleo, Sala, Pernigo, Moretto & Gambina	Cognitive stimulation in a-MCI ⁺ : An experimental study (2012)	30 dyads	Amnesic MCI ⁺ . 73.27 (6.91), 68.53 (8.74): two groups determined by intervention design. Sex unknown.	No details.	Contributed to choosing the intervention. The dyad attended cognitive stimulation sessions and learnt to provide assistance to the participant. Instructed to complete activities at home.	Non-randomised control trial.	In both groups, dyads received three individual sessions, weekly for one month involving teaching and practicing of individualised memory strategies. Caregivers learnt how and when to give assistance. For five months dyads practiced the strategies at home in everyday situations once weekly. Crossover design.	Pre- and immediate and six months post-testing: Participant: 1. Bell test. 2. Attentional matrices. 3. Trial-making test A. 4. Bourdon test. 5. Verbal span. 6. Auditory-Verbal Learning Test (AVLT) immediate and delayed recall. 7. Omissions. 8. False recognition. 9. Listening span. 10. Story recall. 11. Verbal fluency- category. 12. Tower of London. 13. Analogies. 14. Stroop test. 15. Trail-making test B-A.	Immediate memory recall improved significantly after cognitive stimulation for both groups. This improvement was not retained at six months post-testing. Inconsistent results in other cognitive domains between the two intervention groups. Families reported increased confidence in their assistance skills. When not receiving the intervention, cognitive performance declined over time.	57.9
Neely, Vikstrom & Josephsson	Collaborative memory intervention in	30 dyads	Mild-moderate DAT ⁺ or vascular	Spouse. 74.1 (8.6), 72.1 (5.9), 75.3 (8.5): three	Received psycho-education. Collaborative	Randomised control trial.	Psycho-education (30–40 minutes) and eight one-hour home-based, weekly training	Pre- and immediate post-testing: Family member and participant: 1. Collaborative assessment: A novel	Following collaborative intervention, participant recall performance on two collaborative	89.5

	dementia: Caregiver participation matters (2009)		dementia. 74.4 (6.0), 74.8 (6.7), 77.0 (6.6); three groups determined by intervention design. 15 female.	groups determined by intervention design. Dyad living together.	condition: provided cues for spaced retrieval in a face-name task and hierarchical cueing in a table setting task. Research assistant withdrew guidance.		sessions for spaced retrieval and hierarchical cueing. 1. Collaborative: all cues provided by the caregiver. 2. All cues provided by the research assistant. 3. Control condition: no intervention.	15-object memory test (random condition and categorised condition). Individual word recall and collaborative recall. 2. Individual assessment: A 12-noun list learning test (random condition and categorised condition). Individual word recall. Family member: 3. Zarit Caregiver Burden Interview. 4. Beck Depression Inventory (BDI).	and one individual memory tasks increased significantly compared with the individual and control groups. Collaborative recall performance was not significantly affected by any intervention. Interaction between participants and family members was modified by collaborative training. Training had no effect on perceived burden or depressive symptoms of family members.	
Quayhagen & Quayhagen	Differential effects of family-based strategies on Alzheimer's disease (1989)	16 dyads	Probable DAT†. 67.4. 11 female.	Primary caregiver. 65.9. 6 female. Dyad living together.	Instructed to complete cognitive stimulation activities with the participant 6 hours per week (1 hour per day). The emphasis was placed on quality time between dyad. Instructed to keep a log of activities and anecdotal notes. Monthly contact with the caregiver for problem solving of difficulties.	Non-randomised control trial.	Dyads attended weekly module training and implemented one hour of at-home active cognitive stimulation daily for six days each week. The first training session was held in the clinic, with subsequent sessions in the home. 1. Intervention: Caregivers were trained in activities to cognitively stimulate the participant. Eight monthly booster contacts were made with the dyad for problem solving of difficulties. 2. Control condition: no intervention.	Pre- and four and eight months post-testing: Participant: 1. The Dementia Rating Scale (DRS). 2. Logical memory and associated learning items of the Wechsler Memory Scale (WMS). 3. 10 arithmetic problems. 4. The Geriatric Coping Schedule (GCS). 5. The Memory and Behavior Problems Checklist Part A. Family member: 6. The Burden Interview. 7. The Hopkins Symptom Checklist. 8. The Health Assessment Scale. 9. Anecdotal notes.	Participant cognitive functioning and behavioural problems and family member mental health status and burden remained stable in the intervention condition compared with decline in the control group. The logs and written evaluative comments of family members in the intervention group showed that family members felt there had been positive emotional outcomes in the participant and reported more effective coping methods and resources.	78.9
Quayhagen & Quayhagen	Testing of a cognitive stimulation intervention for dementia caregiving dyads (2001)	30 dyads	Possible or probable DAT†. 74.97 (SEM 1.36). 11 female.	Spouse. 72.57 (SEM 1.51). 19 female.	See Quayhagen et al. (1995).	Randomised control trial.	See Quayhagen et al. (1995) with the following amendments: Eight week intervention.	Pre- and three months post-testing: Participant: 1. Composite of 25-point Logical Memory I, Visual Reproduction I subscales of the Wechsler Memory Scale-Revised (WMS-R) and the 25-point memory factor from the Dementia Rating Scale (DRS). 2. Composite of Logical Memory II and Visual Reproduction II of the WMS-R. 3. Composite of words recalled in one minute for the letters F, A, and S animal category and initiation score of the DRS. 4. Composite of the Geriatric Coping Schedule (GCS) and the conceptualisation score of the DRS. Family member: 5. Marital Needs Satisfaction Scale.	The cognitive stimulation group demonstrated a significant increase in problem solving and verbal fluency over time compared with the control group, which tended to decrease. Differences in memory were not found. Change in marital interaction was not significant. Caregivers in the cognitive stimulation program reported enhanced communication and interaction.	78.9
Quayhagen, Quayhagen, Corbeil, Hendrix,	Coping with dementia. Evaluation of four nonpharmacologic	103 dyads	Possible or probable DAT†, cardiovascular dementia or	Spouse. 71.83 (SEM 0.8). 65 female.	Four interventions involved the dyad. Memory intervention: Instructed to complete	Randomised control trial.	8 weeks, one-and-a-half hours of weekly involvement with the research team. 1. Cognitive stimulation- home	Pre- and three months post-testing: Participant: 1. Composite of 25-point Logical Memory I, Visual Reproduction I subscales of the	The cognitive stimulation group showed significant improvement on delayed memory and verbal fluency and caregivers'	73.7

Snyder & Bower	interventions (2000)		Parkinson's dementia, mild-moderate. 74.51 (SEM 0.3). 38 female.		cognitive stimulation activities with the participant 5 hours per week (1 hour per day). Caregivers taught to interact more effectively with the participant: one-and-a-half hours weekly instruction in the home.		based. The caregiver helped to cognitively stimulate the participant one hour daily for 5 days each week. The caregiver was instructed to interact more effectively with their spouse. 2. Dyadic counselling- home based. 3. Day care program- community based group. Four hours weekly of structured activities for participants. Respite for caregivers. Caregivers attended two sessions for education and support. 4. Dual supportive seminar- community based group. A forum for information, discussion and support. 5. Control condition: no intervention.	Wechsler Memory Scale-Revised (WMS-R) and the 25-point memory factor from the Dementia Rating Scale (DRS). 2. Composite of Logical Memory II and Visual Reproduction II of the WMS-R. 3. Composite of words recalled in one minute for the letters F, A, and S animal category and initiation score of the DRS. 4. Composite of the Geriatric Coping Schedule (GCS) and the conceptualisation score of the DRS. Family member: 5. Memory and Behaviour Problems Checklist Part A. 6. Part B. 7. Marital Needs Satisfaction Scale. 8. Brief Symptom Inventory. 9. Geriatric Centre Morale Scale. 10. Health Assessment Scale. 11. Coping Strategies Inventory-Revised. 12. Social Support Questionnaire. 13. Intervention evaluation questionnaire.	depressive symptoms reduced significantly. Qualitative data showed enhanced communication and interaction for the cognitive stimulation group. In the early-stage day-care group only there was a significant decrease in symptoms of hostility in caregivers.	
Quayhagen, Quayhagen, Corbeil, Roth & Rodgers	A dyadic remediation program for care recipients with dementia (1995)	78 families	Possible or probable DAT†. 73.6 (8.0). 27 female.	Family caregiver. 66.7 (10.8). 60 female.	Instructed to complete cognitive stimulation activities with the participant 5 hours per week (1 hour per day). Caregivers taught to provide positive feedback and to interact more effectively with the participant: one-hour weekly instruction at home.	Randomised control trial.	12-weeks. Dyads received one hour of weekly training across 12 modules and implemented one hour of at-home active cognitive stimulation daily for five days each week. 1. Intervention: Caregivers were trained in activities to cognitively stimulate the participant. 2. Placebo condition: trained activities were passive (e.g. watching television). 3. Control condition: no intervention.	Pre- and immediate and six months post-testing: Participant: 1. Dementia Rating Scale (DRS). 2. Visual memory span and digit span from Wechsler Memory Scale-Revised (WMS-R). 3. Memory and Behaviour problems checklist Part A. 4. Composite of 25-point Logical Memory I, Visual Reproduction I subscales of the WMS-R and the 25-point memory factor from the DRS. 5. Composite of Logical Memory II and Visual Reproduction II of the WMS-R. 6. Composite of words recalled in one minute for the letters F, A, and S animal category and initiation score of the DRS. 7. Composite of the Geriatric Coping Schedule (GCS) and the conceptualisation score of the DRS.	The cognitive stimulation group increased in general cognitive functioning, memory (recall) and verbal fluency compared with the control group, which tended to decrease. The placebo group remained stable in memory performance but declined in general cognitive functioning. The improvements in the stimulation group regressed towards baseline at nine months. The experiment and placebo groups had significantly less behavioural problems at immediate and nine-months post-testing. Logs completed by caregivers showed that training generalised to daily life.	78.9
Schmitter-Edgecombe, Howard, Pavawalla, Howell & Rueda	Multidyad memory notebook intervention for very mild dementia: A pilot study (2008)	4 dyads and 1 individual	Very mild dementia. 76 (9.08). 4 female.	Spouse. 76 (10.86). 1 female.	Taught as a dyad to use a memory notebook. Caregivers as "coaches".	Non-comparative: test-intervention-test.	14 group intervention sessions, two one-and-a-half hours sessions weekly. Dyads were taught to use a memory notebook via modelling, psycho-education, and completing activities and homework assignments.	One week pre- and two weeks post-testing: Participant: 1. North American Adult Reading Test (NAART). 2. Repeatable Battery for the Assessment of Neuropsychological Status (RBANS). 3. Rivermead Behavioural Memory Test, Second Edition (RBMT-II). Family member and participant: 4.	No significant improvements in general cognitive status. Significant improvement on the RBMT-II due to increased note taking during testing. Participants and family members noted significant changes in memory strategy use on the MMQ and daily checklist. This did not translate into reports of fewer	78.9

Vikström	Supporting persons with dementia and their spouses' everyday occupations in the home environment (2008)	30 dyads	See Neely et al. (2009).	See Neely et al. (2009).	See Neely et al. (2009).	Randomised control trial.	See Neely et al. (2009).	Multifactorial Memory Questionnaire (MMQ). 5. Daily checklist of everyday memory failures. 6. 21-item Depression, Anxiety and Stress Scale (DASS-21). 7. 26-item Coping Self-Efficacy scale (CSE). Family member: 8. Activities of Daily Living International Scale (ADL-IS). See Neely et al. (2009) with one addition: 5. The Assessment of Communication and Interaction Skills (ACIS).	everyday memory failures or greater everyday independence. Family members reported fewer symptoms of depression. Participants reported significantly greater confidence in their ability to obtain support.	84.2
Yarry, Judge, & Orsulic-Jeras	Applying a strength-based intervention for dyads with mild to moderate memory loss: Two case examples (2010)	2 dyads	Mild-moderate dementia. Age unknown. 1 female.	Primary family caregiver: 1 daughter, living separately; 1 wife, partly living together. Age unknown.	Received psycho-education. Received interactive skills training. Contributed to select skills to practice each session. Interventions determined on a case-by-case basis.	Non-comparative: case study.	Six weekly 90-minutes sessions. Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS): Dyads received information and interactive skills training.	No standard outcome measures. Qualitative. The researcher took structured notes to document skills selected, number of weeks practiced and whether skills were effective.	Each case showed that the tailored intervention was effective in addressing dyads' specific needs.	31.3

†DAT = Dementia of the Alzheimer's Type.

††EMI = Elderly Mentally Infirm

†††MCI = Mild Cognitive Impairment

Study Designs

Seven randomized control trials (RCTs), three non-randomized control trials (non-RCTs) and six single-subject designs were featured. Two studies utilized a non-comparative test-intervention-test design, one a non-comparative intervention with qualitative data and one a within subjects comparative design.

Interventions

Memory intervention as one component of a cognitive stimulation or combined intervention (e.g. including education, support and memory aid training) was the most common (eight studies, 40%). Seven (35%) studies evaluated external memory aids, four (20%) evaluated internal memory aids (e.g. spaced-retrieval) and one study implemented both internal and external memory aids in a cognitive rehabilitation program.

Neurological population

Cause of memory impairment is important in predicting progression of impairment and other associated factors including caregiver and patient coping.

The majority of studies investigated the dementia population alone (11 studies, 55%). Research with this clinical population featured six of the seven RCTs and two of three non-RCT and five studies featured a recurring intervention protocol (Quayhagen & Quayhagen, 1989; Quayhagen, Quayhagen, Corbeil, Roth & Rodgers, 1995; Quayhagen, Quayhagen, Corbeil, Hendrix, Snyder & Bower, 2000; Quayhagen & Quayhagen, 2001; Corbeil et al. 1999) showing the greatest investment of research with this population. The widest range of interventions, roles of family members and outcomes featured.

