Cognitive approaches to enabling people to live well with dementia

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13.1 Introduction

Cognitive deficits are a hallmark feature of dementia, and have a significant impact on the quality of life for people living with dementia and their families. The notion of helping people to live well with dementia is increasingly featuring on national and international public health agendas. Historically, the treatment of people with dementia was embedded in a medicalised approach, in as much as the focus was on treating what were considered to be the symptoms of dementia. These types of views have perhaps also been echoed in the media with representations of dementia focusing on deficits and on people who have been living with dementia for many years, rather than the many people who are striving to find ways to live well with early dementia. There are of course medical treatments which are aimed at slowing the decline, however medications such as actycholinesterease inhibitors, have had modest effects in clinical trials (Birks & Harvey, 2006).

Recent national and international government and policy initiatives emphasise the importance of psychosocial interventions to improve the lives of people with dementia, partly due to the modest effects of pharmacological interventions on cognition. These interventions can be broadly classified as socially orientated or cognitively orientated. This chapter will explore cognitively based interventions (cognitive stimulation, cognitive training and cognitive rehabilitation) that might be useful for supporting the well-being of people with dementia and their families, and familiarise the reader with the steps involved in developing interventions (see Chapter 10 for memory training for cognitively-intact elderly populations).

The interventions we explore will be focused on enhancing the well-being of people in accordance with a person-centred approach (see also Chapters 11 & 12). Person-centred models of dementia care are aligned to a biopsychosocial approach which considers the

psychosocial context of the person alongside the neuropsychological changes in understanding the lived experience of the person. Person-centred approaches necessitate individualised support that takes into account the social and psychological needs of the person in the context of the intervention. To this end we will explore how interventions take account of the individual's needs as part of the process, how they can target the specific nature of the person's deficits and how they take account of the individual's personality and social context.

13. 2 How Cognitive Changes Impact on Everyday Functioning in Dementia

Cognitive abilities are important for all aspects of our everyday functioning. Everyday memory refers to the types of memory that are important for the activities that we complete on a day to day basis, such as navigating our way to work, doing the shopping, or remembering where you parked the car. Investigations about how everyday memory works have primarily been concerned with the functional aspect of memory, i.e. what memory is for. One of the challenges for investigating how everyday memory works (and thus what happens when it stops working) is ensuring that the research is ecologically valid, i.e. the methods, materials and setting of the research approximate the real-world that is being examined. Bruce (1985) stated that ecological memory research must consider how memory operates by identifying the underlying cognitive processes involved, what function it serves, and why it has evolved in this way.

There is a historical debate as to how best to investigate everyday memory function; whether to investigate everyday memory problems by conducting experiments in naturalistic settings, claimed to be more ecologically valid, or in traditional laboratory settings. Conventionally the

main difference between these approaches is methodological: traditional laboratory approaches are conducted in clinical laboratory settings using controlled methods, whereas naturalistic approaches are more ecologically representative but less scientifically controllable (Banaji & Crowder, 1989). The problem of studying everyday memory in laboratory settings is known as the real-world laboratory dilemma, the objective of everyday memory research being to maintain a balance between scientific validity and ecological validity.

Contemporary research makes less of a distinction between these approaches, with scientific investigations frequently incorporating ecological aspects in laboratory settings. Broadly, two approaches to studying everyday memory arose in response to the real-world laboratory dilemma. The first was to generalise laboratory findings to everyday settings, and the second was to identify everyday memory problems that are not currently accounted for by memory models (Baddeley, 2004). Taking the first approach, the idea was to swap stimuli that are not ecologically valid (i.e. unrelated word lists) for ecologically valid stimuli such as songs or rhymes. An example of the second approach is studying memory difficulties, such as prospective memory, i.e. our capacity to perform an action at a specified point in the future. This is pertinent to the development of cognitive interventions since it is recommended that the combination of real world and laboratory approaches works well in understanding of everyday memory problems in clinical populations (Baddeley, 2004).

13.2.1 Types of Everyday Memory

There are different types of everyday memory which are important for everyday functioning and can be affected by the clinical changes of dementia. As an introduction, here we consider autobiographical memory, prospective memory and meta-memory. It is important to

understand the impact of dementia on these cognitive functions, so that interventions can be targeted to compensate.