Three studies (10%) featured mixed neurological populations (Quayhagen et al. 2000; Damienakis, Crete-Nishihata, Smith, Baecker & Marziali, 2010; Crete-Nishihata et al. 2012), one featured amnesic mild cognitive impairment (MCI) (Moro et al. 2012), and one multiple possible diagnoses (Bier et al. 2008).

One study included participants with herpes simplex encephalitis, limbic encephalitis, Korsakoff's amnesia and ABI (Del Grosso Destreri et al. 2002, Berry et al. 2007, de Fatima Alves Monteiro, Prado Bolognani, Strahler Rivero & Amodeo Bueno, 2011 and McDonald et al. 2011 respectively). These four studies featured the only participants aged below 65 years.

Therefore, the majority of research into memory interventions that utilized family members has occurred within the dementia population and consequently, the older adult population. This research spans the broadest range of methodological designs, intervention types and outcomes measured, with established intervention protocols.

Methodological Quality

Total quality scores of the studies ranged from 25.0% to 89.5%, with a mean quality rating of 62.7%. The three studies receiving the lowest quality ratings, scoring 0 on more than 50% of items were Yarry, Judge & Orsulic-Jeras (2010), de Fatima Alves Monteiro et al. (2011) and Crete-Nishihata et al. (2012). To provide an example, Yarry et al. (2010) omitted details of the patient or family member, qualitative reports by the researcher within sessions provided the only outcome data for evaluating the intervention and both formal outcome measures and statistical analysis were absent.

The checklist items receiving the lowest ratings across studies, with total ratings of lower than 50%, were: "Is an accurate sample size/power calculation reported?", "Was the analysis and interpretation of the data unbiased?", "Are the characteristics of the caregiver clearly described?" and "Are the participants representative of the population from which they were recruited?". The main reason for an unrepresentative sample was high educational attainment of participants. Further methodological issues are discussed in the results to follow.

Part 1 Family roles in interventions

In all but two studies (Damianakis et al. 2010; Crete et al. 2012) the family member received training in skills for implementing memory aids, for example learning how and when to provide assistance to the patient (Moro et al. 2012). Similarly, the second most frequent role of family members was to generalize the intervention to the home environment or daily life. For example, family members provided immediate feedback during rehearsal tasks in clinic and at home (Moore, Sandman, McGrady & Kesslak, 2001). Four studies located the intervention entirely within the patient's home (Moniz-Cook, Agar, Gibson, Win & Wang, 1998; Bier et al. 2008; Vikström, 2008; Neely et al. 2009).

In nine studies, caregivers received psycho-education as a component of the intervention. Nine studies utilized family members in an evaluative role, completing observational and anecdotal notes and documenting memory successes and failures (e.g. De Leo, Brivio & Sautter, 2011; McDonald et al. 2011). Three studies used family

evaluations as the only source of outcome data (Corbeil, Quayhagen & Quayhagen, 1999; Bier et al. 2008; McDonald et al. 2011).

Caregivers individualised the intervention in eight studies, most frequently determining the intervention goals (e.g. de Fatima Alves Monteiro et al. 2011) but also contributing personal information to the intervention, for example, in the form of material for a personal biography (Damianakis et al. 2010). In this study the personal biography was used to stimulate long-term memory and aid the sharing of personal history.

Three studies designed the interventions to meet the needs of the family member in the form of respite and group support (Quayhagen et al. 2000), emotional support and stress relief (Yarry et al. 2010; Moore et al. 2001). Interaction within the dyad was targeted in three studies, including problem solving and more effective communication (Quayhagen et al. 2000). These studies featured multi-component interventions, of which memory skills training was one.

It was noted that seven studies did not clearly document the extent and detail of family involvement or details of the caregiver (Moniz-Cook et al. 1998; Del Grosso Destreri et al. 2002; Schmitter-Edgecombe, Howard, Pavawalla, Howell & Rueda, 2008; Damianakis et al. 2010; de Fatima Alves Monteiro et al. 2011; McDonald et al. 2011; Crete et al. 2012). This was reflected in the quality analysis for this item. For example, de Fatima Alves Monteiro et al. (2011) did not distinguish between the roles of family members and paid carers, and in the study by Damianakis et al. (2010), family involvement was inconsistent between participants and not clearly described. This limited the extent of discussion of family involvement in these studies.

Rationale

Relative to the number of studies employing family members in different roles, the rationale provided for doing so was minimal:

Five studies discussed an advantage of employing the intervention within the patient's daily routine, including immediate feedback and correction (Moore et al. 2001), stability of the intervention (de Fatima Alves Monteiro et al. 2011) and enabling the amount of memory training required (Del Grosso Destreri et al. 2002; Damianakis et al. 2010; Bier et al. 2008).

Four studies discussed preexisting factors, or strengths of family members as impacting upon the achieved outcomes: motivation and effort (Quayhagen et al. 1995; Berry et al. 2007; Bier et al. 2008) and compassion (Yarry et al. 2010) were discussed.

Authors less frequently discussed the value of involving family members in interventions to meet family needs. Two studies discussed addressing the care needs of the family member as being a more robust approach to meeting the needs of the patient and family member (Yarry et al. 2010; Berry et al. 2007).

Summary

The design of family involvement in adult memory interventions was variable. Most frequently, family members received training to implement some component of the memory intervention and enabled the transfer of the intervention into the home setting or daily routine of the patient. Less frequent designs included families evaluating the intervention and individualizing the intervention. Studies directly intervening with family support were in the minority. The detail of, and rationale for family involvement provided was variable, suggesting this was not always predominant in the research rationale or intervention protocol.

Part 2 Evidence to support family involvement in interventions

Cognitive outcomes

Cognition was measured by formal psychometric assessments across multiple cognitive domains in 10 studies (Quayhagen & Quayhagen, 1989; 2001; Quayhagen, et al. 1995; 2000; Moniz-Cook et al. 1998; Moore et al. 2001; Del Grosso Destrieri et al. 2002; Schmitter-Edgecombe et al. 2008. De Leo et al. 2011; Moro et al. 2012). In addition, non-formal, task-specific outcome measures assessed patient cognition in five studies (Berry et al. 2007; Vikström, 2008; Neely et al. 2009; McDonald et al. 2011; Crete et al. 2012).

Whilst cognition was the predominant outcome measure, the expected impact of intervention upon cognition was variable, dependent upon neurological disorder. Positive outcomes in the dementia population were discussed as stabilization or reduced deterioration in cognitive abilities. Equally, improvement in cognitive function was expected in patients with herpes simplex encephalitis and Korsakoff's amnesia, irrespective of the intervention. Therefore improved cognitive scores did not necessarily equate with a successful intervention.

One experiment directly compared family involvement with non-family involvement in the experimental design, documented with different outcome measures in two studies (Neely et al. 2009; Vikström, 2008). A 'collaborative' condition, whereby family members cued retrieval for two internal memory strategies, was directly compared with

an 'individual condition where a research assistant provided cues. On memory outcome measures, authors described an increase in supportive acts in the collaborative condition only, where family members contributed less to a shared object recall task and patients contributed more. The study suggested that family members learnt a supportive hierarchical strategy and applied this to a novel task. Total object recall of the dyad did not change significantly following intervention, but patient recall significantly increased.

Four single-case reports further suggested that family involvement facilitated cognitive change due to home practice of memory aids and support provided by the family member within memory tasks (Del Grosso Destreri et al. 2002; Berry et al. 2007; Bier et al. 2008; Moro et al. 2012). However, these four studies did not control for family involvement with a comparison condition and therefore author interpretations of the value of family involvement should be interpreted with caution. Further limitations included family evaluation of the intervention as a potential source of bias (Berry et al. 2007; Bier et al. 2008), confusion of the causal mechanisms of change with researcher involvement and strategy use independent of the family involvement (Bier et al. 2008; Moro et al. 2012) and stability of the patient's neurological condition (Del Grosso Destreri et al. 2002; Moro et al. 2012).

Quayhagen, et al. (1995) showed stability in patient cognitive abilities (general cognitive functioning, recall memory and verbal fluency) following increased family interaction during scheduled daily activities, an intervention not featuring cognitive stimulation activities. However, Quayhagen et al. (2000) and Quayhagen and Quayhagen (2001) did not repeat these initial findings. Taken collectively, these three studies suggested that active cognitive stimulation with at-home practice supported by families resulted in positive cognitive outcomes.

In summary, the evidence supporting the value of family involvement in memory interventions to facilitate change in patient cognitive performance was limited. Concurrent interventions (including medication) were not consistently documented, further confounding the causal relationship between the memory intervention (and hence family involvement) and cognition as an outcome measure. However, it was likely that at-home memory aid use, with support from a family member 'within' memory tasks, could influence cognitive outcomes. Further research is needed, particularly for studies directly controlling for family involvement in methodological design.

Patient wellbeing

Quayhagen and Quayhagen (1989) provided anecdotal evidence from family reporting that patient confidence, mood and interaction with the family member increased

because of increased family interaction within a cognitive stimulation intervention. Yet, multiple reasons existed for either improved patient wellbeing or family reporting of it, including stable patient memory and behaviour problems in the intervention group compared with decline in the control condition, and a multi-component intervention (of psycho-education, problem-solving teaching and daily activities to create quality time between the patient and family member).

Family wellbeing

Corbeil et al. (1999), Quayhagen et al. (2000) and Quayhagen and Quayhagen (2001) consistently showed that scheduled activities between the patient and family member in isolation of a cognitive stimulation intervention did not impact upon caregiver satisfaction or caregiver coping. Nor did home-based dyadic counselling, respite for family members or group psycho-education and support improve family member mood (Quayhagen et al. 2000).

Teaching the dyad cognitive strategies in multiple domains was shown to support increased caregiver satisfaction, with families learning problem-focused strategies and positive appraisal of coping (Corbeil et al. 1999), but this finding was not repeated (Quayhagen & Quayhagen, 2001). The learning of memory aid use was shown to contribute to family wellbeing (defined as the absence of psychiatric symptoms and mood disorders) (Moniz-Cook et al. 1998; Schmitter-Edgecombe et al. 2008), though these findings also lacked replication (Neely et al. 2009).

In some of these studies it was possible that multiple variables confounded with the cognitive stimulation program (Corbeil et al. 1999; Quayhagen et al. 2000) and memory interventions (Moniz-Cook et al. 1998; Schmitter-Edgecombe et al. 2008) contributed to reported improvement in family mood and satisfaction, including: the frequency of memory aid practice, provision of psycho-education, duration of the intervention, number of cognitive domains addressed and patient cognitive stability.

In addition to formal measures of family wellbeing discussed, case reports from Berry et al. (2007) and Damianakis et al. (2010) documented qualitative feedback from families of the social value of the dyadic interventions, which were reported to increase sharing and enhance family coping.

Yet in contrast, the roles required of family members were recognized as demanding and time-consuming in some studies (Moore et al. 2001; Bier et al. 2008).

In summary, family involvement in memory interventions has been demonstrated across a range of interventions and outcome measurements but involvement did not necessarily result in improved family member wellbeing. Family variables including

stress, satisfaction and mood were shown to improve, though the responsible variables for this improvement remain unknown.

Communication within the dyad

This outcome refers to changes in communication between the family member and the patient.

When controlling for family involvement as an independent variable, Vikström (2008) showed increased collaboration and interaction from the family member on a novel memory task following taught collaborative memory strategy use between the family member and patient. However, the increase was not significantly greater than when families had not learnt to collaborate on memory strategy use.

From anecdotal reports in other studies, enhanced communication and interaction was reported following home-based dyadic cognitive stimulation (Quayhagen & Quayhagen, 1989; 2001; Quayhagen et al. 2000) and interactive skills learning (Yarry et al. 2010). This was explained by active cognitive task involvement, and not increased time spent together (Quayhagen et al. 2000). This conclusion was supported by Corbeil et al. (1999) using a formal marital satisfaction outcome measure.

Anecdotal evidence from family members and researchers also suggested immediate benefits of the joint design of multimedia biographies to be enhanced communication and increased empathy from family members (Damianakis et al. 2010).

Therefore, studies were consistent in documenting the social benefits of family involvement in memory interventions, including increased interaction and communication. There was some evidence that active, collaborative interventions caused improved communication, as opposed to increased time spent within the dyad.

Summary

The available evidence suggests that at-home memory aid practice aided by family involvement, and support from a family member within memory strategy use, can positively influence patient cognitive outcomes. In addition, the most consistent finding was of the social benefits of family involvement in memory interventions, including increased interaction and communication between the family member and patient, particularly resulting from shared, active tasks. Improved family member mood or burden was observed following intervention in some studies though the causal factors were unknown. Patient wellbeing was the least well documented and no conclusions could be drawn as to the impact of family involvement upon this.

Discussion and Implications

This review aimed to document how families have been actively utilized in memory interventions for adults to date in the research literature. This was followed by an evaluation of what impact family involvement had upon any measured outcomes for both patients and families.

Using a systematic protocol, 20 studies were reviewed describing seven broad intervention designs featuring family members. The evidence for the effectiveness of each was variable. Study quality also varied considerably. The research featured the dementia population in older adults predominantly. The implications of the findings are summarized below.