Autobiographical memory (AM) has been defined as the ability to remember past events from one's own life (Kopelman et al., 1989). Williams et al. (2008) assert that AM has several functions: a directive function (using memories of past events to guide and direct our future behaviour) a social function (to build and maintain friendships by sharing personal narratives), and a self function (to build and maintain personal identity). As such, AM is of fundamental significance for the self, emotions, and the experience of personhood (i.e. enduring as an individual over time; Conway & Pleydell Pearce, 2000). Research has shown that degradation of AM can lead to an impaired sense of personal identity, in addition to being associated with depression (Williams et al., 2008). Investigation of AM in Alzheimer's disease (AD) has indicated that degradation of AM is related to changes in self-concept and personality (Addis & Tippet, 2004).

There is general agreement that AM consists of personal facts and personal events or incidents (Kopelman et al., 1989). Personal incident memory refers to the episodic component of autobiographical memory and includes memory for specific events located in time and space, while personal factual memory is associated with personal information that is not event-based (Conway & Pleydell-Pearce, 2000). AM is usually investigated by assessing individuals' representations of their past experiences, including the content of the experiences and their spatial-temporal context. Tulving (1985) proposed that the ability to recall past events depends on autonoetic consciousness (conscious experience accompanied by a sense of the self in the past). The factual information associated with AM (e.g. place of birth, where we live, names of friends, schools attended) is one facet of semantic memory, and has been

described as personal semantics (Cermak & O'Connor, 1983; Kopelman et al., 1989) or personal autobiographical facts (Conway & Pleydell-Pearce, 2000). Unlike episodic AM (for personal events), semantic memory (for personal facts) is associated with noetic consciousness (knowledge without a sense of self in the past).

AM is affected in different ways for people with different profiles of impairments. For example, people with Alzheimer's disease (AD) typically have difficulties with recalling the episodic components of AM, particularly for recent events. AM is affected to the extent that people with AD cannot relive the experiences of their personal history, i.e. recollect past personal events in detail (Piolino, 2003). People with semantic dementia also have problems with retrieving episodic details to some extent (Piolino, 2003), but recent memories are better remembered than remote memories (Snowden et al., 1996; Graham & Hodges, 1997; Piolino et al., 2003; Hodges & Graham, 2001), which may have become semanticised (consolidated) over time. People with Parkinson's disease have a slightly different profile of problems: they have difficulty accessing recent episodic memories, but this may be may related to problems accessing the details rather than the integrity of episodic memory itself (Smith et al., 2010). We have presented an overview of the different cognitive processes implicated in AM in Table 1.

<<Table 1>>

Prospective memory (PM) refers to remembering to carry out plans and intentions: this is crucial for tasks such as remembering to buy milk, keep a doctor's appointment or take medication. Estimates indicate that up to 80% of everyday memory difficulties involve PM failures (Crovitz & Daniel, 1984). Additionally, people with diminished PM function may

encounter difficulties carrying out activities of daily living, which may influence quality of life (McDaniel & Einstein, 2007). In characterising PM, Einstein and McDaniel (1990) proposed that it is comprised of two components. Firstly, a retrospective component, which refers to the ability to recall what it is you have to do and when you have to do it. Consequently, completing PM tasks relies on the retrieval of the specific actions to be performed, implicating the declarative memory system responsible for retrieving previously learned facts. However, recalling instructions is not sufficient to perform a PM task. It also necessitates interpretation of an external event as a cue to action, and/or an internal impetus to act (i.e. buying milk when you see a shop), accordingly PM also includes a prospective component. The prospective component of PM requires self-initiation, as it necessitates that a person remembers to remember (Craik, 1986).

Einstein and McDaniel (1990) proposed an important distinction between event-based and time-based PM. Time-based PM refers to the initiation of an activity at a given time, i.e. "At 2pm I must take my medication", whereas event-based PM involves initiating an action in response to an external cue, i.e. "I must get a repeat prescription the next time I visit the GP". As such PM tasks can be classified in different ways, dependent upon the PM cue that is presented (Kvavilashvili & Ellis, 1996). This diversity in the contextual demands of different PM tasks means that some are more attentionally demanding than others. The accepted view is that time-based PM tasks require more cognitive effort than event-based PM tasks (Craik, 1986; Einstein & McDaniel, 1990). In event-based tasks the required behaviour is prompted by an external cue, e.g. responding to a given word in the context of an ongoing task (Einstein & McDaniel, 1990), whereas, time-based tasks rely more on self-initiated mental processes such as checking the time, rather than on contextual cues for the restoration of the remembering state.

Age related differences have been observed on both event-based and time-based tasks, although the impairments are more evident in time-based than event-based tasks (D'Ydewalle et al., 2001; Einstein et al., 1995; Henry et al., 2004). It is hypothesised that the impairments observed are due to the relation of PM tasks to resource demanding self-initiated processes, which are implicated more in time-based tasks (Prull et al., 2000) and are thought to depend upon executive functioning, a cognitive ability that is affected by ageing (Bunce, 2003). Clinically, people with AD can perform poorly in PM tasks due to impairments related to the retrospective component, i.e. recalling what it is they have to do (Jones, Livner & Backman, 2006), whereas people with more frontal-like impairments, such as Parkinson's disease, have problems with tasks requiring self initiation, i.e. time based tasks, but can still retrieve the details of the instructions (Smith et al., 2012).

Everyday memory also pertains to the use of memory strategies and awareness of memory (metamemory). When planning to complete a list of chores, for example, people often start with the chore that they believe they are most likely to forget. Whilst doing the chores they may also have to add or cross off chores from the list as they go along. This means they must monitor their progress; deficient monitoring might lead to missing a chore or appointment, or to repetition or over-checking (Koriat, Ben –Zur, & Sheffer, 1998). Thus, effective self-management of everyday memory relies on accurate knowledge of our abilities and effective on-line monitoring during everyday activities so we can update our knowledge about our memory function to suit our needs.

The metamemory framework provides a conceptual model of these issues (Nelson & Narens, 1990). It suggests that memory operates on two interrelated levels: the object level (where

our memory processes operate) and the meta-level (which contains our knowledge and beliefs regarding our memory function). Information is exchanged between these levels via two processes: monitoring and control. Monitoring refers to the collation of information regarding memory performance. Monitoring may be considered analogous to "listening" through a telephone handset. Control refers to the process by which we use this information to self-regulate our performance. If an individual frequently forgets items when they are shopping, for example, they will monitor this forgetting behaviour. They can regulate their memory performance by providing themselves with cues, like a shopping list (i.e. control), which should improve their performance. This reciprocal relationship suggests that proficient memory function relies on effective metamemory function (Dunlosky & Connor, 1997; Nelson & Narens, 1990).

One way of understanding the relationship between monitoring and control processes is by using recall-readiness tasks. This procedure involves offering a list of items to learn, indicating that participants can spend as much or as little time learning the items as required. One would expect individuals to adjust their study time with regards to the ease of the items to recall, for example, the word "dog" is an easier word to learn than "cataclysmic", thus one would spend longer learning the word cataclysmic than dog. Using this paradigm it has been shown that older adults have difficulty allocating extra study time to difficult tasks (Souchay & Insingrini, 2004). However, when older adults are trained to monitor their study through self-testing, they are able regulate their study time more effectively (Robinson et al., 2006).

In summary, it is useful to know more about the nature of people's everyday memory problems so that we can offer targeted support to compensate for the specific types of problems people are having. For example, if someone is frequently missing appointments, is

it a) because they forget the details of the appointment or making the appointment (episodic memory), b) a problem with initiating their response to appointment time (prospective memory), or c) they have forgotten that have difficulties remembering appointments and failed to compensate for this deficit (metamemory). The different underlying cognitive problems may have different implications for the approaches and support that we offer.

13.3 The Major Types of Cognitive Intervention for Dementia

The main approaches to improving everyday memory functioning of people with dementia are cognitive training, cognitive stimulation and cognitive rehabilitation. These are all based, at least to some extent, on the application of cognitive science. They share two underlying premises: firstly, that it is possible for people with dementia to improve their ability to carry out day-to-day activities and tasks through strengthening extant brain function, which may be under par due to a lack of opportunity or a lack of confidence; and secondly, that it is possible to achieve some new learning or re-learn formerly known information and skills despite the presence of dementia (Fernández-Ballesteros et al., 2003). In addition, cognitive rehabilitation follows the premise that, by informed use of compensatory strategies, we can enable people to get around many problems in everyday functioning that are caused by memory or other cognitive difficulties. In this section we describe cognitive stimulation, cognitive training and cognitive rehabilitation in a little more detail, citing the guiding principles, the application and mode of delivery and the evidence base.