Roles for family members within memory interventions included: receiving information and support, working to improve communication within the dyad, receiving training to implement memory interventions, determining rehabilitation goals, individualizing interventions, and documenting outcomes. It is important to recognize that strong theoretical imperatives exist for each of these roles. Stated briefly, collaborative memory interventions must recognize the role and the needs of the family member for information and support (BSRM, 2003; DH, 2007; Elliott & Pezent, 2008; Vikström, 2008; Neely et al. 2009) expressed in quality standards and both patient (Leith, Phillips, Sample 2004; Alzheimer's Society, 2012) and family self-reported needs (Sinnakaruppan & Williams, 2001). Interventions featuring strategies to improve communication and increase family support recognize the degree of difficulty caused for family members by memory difficulties (e.g. NICE, 2006; Haley et al. 2009; Jennekens et al. 2010) and relationship complexities (Thompson & Walker, 1982). Intervening in a "real world setting" (Camp, et al. 1996, pp.194), in the patient's home, can maximize the gains of rehabilitation, best prepares the family (BSRM, 2003) and can avoid expensive residential care placements (Banerjee & Owen, 2009). Individualization can meet government priorities for patient-centred care (Perry, 2002; DH, 2008; 2009), the value of documenting the outcomes of care interventions is increasingly familiar (Green & Latchford, 2012) and there is a unique and collaborative role for family members to be acknowledged (Thompson & Walker, 1982; Olsen, 2004).

Two important ideas arise from these findings: Firstly, multiple designs for involving family members exist, and these are well supported by theory and by suggested multifaceted gains in real world practice. Second, it is therefore not consistent that family involvement in memory interventions has predominantly been subsidiary to other

elements of intervention, resulting in numerous roles for families with an inadequate evidence base for each. Because few studies implemented comparable interventions and outcome measurement, a much-needed summary of the causal relationship between specific intervention designs and outcomes could not be presented.

Important methodological limitations of studies further limited any meaningful conclusions. As illustrated by the quality analysis, the majority of papers failed to account for potential bias in the interpretation of findings: family and researcher reports of outcomes were not triangulated with more objective measures, limiting the validity of conclusions drawn. Another key methodological limitation concerned the representativeness of participant samples, limiting the generalisability of findings to patients of average and lower education attainment. This limitation is important given the predominance of patient cognition as a measure of outcome. Whilst two papers investigated family involvement as an independent variable in the research design (Vikström, 2008; Neely et al. 2009) other papers did not. This could partly explain the minimal reporting of power size calculations that are required when designing hypotheses-driven research. Uncontrolled variables present in these studies included memory strategy use, elements of multi-component intervention designs not concerning memory aids and organic cognitive changes. Consequently, the impact of family involvement was inferred from inappropriate methods.

Other researchers have reiterated this conclusion that the evaluation of interventions utilising family members is in its infancy (Moon & Adams, 2012). The scarcity of the existing evidence base, upon which quality care standards lay and are therefore validated, is surprising (Shaneyfelt, Mayo-Smith & Rothwangl, 1999; Grol & Grimshaw, 2003).

Importantly, the research situation is incongruent with real world practice (Bowen, Yeates & Palmer, 2010): utilizing family members without this evidenced reasoning prevails in clinical practice. Familial care is provided ultimately and invisibly, when and where it is needed (Oddy & Herbert, 2003; Vikström, 2008; Kreutzer et al. 2009; Wilson, 2009; Foster, 2010; BIRT, 2012). The research literature is subsequently responding, though at a delay.

This review supports family involvement in memory interventions in theory. However, the relationship between family involvement and outcome has not been reliably or validly demonstrated within any outcome domain.

Implications for research

The research literature is currently missing: a clear description of what is meant when discussing rehabilitation provided by family members, the operationalization of useful rehabilitation outcomes and consideration of methodological designs to isolate the effects of family involvement. Each of these is discussed briefly.

No clear definition existed within the featured studies of families as rehabilitators, ultimately concerned with optimizing function and reducing disability of patients and family members (Harada, Sofaer & Kominski, 1993; Wilson, 2002; 2009). Family involvement can be multi-functional, but the different functions must be delineated before each can be evaluated. Active roles for families within cognitive rehabilitation must be differentiated from other roles for families, such as managing symptoms (Schumacher, Stewart, Archbold, Dodd & Dibble, 2000; Wilson, 2002). The predominance of studies featuring the dementia population demonstrated that memory rehabilitation is not restricted to static or improving conditions such as brain injury (Clare, 2009).

Second, the outcomes against which to evaluate family involvement in memory rehabilitation are currently flawed. The aim of rehabilitation is not to improve psychometric test scores or cognitive abilities (Wilson, 2002; 2003), yet this review demonstrated a reliance on patient cognition to evaluate outcome in the research literature. This is a recognized distinction between research and clinical practice (Wilson, 2004): real world evaluation must be individualized, of abilities and real world problems, functioning and participation, and not impairment defined by theoretical models and cognitive testing (Hall, Hamilton, Gordon & Zasler, 1993; World Health Organization, 2001; BSRM, 2003; Wilson, 2009). Outcomes of cognitive rehabilitation extend around the patient to family function (Wilson, 2002). Research studies must decide upon useful outcomes to measure and build upon these preliminary investigations of patient and family wellbeing and communication. Future research must also recognize that all family members are not equally suited or willing to collaborate with the patient in interventions (Gillies & Johnston, 2004; Banerjee & Owen, 2009).

Finally, future studies would benefit from identifying family involvement as an independent variable in methodological design to explicitly evaluate the findings from largely anecdotal and case reporting. Other arising issues in the current review were related to the reliability and validity of the presented findings as assessed by the methodological quality checklist. In particular, future research must adopt unbiased interpretation of results and ensure the generalizability of findings.

The implementation of the most clinically- and cost-effective interventions for adults with memory impairment can only occur according to high quality evidence. Future research will have to address family involvement in memory interventions as being a valuable research question warranting improved research design.

Limitations of this review

Although this review offered a summary of the current evidence base, this did not enable key research questions to be answered. Despite identifying potential new methods of how to involve family members, recommendations made regarding the future implementation of these methods would lack a supporting evidence base. To the author's knowledge, no other review has addressed these questions.

It was also possible that bias was introduced during study selection. Although inter-rater reliability was sought, one researcher conducted the search. Importantly, a substantial proportion of studies were identified via manual searching and contact with key authors. Whilst this demonstrates the nonprominence of this research question in the literature, the implication is that further relevant studies were not retrieved. In addition, although unpublished papers were sought, only one was retrieved in full, introducing the potential for publication bias.

Conclusions

The situation is obscure: family members have multiple important roles in memory rehabilitation, yet there is a paucity of literature documenting the details of how best to utilise family members in adult memory interventions by evaluating this involvement. Although this review has highlighted new potential intervention designs for utilising family members, the evidence to justify each design is in its infancy. This review calls for clarification of the concepts of family involvement in cognitive rehabilitation and outcome measurement and improved methodological design to evaluate the impact of family involvement in memory rehabilitation. These advances can then be reflected in literature and policy.

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PART TWO

EMPIRICAL PAPER

Everyday functioning in individuals with microvascular complications associated with Type 1 Diabetes: How does objective cognitive performance translate into self-reported cognitive skills and diabetes self-management?

This paper is written with the intention of submission to the journal *Diabetic Medicine*⁴

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⁴Appendix B: Diabetic Medicine 'Information for Authors'

⁵Word count excludes abstract, tables and footnotes

Everyday functioning in individuals with microvascular complications associated with Type 1 Diabetes: How does objective cognitive performance translate into self-reported cognitive skills and diabetes self-management?

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Abstract

Aim To investigate how objective cognitive abilities quantified using neuropsychological assessments translate into qualitative accounts of everyday functioning in individuals with Type 1 Diabetes Mellitus (Type 1 DM).

Methods 11 participants with microvascular complications of Type 1 DM were recruited from secondary care diabetes services. A neuropsychological test battery assessed executive and memory skills in all participants. A semi-structured qualitative interview explored individuals' everyday functioning, diabetes management behaviours and self-reported cognitive difficulties. Framework analysis was applied to analyse the qualitative data as a whole and for two separated data sets: participants showing relatively lowered versus unchanged cognitive abilities relative to their predicted premorbid IQ.

Results Differences were not observed between the qualitative accounts of individuals with greater and lesser objective cognitive changes: individuals showing greater cognitive difficulties with cognitive flexibility, working memory span and working memory processing did not self-report greater cognitive difficulties or greater difficulties with everyday functioning and diabetes management behaviours than individuals without objective cognitive difficulties.

Conclusions Findings from this small study suggest that the degree of cognitive impairment consistently detected in individuals with Type 1 DM does not translate into clinically important real world functioning. If replicated using a larger sample with objective measures of real world functioning, findings suggest that neuropsychological assessment should not be used to infer how patients are managing or inform intervention strategies, unless individuals self-report problems.

Introduction

The prevalence of diabetes mellitus is estimated to be 4% of the UK population, with 10-15% of these diagnosed with Type 1 Diabetes Mellitus (Type 1 DM) [1]. Type 1 DM is a metabolic disorder characterized by autoimmune destruction of pancreatic cells resulting in insulin deficiency and high blood glucose levels, or, hyperglycaemia. Insulin replacement leaves individuals vulnerable to episodes of low blood glucose, or, hypoglycaemia, which remains the greatest challenge to optimal glycaemic control [2,3].

Cognitive functioning

The brain is susceptible to structural and functional impairment when its exogenous supply of blood glucose is disrupted during hyperglycaemia and hypoglycaemia [4,5]. Disruption to cognitive abilities has been reported during acute deviations from euglycaemia [6-8]. Yet of greater concern is the cognitive impairment associated with the accumulation of these effects. The growing evidence base recognizes the causal relationship between chronic hyperglycaemia in particular and microvascular pathology: this has been reported to underlie chronic lowered cognitive abilities [9-12].

The most consistent picture of cognitive deficits in adults with Type 1 DM is during tasks that require higher mental efficiency, specifically placing high demands on working memory [13] including visual selective attention, speed of information processing and working memory span. This profile has been shown consistently [14] and across the lifespan [15-17]. Relative to other cognitive domains, memory abilities are under-researched and deficits are inconsistently reported [11,14,18].

The impact of cognitive functioning

Whilst the relationship between diabetes severity and cognitive assessment outcomes has been consistently reported, these findings do not translate into understanding the everyday functioning and diabetes management behaviours of individuals: the relationship between neuropsychological test scores and subjective reports of cognitive difficulties is not linear [19] and the ecological validity of neuropsychological tests is moderate [20]. Currently, research investigating the everyday implications of lowered cognitive abilities in Type 1 DM is limited to neuropsychological assessments of abilities thought to mirror skills necessary for every-day tasks [21].

The current study investigates how objective measures of cognitive abilities assessed using neuropsychological assessments translate into qualitative accounts of everyday functioning and cognitive abilities. To our knowledge, an understanding of the clinical

importance of cognitive changes in Type 1 DM is missing from the literature.

Wessels et al. [22] investigated self-reported memory mistakes using a quantitative checklist and found equivalent difficulties reported by individuals with Type 1 DM as by a control sample. Here we use qualitative methodology to extend these findings, linking subjective accounts with objective measures of cognitive abilities. We present the separate qualitative accounts of individuals showing greater and lesser objective cognitive difficulties. This attempts to further understand the variability of cognitive change and its impact for individuals with Type 1 DM that is missed from group comparisons studies [23].

It is worth noting the multi-faceted requirements of diabetes self-management [24] and the potential circular relationship between deviation from optimal diabetes management and lowered cognitive abilities [25].

Results from the current study will inform the limited guidance available for supporting individuals in managing their diabetes with associated lowered cognitive abilities [26].

Method

Design

Non-experimental comparative design using quantitative and qualitative methods.

Participants

Patients attending one of two secondary care diabetes clinics with Type 1 DM and microvascular complications were invited to participate by diabetes nurses and consultant ophthalmologists. Inclusion criteria served to obtain a sample previously identified as at-risk of lowered cognitive abilities [12,27]. Criteria of microvascular complications were retinopathy of stage 2 or greater, 'high' risk for foot complications, kidney dysfunction of stage 3 or greater or estimated glomerular filtration rate (eGFR) of 177 $\mu\text{mol/l}$ or greater. Age range 18-64 years.

Participants were excluded⁶ if they self-identified neurological illness, brain injury, mental health problems requiring referral to secondary care, current drug or alcohol

⁶Exclusion criteria were consistent with existing literature investigating cognitive performance in individuals with DM1. It is acknowledged that other confounding variables existed and the results will be interpreted within these constraints. Additional exclusion criteria have not been imposed in an attempt to recruit a valid real-world sample of adults with DM1.

dependency, history of heart attack, insufficient visual or auditory functions, English not the first language or diagnosis of learning disability.

Eleven participants agreed to participate and passed their contact details to the researcher. They were contacted via telephone to arrange the postal and clinic components of the study. See Appendix M for sample size calculation.

This research protocol was approved by each site's institutional research ethics committee.

Data collection

Consent, demographics and mood A consent form, demographics questionnaire (requesting details of sex, age and duration of diabetes) and the Hospital Anxiety and Depression Scale (HADS) [28] were mailed to participants and returned in a stamp-addressed envelope prior to interview (see Appendices H and K). Though the research into the validity of the HADS in the diabetic population is limited, the available evidence supports its utility [29]. The HADS served as a screening measure of mood.

Qualitative interview Participants attended one of two diabetes clinics. A face-to-face, semi-structured interview was conducted using scripted questions to ensure topics relevant to the research question were covered consistently [30]. Interview questions were: "How does your diabetes affect you day-to-day? Can you tell us about your experience of managing your diabetes? Have you noticed any changes in your thinking skills (concentration, memory) over time? Do you notice whether any difficulties with concentration or memory affect how you manage your diabetes?" Interviews lasted approximately 20 minutes, were audio-recorded and transcribed in full.