13.3.1 Cognitive stimulation

Aims and principles

Cognitive stimulation aims to reduce excess disability, rebuild confidence and self-esteem, and enhance general social and cognitive functioning. It is an approach that includes elements of reality orientation (Holden & Woods, 1995), reminiscence (Woods et al., 2005) and engagement in activity. It is delivered in a social context, following person-centred values (see below). The approach did not arise from cognitive theories, but its core focus is on cognition and several aspects of delivery are based on broad-base cognitive theory, including that cognitive activity needs to be sustained to avoid decline through disuse (for review, see Salthouse, 2006); that orientation for time, person and place provide us with necessary reference points for keeping track of our lives; that prompts to reminisce can enable people with dementia to better access long-term memories (autobiographical memory;Woods et al., 2005); and that encoding experiences through a range of modalities and senses leads to stronger memory traces (Haxby et al., 2001)

Implementation

Cognitive stimulation can be successfully facilitated by any of a range of health and social care professionals who have interpersonal skills, understanding of the approach and a fundamental appreciation of person-centred care. It is most commonly delivered in a group format with people with mild to moderate dementia on a once or twice weekly basis for 14 or more sessions of 45 – 75 minutes each. Each session has a characteristic format that includes an initial section, during which participants share introductions and orientate themselves to the context in terms of time, place and current affairs, followed by a longer section focused on a topic of interest that varies from week to week. This topic can be anything that connects with the lives, past and present, of the attenders, for example, fashion, food, working life, birthdays. The facilitators come prepared with materials that may trigger memories of past experiences relevant to the theme as well as current issues concerning the theme. All

attenders are invited to join in, with as much sensory and multi-modality experience as possible. If discussing fruit, for example, the facilitator might bring an orange and a lemon to the meeting so that those taking part can feel, smell and taste the items as well as talk about them. The meetings are intended to have a social, rather than a classroom, atmosphere, which boosts confidence.

Evidence

A Cochrane review of 15 randomised controlled trials (RCTs) of cognitive stimulation therapy, and meta-analysis of results for 718 participants confirms the benefits of this approach for cognition and quality of life in people living with dementia (Woods et al., 2012). Much of the UK work in the field has been conducted by a group of researchers, including Bob Woods, Aimee Spector and Martin Orrell. They have carried out a series of studies to refine, manualise and gather evidence of the impact of cognitive stimulation. Specifically, an RCT demonstrated short-term improvements on brief cognitive tests for severity of dementia (Spector et al., 2003) with later studies demonstrating benefits not only for memory, but also for naming, word-finding and comprehension, as well as quality of life (Spector, Orrell & Woods, 2010). A recent study (Orrell et al., 2014) showed that improvements in self-rated quality of life were maintained over 6 months in people with dementia who had the benefit of maintenance CST sessions on a weekly basis following an initial more intensive programme. Continuing cognitive benefits were shown on a general screening test of cognition, the Mini-Mental State Examination (Folstein et al., 1975), in those who received CST as well as anti-dementia medication, in comparison to those who received anti-dementia drugs alone. Most recently, a study has been conducted to assess the benefits of carrying out CST with people with dementia in the home setting on a 1:1 basis led by a relative or carer (Orrell et al., 2012), however, the results of this study have not yet been

published. The overall positive findings of application of CST in groups settings have led to the UK National Institute for Clinical Excellence including cognitive stimulation in its guidelines for dementia interventions (NICE, 2006).

13.3.2 Cognitive training

Aims and principles

Cognitive training consists of guided practice on a set of standard tasks designed to target and "exercise" particular cognitive functions (such as planning, attention or memory). The principle of cognitive training is that the training should improve performance (or at least maintain function) in the targeted domain and should generalise beyond the context of the training task. The tasks are pitched at different levels of difficulty to optimise improvements in performance in line with individuals' ability; levels of difficulty can also be adjusted within the same task to reflect improvements within task. In addition to personalisation on a difficulty level, there is also scope to personalise the cognitive training tasks themselves, for example by practicing recalling items that have some personal relevance (Davis, 2001).

Implementation

Cognitive training can be offered on an individual basis (e.g. Davis, 2001; Loewenstein 2004) or in group sessions (Bernhardt, 2002). Typically, sessions are facilitated by practitioners, but the training can also be completed individually or with input from family support (Quayhagen, 2000). The approaches to training are diverse, and it can be offered in a variety of formats with some tasks emulating everyday activities, some being cognitive-based paper and pencil tasks, and some being computerised or based on virtual reality (Clare, 2003).