Cognitive assessment All participants were administered a neuropsychological test battery in a standardized order for 60-70 minutes following interview. Participants reported no symptoms of hypoglycaemia or hyperglycaemia at the time of testing and were presumed to be functioning routinely. Tests administered were the Trail Making Test, Sorting and Color-Word Interference subtests of the Delis-Kaplan Executive Function System (D-KEFS) [31], List Learning and Design Learning subtests from the BIRT Memory and Information Processing Battery (BMIPB) [32], working memory span forwards and backwards with randomized digits [33] and the Test of Premorbid Functioning, UK version (TOPF^{UK}) [34]. This battery offered assessment of multiple attentional systems, cognitive flexibility, inhibition, initiation, problem solving and psychomotor speed and of problem-solving behaviour, immediate and delayed, visual and verbal memory, working memory span and estimated general intellectual ability. The battery was selected to detect the profile of cognitive abilities most consistently

reported in the literature [14-17].

HbA_{1C} value Each participant's most recent HbA_{1C} value was retrieved from medical records following data collection, providing a measure of average blood glucose over two-three months.

Analysis

Quantitative

To enhance comparability, neuropsychological test scores were converted to standardized scores using available norms [31,35,36] and presented as z-scores.

95% confidence intervals calculated from z-scores were used to determine the difference between mean scores of the participant group and the normative sample on selected subtests. Whilst lower group SDs were observed for some subtests, the normative sample SD of 1 was assumed to avoid underestimating the width of the intervals. Z-Intervals that did not contain the normative mean (0) were considered to show a reliably different group mean from the normative sample on that subtest, hence a significantly different performance from normative sample at the $p < 0.05$ level [23].

Z-scores of difference, with 95% interval estimates of the effect sizes, were calculated to determine discrepancies between the TOPF^{UK} score and six selected subtests for each participant [37]. The interval estimates show whether a participant's difference between two tests is reliably different from the mean difference observed in the normative population. Correlations between the TOPF^{UK} and six selected subtests were estimated to be as follows: D-KEFS Trail Making Test Number-Letter Switching vs Combined Number Sequencing + Letter Sequencing, 0.3; D-KEFS Color-Word Interference Test Inhibition/Switching vs Combined Naming + Reading, 0.2; D-KEFS Sorting Test Condition 1: Free Sorting Confirmed Correct Sorts, 0.4; BMIPB List Learning A1-A5, 0.2; digit span forwards, 0.7; digit span backwards, 0.7. Correlations were estimated from available data [32,38,39].

A Bonferroni correction for multiple significance tests across subtests could not be applied using the available methods because confidence intervals were fixed at 95% [37]. Correcting for an overall 5% Type 1 error rate for repeat testing across six subtests for each participant (with approximated correlations of 0.5 between all subtests) would require more conservative interval estimates of approximately 99% to detect reliable difference. Therefore, in repeating the difference analysis a total of 66 times across subtests and participants, the risk of a Type 1 error is acknowledged.

Correlations between the selected subtests, HbA_{1c} values, duration of diabetes and age were calculated using pairwise bivariate correlation (Pearson's *r*), analyzed using the SPSS version 20.0 statistical package [40].

Qualitative

Framework analysis was undertaken [41,42]. Themes were developed inductively from the complete data set and were organized beneath a framework to address the research questions. This framework was applied to describe the data set as a whole and then to describe two separated data sets: 1) participants scoring significantly lower than their TOPF^{UK} predicted premorbid IQ on >2 subtests (in attempt to account for a type 1 error), showing relatively lowered cognitive abilities; 2) all remaining participants.

Quality was ensured by adhering rigorously to guidelines of analysis. The method was detailed transparently (see Appendix N) and reviewed by an independent researcher to provide a check that conclusions drawn were a valid reflection of the data. Verbatim quotes were used to qualify the framework. Data from all participants was equally weighted.

Results

Eleven participants were recruited (7 male). Demographic and clinical data are presented in Table 1. One participant opted out of completing all neuropsychological assessments: results of the completed subtests were included. One subtest score of one participant was considered to be an outlier and excluded from the analysis: performance on the Number Sequencing condition was lower and inconsistent with performance on the Letter Sequencing and Number-Letter Switching conditions of the D-KEFS Trail Making Test and was excluded.

Table 1 Demographic and clinical data of Type 1 DM sample

	Type 1 DM participants (n=11)
Age (years)	51.09 (7.80)
Duration of DM1 (months)	392 (191)
HbA _{1c} [‡]	73 (18.76) mmol/mol, 8.9 (1.71) %
HADS [‡]	5.55 (3.88)

Means are presented, standard deviations in parentheses.

[‡]Retrieved from medical records following data collection, taken within 3 months of participation.

[‡]Hospital Anxiety and Depression Scale total score, ≤7 = non-clinical range.

Cognitive tests

Group comparison Participants did not score reliably below the normative mean on any subtest as shown in Table 2. Participants tended to show difficulties- though not reliably below normative performance- with cognitive flexibility and working memory processing.

Table 2 Mean subtest scores (standardised as z-scores) of the Type 1 DM sample

Subtest	DM1 mean (SD)	Z-interval (95%)
D-KEFS TMT	-0.53 (0.39)	-1.15 – 0.09
D-KEFS CWIT	-0.06 (0.61)	-0.65 – 0.53
D-KEFS Sorting	0.40 (0.94)	-0.22 – 1.02
BMIPB List	-0.05 (1.10)	-0.67 – 0.57
DS forwards	0.20 (0.82)	-0.42 – 0.82
DS backwards	-0.27 (0.94)	-0.89 – 0.35

Subtests are: D-KEFS TMT, Trail Making Test Number-Letter Switching vs Combined Number Sequencing + Letter Sequencing; D-KEFS CWIT, Color-Word Interference Test Inhibition/Switching vs Combined Naming + Reading; D-KEFS Sorting, Sorting Test Condition 1: Free Sorting Confirmed Correct Sorts; BMIPB List, List Learning A1-A5; DS forwards, digit span forwards; DS backwards, digit span backwards. Confidence intervals calculated from z-tests show whether means differ reliably from the normative mean.

Individual comparison Results are presented in Table 3. Four participants showed a statistically significant difference between their TOPF^{UK} predicted premorbid IQ and more than two subtests. These participants were considered to represent a subgroup of this sample showing relatively lowered cognitive abilities. This subgroup scored, on average, one standard deviation below their predicted performance. In using individual comparison standards, an individual's score is understood relative to their estimated premorbid abilities, irrelevant of whether the score falls within the average normative range [43]. In this way, an 'average' score might demonstrate a significant change in abilities for the person [23].

Significant correlations between selected subtests, demographic and clinical variables were: age and duration of diabetes both with D-KEFS Trail Making Test Number-Letter Switching vs Combined Number Sequencing + Letter Sequencing ($p < 0.05$), digit span forwards with digit span backwards ($p < 0.01$) and age with duration of diabetes ($p < 0.01$). For correlational data see Appendix O.

Table 3 Standardised subtest scores for all participants (z-scores)

Participant	TOPF	DKEFS TMT	DKEFS CWIT	DKEFS Sorting	BMIPB List	DS forwards	DS backwards
1	-0.46	-0.33	0.00	-0.33	-0.60	-0.40	-1.04*
2 [§]	0.00	-1.00*	-1.00*	0.33	-0.70*	0.35	-0.61*
3 [§]	-0.40	-1.33*	-0.33	0.67	0.30	-0.69*	-1.04*
4 [§]	1.07	-0.67*	1.00	1.00	1.60	-0.40*	-0.18*
5	-0.07	-	0.67	0.67	0.10	1.76	1.95
6	-0.67	-0.33	0.33	-2.00*	-0.60	0.35	-0.18
7	-0.40	-0.33	0.00	0.67	1.60	0.47	0.24
8 [§]	0.07	0.00	0.33	1.00	-1.70*	-0.40*	-1.04*
9	-1.20	-0.67	-0.67	-	-	-	-
10	-0.20	-0.33	-0.33	1.00	-1.10*	1.33	0.24
11	-0.53	-0.33	-0.67	1.00	0.60	-0.40	-1.04*

*Subtest score significantly lower than TOPF^{UK} predicted premorbid IQ ($p < 0.05$) using z-score difference and interval estimates of effect size calculation [37].

[§]Participants with >2 subtest scores significantly lower than TOPF^{UK} predicted premorbid IQ.

Qualitative data

Key findings are summarized here alongside illustrative references. We report here on four themes shown in Table 4.

Cognitive demands of diabetes management

The majority of participants described the all-encompassing and active nature of diabetes management, requiring constant vigilance. This was described as being contrary to a relaxed approach to management or the diabetes managing itself.

“Because it is central to everything you do isn't it. Your diabetes. Everything.” (P10)

“You have to think one step ahead, it is on your mind all the time.” (P9)

“Yes it's something that you can't ever let up and think oh it'll take care of itself today. That doesn't happen.” (P1)

Planning in diabetes management was the theme discussed to the greatest extent. In describing how all-encompassing planning has to be, many discussed the need to be

Table 4 Framework of themes derived from qualitative interview data

1 COGNITIVE DEMANDS OF DIABETES MANAGEMENT

a) Active management

b) Planning

2 EMOTIONAL DEMANDS OF DIABETES MANAGEMENT

a) Worry about management and the future

b) Diabetes as ordinary

c) Support with management

3 EPISODES OF HYPOGLYCAEMIA AND HYPERGLYCAEMIA

a) Awareness of warning signs

b) Temporary changes to cognition

4 COGNITION IN THE LONGER TERM

a) Concentration and memory

b) No changes to cognition

c) Explanations for cognitive change

d) Impact of cognitive changes on diabetes management

constantly aware of time, activity levels, blood sugar levels and eating requirements.

Planning was further understood as:

1) Planning ahead to create structure and routine, particularly in the context of the chaos of work and family life. For example, some participants described usually carrying testing equipment and food.

“Well, just by planning really and looking ahead... and seeing how you are going to work through the day. But you know you just build it in really.” (P1)

2) Planning flexibly: the ability to respond to changing circumstances and balance insulin and food intake accordingly. Examples of challenges included early mornings, travel, shift patterns, job demands, limited food options at buffets and fish and chip shops, caring for others, sports and exercise, nights out and driving.

In relation to reactive planning, participants found the ups and downs of blood sugar levels to be strange and fluid. “Touch wood” was a repeated phrase (P5, P6, P10), used in the context of outcomes being good at the moment. Some participants did not

understand the unpredictable nature of blood sugar going up and down. Some described management strategies as being “trial and error” (P1), “hit and miss” (P9).

“It puts you into a false sense of security you think ‘oh I know what is going to happen now because this is what has happened before’ but it changes. That is the thing I find with diabetes, it is never constant.” (P11)

“And whatever is best at the moment, or whatever works, that is what you have to go with.” (P5)

3) The mathematical component of planning. Some participants described the calculations involved in working out the relationships between different foods, levels of activity, blood sugar levels and the amounts of insulin required.

“I found it very hard trying to fit it in, to sit down and do my sugars, to have my insulin and work out what to eat.” (P7)

Collectively participants described diabetes management as requiring a range of cognitive skills, largely executive abilities of planning, flexible problem solving and calculations. Participants were consistent when describing diabetes management as an ongoing demand on attentional resources.

Emotional demands of diabetes management

The active management of diabetes was associated with worry for some participants. In particular, many explained that the development of microvascular complications suggested that things had not been done correctly and discussed changes made to manage glucose levels more tightly. Some mentioned the seriousness of diabetes and knowing the long-term consequences of not “being careful” (P4).

For some, worry was about feeling embarrassed by the opinion of others and the need to hide or explain their management behaviour.

“I think the biggest problem is embarrassment and maybe doing it in public where you don't know anybody... you felt like a bit of a junkie.” (P3)

In addition, emotional investment was expressed in participants’ relationship with diabetes, described as a fight, of winners and losers. Some mentioned getting things “right” versus “wrong” (P1, P5, P9, P10, P11) and rules that “should” be abided by (P2, P4, P7, P11).

“You have to look after yourself we know that. I'll determine my future. No one else will.” (P10)

These accounts contrasted with “living with” diabetes (P3, P11) and management as being ordinary and inevitable and flexible. Some said that they knew nothing other than managing diabetes.

“But it never really affects me... I just get on with life and that is it... I manage very well. It all fits in nicely.” (P6)

Both attitudes were present within the majority of individual participant accounts.

Support from family members, employers and health care professionals was said to ameliorate and prevent problems that could arise with diabetes. Examples included others being there when needed at times of low blood sugar and others looking out for symptoms of high and low blood sugar. Feeling supported by employers to work flexibly was also valued.

Episodes of hypoglycaemia and hyperglycaemia

All participants used bodily symptoms as measures of blood sugar levels and used these to direct management strategies. Symptoms were individually variable and frequently said to be difficult to describe. Participants predominantly described responding to signs of low blood sugar. Physical symptoms of low blood sugar included tingling in the extremities and trembling, sweating and changes to vision such as seeing floating lights. In addition to physical symptoms, changes to cognition were commonly reported: confusion and disorientation, not thinking clearly and light-headedness, dis-coordination and feeling out of control, jumbling words and finding it difficult to form sentences, difficulties with taking in information and being slowed down. Several participants acknowledged the impact of low blood sugar on driving abilities. Participants increased their blood sugar monitoring around times of driving to avoid low episodes. High blood sugar was associated with a different list of symptoms including lethargy, tiredness, aching legs and cramp, irritability and thirst, with no mention of cognitive changes.

“You know your own body. It's very hard to describe, it's no one thing.” (P4)

“And you get to feel it, you can feel it when you are going low and you can feel it when you are going high.” (P8)

“You get the warning signs, so that you know what to do.” (P6)

Episodes of low, but not high blood sugar were associated with temporary cognitive changes. Participants reacted to both physical and cognitive warning signs with methods to regulate sugar levels.

Cognition in the longer term

Participants noticed changes in a range of cognitive abilities over time, not associated with acute episodes of low or high blood sugar. Changes in memory abilities included recent memories for people's names, conversations and where items had been put and memory for prospective tasks. Memory changes were often qualified with "a bit", "little things", "not majorly", "nothing sudden" or "nothing significant". Less frequently, changes in concentration abilities were discussed. Examples given were losing interest when reading and not feeling "on-the-ball" (P7). Some participants who reported noticing cognitive changes concurrently said "no" and "not really". Some participants reported noticing no cognitive changes.

Participants did not associate cognitive changes with diabetes. Reasons volunteered to explain changes included aging, tiredness, a busy lifestyle, fitness, being lazy, "that's just me" (P5, P10) and changes in memory and concentration being normal.

"I mean everybody forgets little things don't they." (P8)

"I remember things and sometimes I forget things but that to me is really quite standard." (P11)

When asked about noticing how cognitive changes impact on diabetes management, some participants missed insulin injections. This occurred usually on a "busy day" (P5) or when "your mind is on other things" (P2), when distracted, on the "odd occasion" (P1, P11). The circular consequences of cognitive changes were observed in participants forgetting to take insulin injections.

"It's sometimes difficult to remember whether you went through the routine and everything fitted in." (P2)

"Have I injected? Haven't I injected? How much have I injected? Things like that."
(P5)

Using the framework as a point of reference to separately analyse and compare the qualitative accounts of individuals with greater and lesser objective cognitive changes (see Appendix N), meaningful differences were not apparent: the same patterns of self-reported cognitive difficulties, everyday functioning and diabetes management behaviours were consistent within both participant groups.

Discussion

For individuals with Type 1 DM, the real world validity and consequences of lowered cognitive abilities detected using neuropsychological assessment is not yet understood. This study went beyond the known group effects between individuals and a control population [10,11,14,21] to explore the clinical utility of these findings. Qualitative accounts of everyday functioning and diabetes management behaviours of individuals with greater and lesser objective cognitive changes were presented.

Clinically significant cognitive impairment was not detected in this sample at the individual or group level, as expected: whilst statistically significant differences between individuals with Type 1 DM and control sample test scores have been reported [10,11,14,21], the degree of impairment detected falls within normal variability [23]. The statistical significance of our findings at a group comparison level was limited by the sample size and hence the statistical power. However, the degree of difficulty observed with cognitive flexibility and working memory (represented as z-scores) is consistent with the existing literature [10,11,14]. Average blood glucose levels and mood were also comparable with previous samples [10,11,18,21]. Therefore these qualitative findings are a valid extension of existing research.

In addition, our findings went beyond what is known of group differences to understand the degree of cognitive change shown by individuals, relative to their estimated premorbid abilities. The significance of cognitive change for individuals has previously been lost using group comparison when test scores fall within the average range of the normative population [23]. Here, a subgroup of individuals scored significantly below their expected level of performance on a range of objective assessments, including cognitive flexibility, working memory span, working memory processing and verbal memory.

Collectively, participants commonly self-reported subtle changes to memory for recent information and less frequently reported changes to concentration. Not all participants recognized cognitive changes. All individuals who reported memory and concentration difficulties described them as normal and did not associate cognitive change with diabetes. This minimal reporting of longer-term cognitive difficulties is in agreement with previous findings [22].

Of greater interest here: self-reported cognitive abilities were uniform across the sample and were not consistent with objectively assessed cognitive abilities by neuropsychological assessment. Individuals with relatively lowered cognitive abilities, demonstrating significant change from their premorbid abilities, did not self-report greater cognitive difficulties or greater everyday difficulties than individuals with

relatively unchanged cognitive abilities. Therefore, the degree of cognitive difficulties consistently detected in Type 1 DM [10,11,14] did not translate into real world difficulties in this sample.

These findings address the clinical importance of neuropsychological assessment. Everyday difficulties and reduced quality of life cannot be presumed [21,44].

This qualitative analysis emphasised the 'whole individual' managing their diabetes in a responsive and dynamic way. Participants described emotional burden and social support, behavioural management strategies and longer-term risks of diabetes as being interdependent. This shows the potential to prevent and respond to changes in cognitive abilities in a more holistic way, as is recommended more broadly for optimal diabetes management [45,46]. Similarly, the development of competence within habitual and functional routines can reduce the reliance on attentional and executive cognitive abilities and can promote everyday functioning [47]. This protection provided by procedural abilities could help to explain the minimal reporting of everyday difficulties. Such an understanding goes beyond cognitive difficulties understood at the group level as a clinical outcome measure [10,11,18] and shows the value of individuals informing their healthcare [26].

In this study, participants expressed concerns relating to the risk of future physical but not cognitive complications of diabetes. Whilst this preliminary evidence suggests limited real world consequences of mild cognitive complications, knowledge of longer-term cognitive risks could contribute to increased preventative strategies [48]. It is important to recognise that the degree of objective cognitive difficulties being discussed is mild and reported everyday difficulties reflect this. Yet the real world functioning associated with mild cognitive difficulties cannot be presumed to apply to greater cognitive difficulties, and prevention remains a priority. Further exploration of information processing speed and its impact on everyday functioning could also be better understood given the physiological changes in Type 1 DM [12].

In summary, individuals with Type 1 DM showing objective cognitive difficulties with cognitive flexibility, working memory span and working memory processing did not self-report greater cognitive difficulties or greater difficulties with everyday functioning and diabetes management behaviours than individuals without objective cognitive difficulties. Findings from this small study suggest that the degree of cognitive impairment consistently detected in Type 1 DM does not translate into self-reported real world difficulties.

Limitations

Change in cognitive abilities was defined as difference from premorbid ability estimates, yet the predictive validity of the TOPF^{UK} for D-KEFS and BMIPB subtests is not yet known. Whilst individual comparison standards are preferable to cohort comparisons [23,49], longitudinal data is needed to validate these findings. The method of determining subgroups for comparison was also limited by the statistical analysis and the potential for a type 1 error. Future studies should consider multivariate analysis methods with a larger sample.

A participation selection bias could have contributed to the degree of cognitive difficulties measured and reported, limiting the generalizability of the findings: participants volunteered to complete a cognitive assessment battery and discuss their management behaviours. Data was not collected regarding reasons for non-participation. Alternative sampling methods should be considered.

Further research would also benefit from triangulation of self-report accounts with observer ratings and objective data of everyday functioning and diabetes management. Longitudinal changes in accessing of support and blood glucose control would be valuable. Whilst participants reported acute cognitive changes with blood sugar fluctuations and described diabetes management as requiring cognitive investment, it remains possible that minimal reporting of cognitive difficulties reflected a lack of insight into cognitive changes. In particular, executive abilities operate differently in the everyday context than when assessed in isolation using neuropsychological tests and the limited spontaneous reporting of real world difficulties might reflect difficulty with isolating and describing them [50].

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PART THREE
APPENDICES

Appendix A: Reflective statement

Producing this doctoral portfolio has certainly provided me with a wealth of reflective potential. I hope to document my journey through this process, focusing on both the challenging bits and the times of smoother sailing, from start to finish.

I think delving into the world of the unknown was a prospect that I found more frightening than exciting at the beginning. This was because I felt the pressure to carry out a good and worthwhile piece of research whilst it seemed as though good outcomes meant a great deal of crossing your fingers.

I knew that my interests fell within neuropsychology and that the personal experience of each individual was as important to me as scores and test norms. The project was borne from my belief in the importance of understanding individual experiences, as I do in my clinical work, and tying this to the world of research.

After lots of reading and planning and feeling as though I was making lots of progress in the realm of controlled, achievable, academic work, I felt very proactive in submitting to ethics early. I was successful- hooray! and began the real world challenge of recruiting participants. A “simple” and “manageable” design, as advised, didn’t feel ambitious enough at the planning stage. On reflection, perhaps I showed a little too much ambition, or at least had too high expectations of plain sailing.

For the first stage of participant recruitment I had to establish support from multiple NHS sites. This felt difficult and slow. I emailed and visited in person with as much enthusiasm as I could muster, to be continuously passed to another person for approval. Seeking local R&D approval seemed to be another huge hurdle. I just wanted to reach potential participants. Nine months since submission to ethics and I had no participants. I was quickly losing my enthusiasm for research and began to see it as a compulsory struggle. I had thoughts of wishing I had designed a simpler study, without NHS patients. Research days were the worst days.

I think something that I didn’t foresee was how much of the research process I was leaving outside of my own control. I was forever waiting: to be contacted by recruiters, or by potential participants to express interest. And the rate of interest ebbed and flowed. Despite the seemingly manageable sample size required and the number of potential participants in the local areas, this didn’t translate into participation. The potential to stay stuck felt overwhelming. Annual leave and job pressures and staffing changes at the NHS sites put a huge strain on how much I could do. I had to readjust my expectations of participant numbers and the speed with which I could progress. I think I managed the conflict of needing to move forward whilst feeling held back by conducting my systematic literature review early. However, the feeling of uncertainty

and uncontrollability of data collection for the empirical paper was mirrored by the chaos in the literature for my review. 'Platting fog' seemed a fitting metaphor!

But I can see now that the greatest rewards came from these difficulties. Perhaps this is the most valuable lesson I learnt during my research journey.

Whilst months of waiting and frustration equated to meeting with one participant, perhaps this made me value each one all the more. I remember the excitement of hearing from each interested participant. The process of data collection was more in line with my goals as a clinician and researcher. Both the interview and the neuropsychological findings provided a wealth of useful information when looked at in closer detail, which might have been lost with larger participant numbers. And another valuable learning experience was of staying silent during the interviews to hear what people were saying. I learnt how resourceful people can be in coping with difficult life experiences- this is an important message I don't want to forget for my clinical work.

It felt important to represent each participant well, represented together as individuals and not merged. This seemed to be the theme linking the empirical paper and systematic literature review. I concluded in the review that the meaning of impairment in the lives of individuals needed to be at the heart of intervention. Conducting the review highlighted the notable absence of research connecting real world functioning and normed test scores. And this is just what my empirical paper aimed to do.

In retrospect, the variety and challenge of working with other health professionals in real NHS settings with participants is what kept the research exciting. The need to maintain working relationships with recruiters in addition to travel, face-to-face participant interviews and working with both quantitative and qualitative data provided me with enough variety to always be doing something different. On reflection, it was the initial groundwork of meeting with staff and developing personal relationships that made any recruitment possible. The turning points seemed to be discovering the motivation of one or two key people who allowed the wheel to begin to turn. I learnt just how important the people are in facilitating research on a large scale, above and beyond planned strategies. Having a wise supervisor a little bit removed to see the bigger picture also kept me moving forwards.

The research process has built my resilience for tackling bigger problems, delving into uncertainty and tolerating feeling out of control. 'Good enough' was a recurring theme throughout my clinical training, in research and when working in the real world.

I would like to give a special thanks to everybody who has invested their time and efforts into making this research what it is.

Appendix B: Instructions for Authors:

i SLR - Neuropsychological Rehabilitation

Taylor & Francis Online: Neuropsychological Rehabilitation: An International Journal

Instructions for authors

The instructions below are specifically directed at authors who wish to submit a manuscript to *Neuropsychological Rehabilitation*. For general information, please visit the Author Services section of our website.

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Manuscript preparation

1. General guidelines

Papers are accepted only in English. British English spelling and punctuation is preferred. Please use double quotation marks, except where "a quotation is 'within' a quotation". There is no word limit for manuscripts submitted to this journal. Authors should include a word count with their manuscript. Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; appendices (as appropriate); references; table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Abstracts of 150-200 words are required for all papers submitted. Avoid abbreviations, diagrams, and references to the text in the abstract. Each paper should have 5 keywords. Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance here. Authors should supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Section headings should be concise and should not contain numbering. All the authors of a paper should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. The affiliations of all named co-authors should be the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no

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· Acknowledgements should be gathered into a brief statement at the end of the text. All sources of financial sponsorship are to be acknowledged, including the names of private and public sector sponsors. This includes government grants, corporate funding, trade associations and contracts.

· Tables should be kept to the minimum. Each table should be typed double spaced on a separate page, giving the heading, e.g., "Table 2", in Arabic numerals, followed by the legend, followed by the table. Make sure that appropriate units are given.

Instructions for placing the table should be given in parentheses in the text, e.g., "(Table 2 about here)".

· Results of statistical tests should be given in the following form: "... results showed an effect of group, $F(2, 21) = 13.74$, $MSE = 451.98$, $p < .001$, but there was no effect of repeated trials, $F(5, 105) = 1.44$, $MSE = 17.70$, and no interaction, $F(10, 105) = 1.34$, $MSE = 17.70$." Other tests should be reported in a similar manner to the above example of an F -ratio. For a fuller explanation of statistical presentation, see the *APA Publication Manual* (6th ed.).

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2. Style guidelines

- Description of the Journal's reference style
- Guide to using mathematical symbols and equations

3. Figures

· It is in the author's interest to provide the highest quality figure format possible.

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ii Empirical paper – Diabetic Medicine

1. ABOUT DIABETIC MEDICINE

Aims & Scope

Diabetic Medicine, the official journal of Diabetes UK, is published monthly in simultaneous print and online editions.

The journal publishes a range of key information on all aspects of diabetes mellitus and issues regularly include original articles, reviews, reports, editorials, comment, news and correspondence. All material is peer-reviewed. The journal seeks to provide a forum for the exchange of information between clinicians and researchers worldwide and all health professionals responsible for the care of patients with diabetes. Surplus generated from the sale of Diabetic Medicine is used by Diabetes UK to care for, connect with and campaign on behalf of all people affected by and at risk of diabetes.

2. MANUSCRIPT CATEGORIES

Diabetic Medicine invites the following types of submission:

Research articles

Original research articles relevant to diabetes mellitus science and practice are the journal's primary mode of communication. Clinical science and clinically-relevant basic science papers will be considered. Original articles must include a structured abstract (maximum 250 words), should not exceed 3,000 words of text and should be limited to 30 references. Inclusion of supplementary materials in the form of underlying datasets,

multimedia files or accompanying slidesets is encouraged. Authors of qualitative research articles are advised to contact the Editorial Office for guidance on manuscript length prior to submission. Manuscripts should adhere to reporting standards.

Randomised controlled trials should adhere to the CONSORT Checklist. Observational studies should adhere to the relevant STROBE Checklist. Systematic reviews and meta-analyses should adhere to the PRISMA Checklist. Checklists must be completed and submitted electronically with the manuscript using file designation 'Supporting Document NOT for Publication'. For purposes of presentation only, accepted research articles are divided into the following sections:

Care Delivery Complications Educational and Psychological
Aspects Epidemiology Genetics Health
Economics Metabolism Pathophysiology Treatment
Reviews

The journal aims to publish concise, high-quality review articles of recent advances in laboratory or clinical research. Review articles are usually solicited by the Editor-in-Chief but unsolicited reviews are welcome. All will undergo peer-review. Review articles must include an unstructured abstract (maximum 250 words), should not exceed 5,000 words of text and should be limited to 50 references. Use of illustrations and figures is encouraged.

Short reports

Concise reports of original or important observations, short reports should not exceed 1,500 words and are limited to one figure, one table and 30 references. A structured abstract is required.

Case reports

Case reports submitted after 1 May 2012 will be published online-only in Diabetic Medicine. The abstracts of case reports will continue to be published in the relevant print issue. Case reports remain fully citable and will continue to be indexed by PubMed.

Case reports should describe unusual clinical cases and must carry a new or important message. Cases that present a diagnostic, ethical or management challenge, or that highlight aspects of mechanisms of injury, pharmacology or histopathology are deemed of particular educational value. Descriptions of a series of cases stand a greater chance of being accepted. The Editors reserve the right to ask authors to revise a single case report into a Letter to the Editor.

Case reports should not exceed 1,500 words and are limited to 3 tables and/or 3 figures and 20 references. A structured abstract (maximum 250 words) must be provided using the following sub-headings: Background, Case Report, Discussion. The submission of supplementary materials (additional figures, tables, datasets, multimedia files, etc.) which add value to cases is encouraged.

Letters

Items of correspondence may be in response to issues arising from recently published articles, or short, free-standing pieces expressing an opinion. Letters should be formatted in one continuous section and should not exceed 800 words, 1 figure/table and 10 references. No abstract is required. Please give the name(s) and affiliation(s) of authors at the end of the letter. All letters are subject to peer-review.

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Manuscripts must be written in English. Manuscript text must be saved in Word (.doc or .docx) or Rich text Format (.rtf). Please do not submit text in PDF format (.pdf). Figures must be saved as separate figure files. Abbreviations must be defined when first used in the abstract and in the main text, as well as when first used in table and figure captions. Manuscripts must be as succinct as possible. Repetition of information or data in different sections of the manuscript must be carefully avoided. Text must comply with the word limits defined in Section 2, and, where appropriate, include:
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The first page of all manuscripts should contain the following information:

1) the title of the paper (maximum 50 words) 2) a running head not exceeding 75 characters 3) names of authors as initial(s) followed by surnames 4) names of the institutions at which the research was conducted, clearly linked to respective authors 5) name and email address of corresponding author 6) manuscript word count 7) a statement of all funding sources 8) any conflicts of interest disclosures (see Section 5) 9) a bulleted novelty statement (maximum 100 words) which describes the novelty of the data presented and their impact on the field (Research Articles, Short Reports and Case Reports only).

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Authors submitting research articles and short reports should note that structured abstracts (maximum 250 words) are required. The structured abstract should adopt the format: Aims, Methods, Results, Conclusions. Structured abstracts for case reports should adopt the format: Background, Case Report, Discussion. Abstracts should contain no citations to previously published work. Review articles require abstracts but they need not be structured. Letters do not require abstracts.

Text

This should in general, but not necessarily, be divided into sections with the headings: Introduction, Patients and Methods, Results, Discussion, Funding, Conflicts of Interest, Acknowledgements, References, Tables, Figure Legends.

Tables & figures

Tables and figures should not be inserted in the appropriate place in the text but should be included at the end of the manuscript, each on a separate page.

Tables and figures should be referred to in text as follows: Fig. 1, Figs. 2–4; Table 1, Table 2. Each table and/or figure must have a legend that explains its purpose without

reference to the text; legends should include keys to symbols and indicate the statistical significance of differences. Where a figure has more than one panel, each panel should be labelled in the top left-hand corner using lower case letters in parentheses, i.e., (a), (b), etc., and a brief description of each panel given in the figure legend. Colour illustrations are welcomed and all colour is published free of charge to the author. Authors are themselves responsible for obtaining permission to reproduce previously published figures or tables. When an individual is identifiable in a photograph written permission must be obtained (see Section 5 below).

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1. Department of Health. The New NHS: Modern, Dependable. London: The Stationery Office, 1997.
2. Fogari R, Mugellini A, Destro M, Corradi L, Lazzari P, Zoppi A et al. Losartan and amlodipine on myocardial structure and function: a prospective, randomized, clinical trial. *Diabet Med* 2012; 29: 24–31.
3. Eye Care Wales. Screening for Diabetic Retinopathy. March 2009. Available at <http://www.wales.nhs.uk/sites3/page.cfm?orgid=562&pid=12776> Last accessed 1 January 2012.

Reporting standards

Manuscripts should adhere to reporting standards. Randomised controlled trials should adhere to the CONSORT Checklist. Observational studies should adhere to the relevant STROBE Checklist. Systematic reviews and meta-analyses should adhere to the PRISMA Checklist. Checklists must be completed and submitted electronically with the manuscript using file designation 'Supporting Document NOT for Publication'.

Style guide

Diabetic Medicine does not recognise the term 'diabetic' as a noun. Preferred style is 'patient with diabetes' or 'in the group without diabetes', rather than 'diabetic patient' and 'non-diabetic group'. The terms 'Type 1' and 'Type 2 diabetes mellitus' (abbreviated to Type 1 and Type 2 DM) are preferable to IDDM and NIDDM. 'Men' and 'women' should be used in preference to 'males' and 'females'.

Abbreviations & units

Except for units of measurement, abbreviations are strongly discouraged. Avoid abbreviations in the title of the manuscript and in the Abstract. The spelled-out abbreviation followed by the abbreviation in parentheses should be used on first mention unless the abbreviation is a standard unit of measurement.

SI units must be used throughout except for blood pressure (mmHg) and haemoglobin (g/l). Gas or pressure values should be given as mmHg with kPa in parentheses or vice versa. Where molecular weight is known, the amount of a substance should be expressed in mol or appropriate subunit (mmol). Energy should be expressed in kcal or joules (J). The solidus may be used in a unit as long as it does not have to be employed more than once (e.g. mmol/l is acceptable), but ml/min/kg is not acceptable and should be replaced with ml min⁻¹ kg⁻¹.

HbA1c Measurement

Diabetic Medicine has adopted dual reporting of glycated haemoglobin (HbA1c) measurement. HbA1c measurements must be reported in IFCC units (mmol/mol - no decimal point) in addition to derived NGSP units (% - one decimal). IFCC units should be listed first followed by NGSP units in parentheses. A HbA1c conversion table is available [here](#). NGSP SD's can be converted directly to IFCC SD's. To do so the slope of the Master Equation to convert NGSP results to IFCC units must be used. For example: $0.3\% \text{ SD NGSP} = 0.3 \times 10.93 = 3.3 \text{ mmol/mol SD IFCC}$ (then round to the nearest integer).

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Submission of a manuscript will be held to imply that it contains original unpublished work and is not being submitted for publication elsewhere at the same time. The author must supply a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work. Data that have been published as an abstract of no more than 300 words in a scientific meeting are acceptable; the abstract reference should be quoted under the abstract.

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When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) and with the Helsinki Declaration of 1975, as revised in 1983. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate whether the institution's or a national research council's guide for, or any national law on, the care and use of laboratory animals was followed. A statement describing explicitly the ethical background to the studies being reported should be included in all manuscripts in the Materials and Methods section. Ethics committee or institutional review board approval should be stated.

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Appendix C: SLR Selection Strategy

Inclusion criteria

Studies were required to meet seven criteria:

- (1) Published in the English language.
- (2) From peer-reviewed and non-peer reviewed and unpublished sources.
- (3) Featured the implementation and evaluation of a memory intervention of any kind (e.g. internal or external memory aids). Studies that implemented a memory intervention as one component of a wider intervention were included.
- (4) Featured family involvement as a defined component of the intervention protocol.
- (5) Participants with memory impairment of any severity, of any cause.
- (6) Adult participants (≥ 18 years).
- (7) Had primary source quantitative or qualitative data, with any outcome aims.

Exclusion criteria

- (1) Non-English studies.
- (2) Review or discussion papers.
- (3) Only featured psycho-education as an intervention.
- (4) Featured family involvement for evaluation purposes only.

Search strategy

Fields: Abstract

Key words (couple OR spouse OR partner OR dyad OR wife OR husband OR
family OR caregiver)
AND (memory)
AND (interven* OR training OR technolog*)

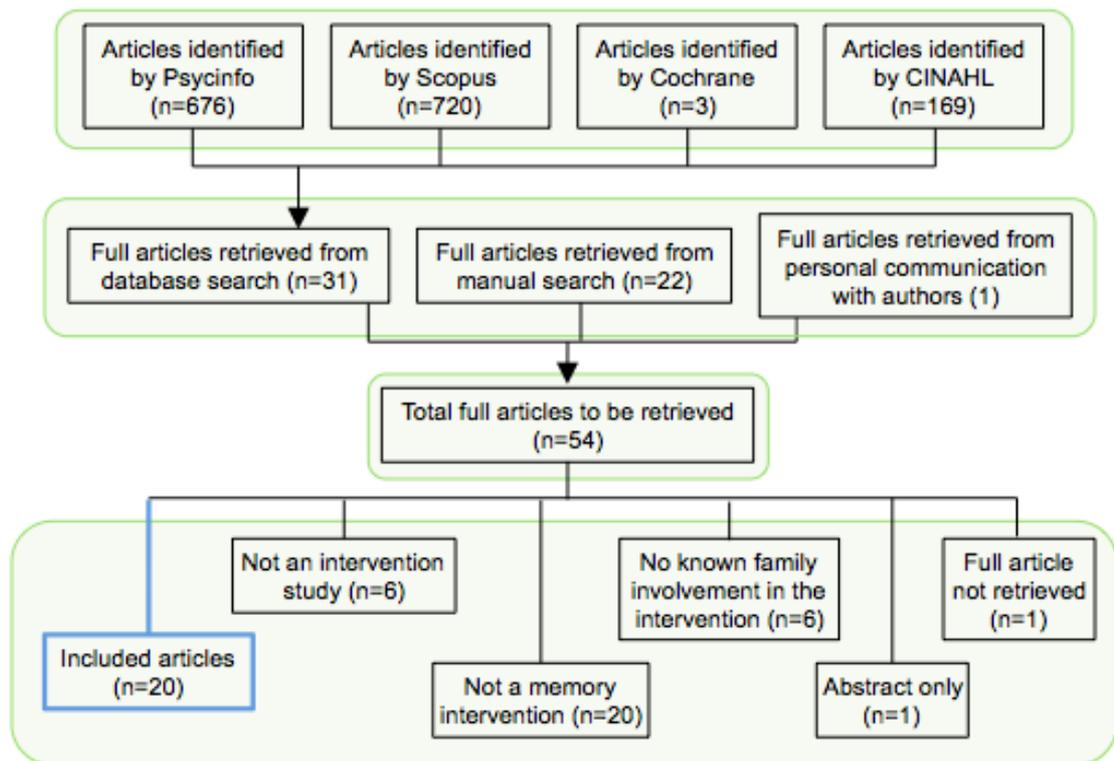


Figure 1 Full search results and the selection of studies for the current systematic literature review

Appendix D: SLR - Excluded Study List

	Study details	Reason for exclusion
1	Berry, E., Conway, M., Moulin, C., Williams, H., Hodges, S., Williams, L., Wood, K., & Smith, G. (2006). Stimulating episodic memory: Initial explorations using SenseCam. <i>Abstracts of the Psychonomic Society, 11</i> , 56–57.	Abstract only
2	Cahn-Weiner, D. A., Malloy, P. F., Rebok, G. W., & Ott, B. R. (2003). Results of a randomized placebo-controlled study of memory training for mildly impaired Alzheimer's disease participants. <i>Applied Neuropsychology, 10</i> (4), 215-223.	No known family involvement
3	Camp, C. J., Foss, J. W., Stevens, A. B. & O'Hanlon, A. M. (1995). Improving prospective memory task performance in persons with Alzheimer's disease. In M. McDaniel and G. Einstein (Eds.), <i>Prospective memory: Theory and applications</i> . Hillsdale, NJ: Lawrence Erlbaum.	No known family involvement
4	Camp, C. J., Foss, J. W., O'Hanlon, A. M., & Stevens, A. B. (1996). Memory interventions for persons with dementia. <i>Applied Cognitive Psychology, 10</i> , 193-210.	Did not feature an intervention
5	Cavanaugh, J. C., Dunn, N. J., Mowery, D., Feller, C., Niederehe, G., Fruge, E., & Volpendesta, D. (1989). Problem-solving strategies in dementia participant–caregiver dyads. <i>Gerontologist, 29</i> , 156-158.	Did not feature an intervention
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Appendix E: SLR - Data Extraction Template

Author(s)	
Title of study and year of publication	
Sample size	
Participants characteristics (diagnosis, age and gender)	
Caregiver characteristics (age, relationship to participant and living arrangement)	
Research aims	
Caregiver involvement	
Study design methodology	
Intervention	
Outcome measures	
Statistical analysis	
Results	
Conclusions	
Methodological quality	

Appendix F: SLR - Quality Assessment Checklist with Study Ratings

	Yes	No	N/A
	1	0	N/A
1	Is the research question/study aim clearly described?		
2	Are the main outcomes to be measured clearly described with rationale?		
3	Are the characteristics of the participants clearly described? Including age, gender, diagnosis or cause of memory impairment and degree of memory impairment.		
4	Are the characteristics of the caregiver clearly described? Including age, relationship to the participant and living arrangements.		
5	Are the participants representative of the population from which they were recruited?		
6	Are the reasons for non-participation and drop-out stated?		
7	Are all components of the intervention clearly described? E.g. is the intervention featuring an internal or external memory aid described to the detail required for replicability?		
8	Is the primary aim of the study to evaluate a memory intervention? (i.e. a defined, stand-alone memory intervention)		
9	Is the memory component of the intervention explicitly evaluated/ considered to be fundamental to the measured outcomes?		
10	Does the intervention protocol clearly document the extent and detail of family involvement in the intervention?		
11	Is family involvement in the intervention considered by authors to be fundamental to the measured outcomes?		
12	Is family involvement in the intervention explicitly evaluated, whilst controlling for principle confounding variables. E.g. is family involvement considered to be an independent variable?		
13	Was the intervention feasible to implement by participants and caregivers in this population- compliance		
14	Were those evaluating the intervention blind/unbiased? Was the analysis and interpretation of the data unbiased?		

- 15 Were appropriate statistical tests used and described? For example non- parametric methods should be used for small sample sizes.
- 16 Is an accurate sample size/power calculation reported? If so, did the study have sufficient power to detect a clinically important effect?
- 17 Have actual probability values been reported for the main outcomes (except where the probability value is <0.001)?
- 18 Were the main outcome measures used accurate (valid and reliable) and relevant to answering the research question?
- 19 Are the findings discussed in relation to the study aims and in the context of study limitations?

Quality Item No.	Neely (2009)	Yarry (2010)	Schmitter-Edgecombe (2008)	Corbeil (1999)	Quayhagen (1989)	Quayhagen (2001)	Quayhagen (1995)	Quayhagen (2000)	Bier (2008)	Vikström (2008)	Moniz-Cook (1998)	Damianakis (2010)	Berry (2007)	Crete-Nishihata (2012)	Moore (2001)	De Leo (2011)	De Fatima (2011)	Moro (2012)	McDonald (2011)	Del Grosso (2002)	Total (%)	
1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	95
2	1	0	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	0	0	85
3	1	0	1	1	1	1	1	1	1	1	1	1	1	0	0	1	1	0	1	1	1	80
4	1	0	1	0	0	1	1	1	0	1	0	0	1	0	0	1	0	0	0	0	0	40
5	1	1	1	0	1	0	1	0	0	1	1	0	0	0	0	0	0	1	0	1	1	45
6	1	NA	1	0	1	0	1	0	NA	1	0	1	NA	NA	0	NA	NA	0	1	NA	NA	50
7	1	0	1	1	1	1	1	0	1	1	0	1	1	1	1	1	0	0	1	1	1	75
8	1	0	1	0	0	0	0	0	1	1	0	0	1	1	1	1	0	0	1	0	0	45
9	1	0	1	0	1	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	85
10	1	1	0	1	1	1	1	1	1	1	0	0	1	1	1	1	0	0	0	0	0	65
11	1	1	1	1	1	1	0	1	1	1	1	0	1	0	1	0	0	1	1	1	1	75
12	1	0	1	1	1	1	1	1	0	1	1	1	0	0	1	0	0	0	0	0	0	55
13	1	1	1	1	1	1	1	1	0	1	1	1	1	1	0	0	0	1	0	1	1	75
14	1	0	0	1	1	1	1	1	0	1	0	0	0	0	0	0	0	1	0	0	0	40
15	1	0	1	1	1	1	1	1	1	1	1	0	1	1	1	0	0	1	1	0	0	75
16	0	NA	0	0	0	0	0	0	NA	0	1	NA	NA	0	0	NA	NA	0	0	NA	NA	7.7
17	1	NA	0	0	0	1	1	1	1	0	1	NA	1	1	1	NA	NA	1	1	NA	NA	73.3
18	0	0	1	1	1	1	1	1	0	0	1	0	0	0	1	0	1	1	0	1	1	55
19	1	0	1	1	1	1	0	1	1	1	1	1	1	0	0	0	0	1	1	1	1	70
Total (%)	89.5	31.3	78.9	63.2	78.9	78.9	78.9	73.7	64.7	84.2	68.4	52.9	76.5	38.9	52.6	50.0	25.0	57.9	52.6	56.3		

Appendix G: NHS Research Ethics Committee Approval; Research & Development Approval

i. REC Conditional Ethical Approval

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ii. R&D Approval: York Teaching Hospital NHS Foundation Trust

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iii. R&D Approval: Hull and East Yorkshire Hospitals NHS Trust

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Appendix H: Participant Consent Form

Version 1.1
Date 13.2.12



Consent Form

Title of research

Everyday functioning in individuals with Type 1 Diabetes: how does cognitive performance translate into diabetes self-management?

Name of researcher

Miss Stephanie Petty

Please **initial**
each box

1. I confirm that I have read and understand the information sheet dated 13.2.12 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the research. I give permission for these individuals to have access to my records.

4. I agree to direct quotes from the interview being used in any research publications.

5. I agree to my GP being informed of my participation in the study.

6. I agree to take part in the above study.

Name of
participant

Date

Signature

Name of
researcher

Date

Signature

Version 1.1
Date 13.2.12

Please tick this box if you would like to receive a telephone call from the researcher to remind you of your research appointment one week before.

Yes I would like to be reminded of the research appointment
one week before.

Please tick

Please tick this box if you would like to receive a summary of the research findings when the project has been completed. The findings will contain anonymous information about all of the research participants grouped together.

Yes I would like to receive a summary of the research findings
by post.

Please tick

This information will be stored securely, in a different place to any confidential data that you submit as part of this research study. There are two copies of this form: one for you to keep and one for the researcher.

Appendix I: Participant Brief Information Form

Version 1.1
Date 13.2.12



Brief Information Sheet

You are invited to take part in a research project. Please read this brief information sheet to see whether you might be interested in taking part. It is entirely up to you to decide if you want to take part. If you decide not to it will not affect the care you receive in any way.

About the research

The main purpose of the research project is to see how people who have Type 1 Diabetes manage their everyday activities.

We will be asking a group of people with Type 1 Diabetes who show physical problems as a result of their diabetes (including problems with their eyes, kidneys or feet) to tell us about their everyday experiences.

The research also looks to see how a person's thinking and memory skills are related to their everyday experiences. We will measure memory and thinking by asking people to complete some tests.

The findings of the study will help us to understand what support people who have Type 1 Diabetes might benefit from.

Can I take part?

To take part in the research you must:

- Have a diagnosis of Diabetes Mellitus Type 1
- Be aged 18-64 years
- Have at least one physical problems of diabetes which means having problems with *either* your eyes (retinopathy), *or* kidneys (kidney dysfunction) *or* feet (high risk of foot complications)
- Be able to read single words
- Be able to hear well enough to have a spoken conversation
- Have English as your first language

You must not have received a formal diagnosis in the past of:

- Neurological illness
- Brain injury
- Learning Disability
- Heart attack

and you must not have current problems with:

- Drugs or alcohol
- Mental health difficulties such as depression

What does the research involve?

1. We will ask you to complete a 'screening package' posted out to you at home. This will include
 - o a brief mood questionnaire
 - o a form asking for details of your age, sex and the how long you have had diabetes
 - o a consent form.

This should take approximately 20 minutes to complete. A stamp-addressed envelope will be provided for you to post the screening package back to us.

1. You will meet with the researcher- Stephanie Petty, to complete
 - an interview about managing your everyday activities
 - an assessment of your thinking and memory skills.

This appointment will last up to 1½ hours. If possible, this appointment will be arranged to follow your routine diabetes clinic check-up and will take place at the diabetes clinic.

The care you receive will not be affected whether you choose to take part in the research project or not. There will be no payment if you do choose to take part in the research- taking part is voluntary.

If you would like to find out more about taking part in this research
Please

- contact the researcher, **Miss Stephanie Petty on 07540477818** to leave your name and contact number. The researcher will call you back
- or
- fill in the slip below and hand it to a member of staff at the diabetes clinic. The nurse will pass these details to the researcher and the researcher will call you.

Kind regards,

Stephanie Petty
Researcher

I would like to find out more about the research project run by Miss Stephanie Petty. Please pass these details to her so she can call me with more information.

Name:

Telephone number:

The best times to contact me:

Appendix J: Participant Information Sheet

Version 1.1
Date 13.2.12



Dear

Following our telephone conversation, here is the screening package for the research project looking at **how people who have Type 1 Diabetes manage their everyday activities**.

Please

1. read this information sheet
2. read and sign the consent form
3. complete the Hospital Anxiety and Depression Scale (HADS) mood questionnaire
4. complete the short Demographics Questionnaire
5. use the stamp-addressed envelope to post these forms back to the researcher if you would like to take part in the research.

You can change your mind about taking part in the research at **any time**. If at any time you decide you no longer want to take part in the research, please let the researcher know. If you do not return the forms above to the researcher you will not be contacted again and will not participate in the study.

If you do want to take part in the research and do return the HADS, demographics questionnaire and consent form, we will meet on:

We will meet for up to 1½ hours in total.

If you have any questions or if you want to change your research appointment, please contact the researcher- Miss Stephanie Petty.

Information Sheet

We would like to invite you to take part in our research study. Before you decide whether to take part we would like you to understand why the research is being done and what it would involve for you.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please ask the researcher if there is anything that is not clear. Please talk to others about the study if you wish.

Part 1

Title of the research

Everyday functioning in individuals with Type 1 Diabetes: how does cognitive performance translate into diabetes self-management?

What is the purpose of the research?

The main purpose of the research project is to see how people who have Type 1 Diabetes manage their everyday activities. We will be asking a group of people with Type 1 Diabetes who show physical problems as a result of their diabetes (including problems with their eyes, kidneys or feet) to tell us about their everyday experiences. These physical problems of diabetes are sometimes called 'microvascular complications'.

The research also looks to see how a person's thinking and memory skills are related to their everyday experiences. We will measure memory and thinking by asking people to complete some tests.

The findings of the study will help us to understand what support people who have Type 1 Diabetes might benefit from.

The research will form part of a research degree.

Why have I been invited?

You have been chosen to take part because you meet the following criteria:

- have a diagnosis of Diabetes Myelitis Type 1
- are aged 18-64 years
- have at least one physical problem of diabetes which means having problems with *either* your eyes (retinopathy), *or* kidneys (kidney dysfunction) *or* feet (high risk of foot problems).

A specialist diabetes nurse who works directly with you thought that you may be interested in taking part.

Around 20 people will take part in the research in total.

Do I have to take part?

No, It is up to you to decide to join the study. Please read this information sheet and contact the researcher if you have any questions. If you agree to take part, please

sign the consent form.

You are free to withdraw at any time, without giving a reason and your information will not be used. This would not affect the standard of care you receive.

What does the research involve?

1. Completing three forms posted to you in this screening package and posting them back to the researcher in the stamp-addressed envelope provided. These are:

- The HADS mood questionnaire
- The demographics questionnaire
- The consent form

2. If you return the written consent form giving your permission, the researcher will access the records held within your diabetes clinic to record two pieces of information:

- any physical problems of diabetes that you have. The researcher will only record information of whether you have complications with your eyes, kidneys or feet and how severe this is.
- The most recent measure of your average blood glucose level. This is measured by a HbA_{1c} value.

You do not need to do anything for this step.

3. You will meet with the researcher- Miss Stephanie Petty. The research appointment will take place in one session that will take between 1 and 1½ hours. This will take place in the hospital diabetes clinic that you routinely attend. The research appointment will include

- answering some questions about your everyday experiences. The researcher will record your answers on a Dictaphone.
- completing a number of 'pen-and-paper' tasks with the researcher which assess your thinking and memory skills.

The research aims to get an idea of how you are usually, everyday, and for this reason you must be feeling well at the time of the research appointment. Your wellbeing is more important than the research. During the research appointment you can take breaks, go to the toilets and eat or drink any refreshments that you bring. You are encouraged to bring food and drink to best take care of yourself. There are seven pen-and-paper tasks in total that assess your thinking and memory skills. Each will take approximately 5-10 minutes to complete. You can take breaks at any time during the research appointment.

If you experience any symptoms of low or high blood sugar (hypoglycaemia or hyperglycaemia) or feel unwell before or during the research appointment, the assessment will not go ahead and your results will not be used for the study.

During the research appointment, yourself and one researcher will be present. You will not meet other research participants. The appointment will take place in a private clinic room at the diabetes centre that you routinely attend.

After the appointment has finished, you will not be approached again, or asked to provide follow-up information.

If any concerns are raised for you as a result of taking part in the research, you will be encouraged to speak with the specialist diabetes nurses or with your GP. With your permission, a brief letter will be sent to your GP letting him/her know that you are taking part in this research study. This is in case you want to speak to your GP about any concerns following taking part in the study.

Will my information be kept confidential

Yes, all of the information that you provide will be kept confidential. We will follow ethical and legal practice and all information about you will be handled in confidence. The only people who have access to this information are

- the main researcher- Miss Stephanie Petty
- the research supervisor- Dr Catherine Derbyshire.

All information will be stored securely either in a locked filing cabinet at The University of Hull or on a secure, encrypted memory stick.

Quotations from the interview may be used in publications of the research. However, any information used when writing about the research findings will only use anonymised information. This means that no names or personal details will be used in the research so that yourself or anybody you mention will not be identified.

The researcher will only share information with other people if you tell us about an immediate risk of harm to yourself or other people. The researcher will then have to tell a member of your treating team.

All personal data, including the audio recordings of the interview, will be destroyed three months after the study has been completed. This will be no later than 30th September 2013.

Expenses and payment

Expenses or payment are not available for this study.

What are the possible disadvantages and risks of taking part

Some people can feel tired or anxious when completing the tasks used to assess thinking and memory skills. But the assessment will go at a pace comfortable to you and you can take breaks or stop at anytime. This part of the appointment will take up to an hour.

You may choose to talk about sensitive topics during the interview, but you will not be asked to do so.

You will be directed towards the specialist diabetes nurses or to your GP if you have any concerns or require further support following the research.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help us to better understand how people with Type 1 Diabetes manage on a day-to-day basis.

What happens when the research study stops?

At the end of the study you will be able to ask any questions that you have. After this, there will be no further contact, unless you have indicated that you would like to be informed of the results of the study.

Part 2

Will my taking part in this study be kept confidential?

- Your participation in this study will be kept confidential.
- All questionnaire data will be anonymised and identified only by a participant number that is given at the beginning of the study. Your name will not be used in any report or published document.
- All data will be stored in a secure place for 5 years, whilst the results of the research are being prepared for publication. After this, all questionnaires etc. will be destroyed.

Involvement of the General Practitioner/Family doctor (GP)

Your GP will not receive any personal information that you give to the researcher as part of the study. All study information will remain confidential. During the study, if the researcher has concerns that you are experiencing depression you will be advised to inform your GP of this. Your participation in this study will not affect your current or future medical or psychological treatment.

Only if the researcher is told about an immediate risk of harm to yourself or to other people will she have to share this information with a member of your treating team.

What will happen to the results of the study?

You will not receive individual feedback about any information you give during the research. All of the information will be anonymised. A summary of the research findings can be posted out to you when the research has finished and this will include information given by all anonymous participants grouped together.

It is intended that this research will be published in a peer-reviewed journal, which is accessible to the public.

What will happen if I don't want to carry on with the study?

You may withdraw your participation at any stage of the study, up to seven days after completing the study. Following this time, it may not be possible to remove your data from the analysis. There will be no negative consequences of withdrawing from this research.

What if relevant new information becomes available?

Sometimes new information about the disorder being investigated becomes available whilst the study is being completed. If this happens, the researcher will tell you and discuss whether you should continue in the study. You may be asked to sign an agreement outlining this discussion.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details of this will be available from your local hospital. You can also contact NHS Direct on 0845 4647 for advice about making a complaint.

Harm

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for legal action for compensation against the Humber NHS Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Who is organising and funding the research?

The chief investigator is being paid to carry out this research by the Humber NHS Foundation trust as part of their job role. However, this piece of research is receiving no external funding, and there are no identified conflicts of interest.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by Yorkshire and the Humber NHS Research Ethics Committee.

Contact details

Miss Stephanie Petty

Tel 07540477818

Address Miss Stephanie Petty
Department of Clinical Psychology and Psychological Therapies
Hertford Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Email stephaniepetty@hotmail.com

Further information

If you would like further information on taking part in research you may wish to look at the NHS Choices website: <http://www.nhs.uk/Conditions/Clinical-trials/Pages/Introduction.aspx> or the National Research Ethics Service: <http://www.nres.npsa.nhs.uk/>

Thank you for considering taking part in this study and taking the time to read this information sheet.

Appendix K: Demographics Questionnaire

Version 1.0
Date 21.12.11



Demographics Questionnaire

Please answer the following questions.

1. Sex: Male Female Other

2. Age: (years)

3. How long have you had a diagnosis of Type 1 Diabetes?

..... (years)

..... (months)

Appendix L: GP Letter

Version 1.0
Date 13.2.12



Miss Stephanie Petty
Clinical Psychology Department
Hertford Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Dear Dr

RE:

Address:

Date of Birth:

I am writing to inform you that the above patient has consented to take part in a research study conducted as part of a university doctorate. The research is looking into the cognitive abilities of people who have Type 1 Diabetes and have associated microvascular complications. A participant information sheet is enclosed which describes the details of the study. Should the participant have any concerns raised by taking part in the study they will be advised to contact yourself. Should you have any queries please do not hesitate to contact me on 07540477818.

Yours sincerely,

Stephanie Petty
Trainee Clinical Psychologist

Appendix M: Sample size calculation

An assumed standard deviation of 1, mean of 0 and a hypothesized mean of -0.67 for the Type 1 DM population gave an effect size of 0.67. To detect this with 80% power using a 5% significance level and a two-tailed one-sample t-test, 20 participants would be required. A hypothesized mean of -0.67 represents the upper-estimate of the degree of cognitive difficulties shown to be statistically significant from the control sample in the literature [14]. The upper estimate was selected given the inclusion criteria of microvascular complications in this sample and the estimated greater degree of cognitive difficulties.

Appendix N: Data Analysis – Framework analysis

1) Familiarization

All interviews were read in full to gain an overview of the entire data set. This served to appreciate the depth and variety of ideas present.

2) Identifying a thematic framework

Recurrent themes were listed and broadly grouped beneath headings of more abstracted or conceptual ideas. In a 'back and forth' approach, the framework was used as a sieve to read the interviews through and was subsequently edited to incorporate the breadth of individual accounts.

Example First framework.

3. *The challenges of diabetes management*

a) Pre-planning

i "It's in my coat pocket now" / "exhibit A" / "Too many ifs" / "More obstacles are thrown at you". Driving.

3) Indexing

This framework of headings and subheadings was used to sort the entire data set: all text falling beneath a heading was given an index reference from the framework (i.e. '3 a) i'), creating manageable "bites" of text (pp.180). These 'bites' were pulled from the interviews and organised beneath the framework. This attempted to demonstrate clearly how the researcher had sorted the data. It also presented the data in such a way that patterns within and across themes could be better identified.

Example Bites of text indexed as '3 a) i'.

3. *The challenges of diabetes management*

a) Pre-planning

i "It's in my coat pocket now" / "exhibit A" / "Too many ifs" / "More obstacles are thrown at you". Driving.

“You have to do pre-plan everything ... you have to be a little bit more structured to allowing time for to have your breakfast before you leave on morning to test your blood sugar first thing. Well, just by planning really and looking ahead and seeing you know what that day you've got on and how you are going to work through the day. But you know you just build it in really.” (P1)

“Yes yes, it's in my coat pocket now. It's usually with me.” (P2)

“And I also take into account what I've done during the day, when my next meal is, what size my next meal is, is it a short break between the last meal and this meal. I always have [glucose tablets] with me, exhibit A.” (P4)

“I carry glucose tablets” (P5)

“But we do carry stuff, [chocolate] bars, [glucose tablets]. We always carry glucose.” (P9)

“So I have to make plans put generally it doesn't hold me back. But I have to keep aware of what I am eating, what I am doing, where I am going, make sure I have my rucksack with me with my meter. Depending on what I am doing and where I am going I might have a sandwich, just making sure I have something.” (P10) ...

4) Charting

The indexed data was rearranged beneath appropriate headings and subheadings to address the research questions. The ‘bites’ of text were translated into useful summaries that abstracted meaning across individual accounts. Illustrative examples of verbatim text were retained.

Example Revised framework.

1. COGNITIVE DEMANDS OF DIABETES MANAGEMENT

a) Active management

b) The need to plan

“Planning in diabetes management was the theme discussed to the greatest extent by participants. When describing how all-encompassing planning has to be, many discussed the need to be constantly aware of time, activity levels, blood sugar levels and eating requirements. Planning was further understood as: 1) Planning ahead to

create structure and routine 2) Planning flexibly 3) The mathematical component of planning.”

Well, just by planning really and looking ahead... and seeing how you are going to work through the day. But you know you just build it in really. (P1)

At this stage, separate charts were constructed for the two participant groups of interest: 1) individual showing relatively lowered cognitive abilities, ‘lowered’ 2) individuals showing relatively unchanged cognitive abilities, ‘unchanged’. The accounts of the two groups were translated into useful group summaries.

Example ‘Lowered’

“Yes yes, it’s in my coat pocket now. It’s usually with me.” (P2)

“And I also take into account what I’ve done during the day, when my next meal is, what size my next meal is, is it a short break between the last meal and this meal. I always have [glucose tablets] with me, exhibit A.” (P4)

“So I have to make plans put generally it doesn’t hold me back. But I have to keep the aware of what I am eating, what I am doing, where I am going, make sure I have my rucksack with me with my meter. Depending on what I am doing and where I am going I might have a sandwich, just making sure I have something.”

‘Unchanged’

“You have to do pre-plan everything ... you have to be a little bit more structured to allowing time for to have your breakfast before you leave on morning to test your blood sugar first thing. Well, just by planning really and looking ahead and seeing you know what that day you’ve got on and how you are going to work through the day. But you know you just build it in really.” (P1)

“I carry glucose tablets” (P5)

“But we do carry stuff, [chocolate] bars, [glucose tablets]. We always carry glucose.” (P9)

5) Mapping and interpretation

From charting, the data as a whole was reviewed and interpreted. The importance of certain issues and the meaning of these were discussed. In particular, patterns across

the two groups were explored and possible explanations for any differences were discussed.

Example

“...self reported cognitive abilities were not consistent with objective cognitive abilities assessed using neuropsychological assessment.”

See Ritchie and Spencer (1994) for a detailed account of the method.

Appendix O: Correlation matrix

		TOPF	DKEFS_TMT	DKEFS_CWIT	DKEFS_SORTING	BMIPB_LIST	DS_FORWARDS	DS_BACKWARDS	Age	Duration	HbA1c
TOPF	Pearson Correlation	1	-.039	.583	.467	.271	-.076	.140	.257	.318	.015
	Sig. (2-tailed)		.914	.060	.173	.449	.835	.700	.445	.341	.964
	N	11	10	11	10	10	10	10	11	11	11
DKEFS_TMT	Pearson Correlation	-.039	1	.348	-.085	-.273	.236	.164	-.647 [*]	-.736 [*]	.259
	Sig. (2-tailed)	.914		.325	.828	.477	.541	.673	.043	.015	.471
	N	10	10	10	9	9	9	9	10	10	10
DKEFS_CWIT	Pearson Correlation	.583	.348	1	-.084	.244	.106	.444	-.006	.063	-.091
	Sig. (2-tailed)	.060	.325		.818	.496	.771	.198	.986	.854	.789
	N	11	10	11	10	10	10	10	11	11	11
DKEFS_SORTING	Pearson Correlation	.467	-.085	-.084	1	.227	-.010	.044	-.319	-.284	.019
	Sig. (2-tailed)	.173	.828	.818		.529	.979	.904	.370	.427	.959
	N	10	9	10	10	10	10	10	10	10	10
BMIPB_LIST	Pearson Correlation	.271	-.273	.244	.227	1	-.131	.202	-.027	.126	.491
	Sig. (2-tailed)	.449	.477	.496	.529		.719	.575	.940	.729	.149
	N	10	9	10	10	10	10	10	10	10	10
DS_FORWARDS	Pearson Correlation	-.076	.236	.106	-.010	-.131	1	.888 ^{**}	-.631	-.206	.156
	Sig. (2-tailed)	.835	.541	.771	.979	.719		.001	.051	.568	.667
	N	10	9	10	10	10	10	10	10	10	10
DS_BACKWARDS	Pearson Correlation	.140	.164	.444	.044	.202	.888 ^{**}	1	-.571	-.074	.118
	Sig. (2-tailed)	.700	.673	.198	.904	.575	.001		.085	.840	.746
	N	10	9	10	10	10	10	10	10	10	10
Age	Pearson Correlation	.257	-.647 [*]	-.006	-.319	-.027	-.631	-.571	1	.810 ^{**}	-.266
	Sig. (2-tailed)	.445	.043	.986	.370	.940	.051	.085		.002	.429
	N	11	10	11	10	10	10	10	11	11	11
Duration	Pearson Correlation	.318	-.736 [*]	.063	-.284	.126	-.206	-.074	.810 ^{**}	1	-.288
	Sig. (2-tailed)	.341	.015	.854	.427	.729	.568	.840	.002		.391
	N	11	10	11	10	10	10	10	11	11	11
HbA1c	Pearson Correlation	.015	.259	-.091	.019	.491	.156	.118	-.266	-.288	1
	Sig. (2-tailed)	.964	.471	.789	.959	.149	.667	.746	.429	.391	
	N	11	10	11	10	10	10	10	11	11	11

Correlation matrix between selected neuropsychological assessment subtests, demographic and clinical variables. Subtests are: TOPF^{UK}, D-KEFS TMT, Trail Making Test Number-Letter Switching vs Combined Number Sequencing + Letter Sequencing; D-KEFS CWIT, Color-Word Interference Test Inhibition/Switching vs Combined Naming + Reading; D-KEFS Sorting, Sorting Test Condition 1: Free Sorting Confirmed Correct Sorts; BMIPB List, List Learning A1-A5; DS forwards, digit span forwards; DS backwards, digit span backwards.

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

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