The concept of cognitive training has been popularised in recent years with the advent of Dr Kawashima's brain training programmes, which are available on personalised and hand held

computers. The objective is to improve performance on a set of tasks that reflect different cognitive skills to reduce your "Brain Age". Computerised cognitive training packages are increasingly being developed for clinical applications, and the improvements that these types of tasks elicit are also being assessed.

Evidence

The evidence for the efficacy of cognitive training is still mixed. An early review indicated that cognitive training may be useful for slowing decline in dementia (Gatz, 1998). A more recent review found no significant benefits of cognitive training in people with or without dementia (Bahar-Fuchs, Clare & Woods, 2013). There were methodological limitations within the studies identified in the review, one being that the target outcome measures may not have been sensitive enough to measure the effects of the training. Indeed, there is evidence that performance can be improved on specific training tasks. Questions remain as to whether these tasks in turn offer improvements to the real life difficulties people may be having.

Other investigations relate to the format of interventions: Lorant-Royer et al. (2008) tested the benefits of a computerised brain training programme and found it did not demonstrate benefits over and above paper based cognitive training tasks, or no training group. Other studies have shown that video based games can develop specific cognitive capacities. Owen et al. (2010) tested 11,430 participants without dementia on online cognitive training tasks over a period of six week finding that, whilst improvements were observed on all of the tasks that people were trained on, no evidence was found of transfer effects to other tasks.

13.3.3 Cognitive rehabilitation

Aims and principles

The aim of using cognitive rehabilitation is to improve a person's ability to successfully manage those aspects of day-to-day life that have a cognitive component and that have become impaired or abandoned by the impact of dementia on cognitive processes, thereby improving the person's quality of life and wellbeing. Cognitive rehabilitation includes "any intervention strategy or technique which intends to enable clients or patients, and their families, to live with, manage, by-pass, reduce or come to terms with deficits precipitated by injury to the brain" (Wilson, 1997, p. 488). The approach is applied through individually tailored interventions that employ the principles of effective learning and information processing to address specific goals in real-life settings. It involves the sophisticated application of cognitive theory and research findings to find ways of benefitting individuals with acquired brain problems, in this case dementia.

Implementation

The starting point for cognitive rehabilitation is a discussion with the person with dementia and close others involved in their care, to identify whether there are specific tasks that might be addressed using the approach. Personally relevant goals can include things such as (re-) learning to use equipment (e.g., a mobile phone, or a microwave oven), re-learning everyday tasks (e.g., doing the shopping, baking) and (re-)learning names (e.g., grandchildren or club members). Development of the tailored intervention requires a full analysis of the difficulties a person with dementia is having with a task, as well as understanding of their cognitive strengths and weaknesses, awareness, and the environmental context and resources. This rounded understanding leads to a formulation that informs the intervention.

Whilst many interventions are focused on memory problems, a number of other cognitive processes may also be involved and, where this is the case, need to be addressed, including

attention, planning, sequencing, keeping track, object recognition, searching, and spatial aspects of behaviour. The tailored intervention then draws on the latest knowledge of effective strategies for promoting whichever aspects of cognitive processing are impaired, including encoding, storage and retrieval of information. Strategies may be compensatory or restorative in nature. Those that aim to restore function or promote new learning include errorless learning, in-depth processing, spaced retrieval, active rehearsal, modelling and use of fading cues. Compensatory strategies include the use of external aids such as alarms, labels and white boards; diaries and memory wallets, instructions and checklists; and environmental adaptations. The intervention usually takes place in the environment in which the activity will be performed (for example, the person's own home) and involves about six to 12 45-60 minute sessions depending on the complexity of the intervention and the progress of the individual. Due to its specialist nature, cognitive rehabilitation is generally undertaken by a clinical psychologist or an occupational therapist.

Evidence

Although the cognitive rehabilitation approach has been quite widely applied in clinical work with people with dementia, published research evidence is scant and often related to single case designs or small studies; therefore, more rigorous and large-scale studies are needed (Hopper et al., 2013; Bahar-Fuchs et al., 2013). In the UK, a series of studies has been conducted and published by Linda Clare (see Clare, 2008 for a summary). These have shown, for example, that for one person, being supported to learn the names of fellow attenders at a social club had the benefit of giving him continued confidence to attend, so reducing risk of social isolation (Clare et al., 1999). In contrast to this study with a person with early dementia, cognitive rehabilitation approaches have also been successfully used to address specific issues for people with more advanced dementia living in care home settings. Bird

(2001), for example, describes the combined use of external memory aids, cued recall and learning-by-doing to assist a woman with dementia to remember what she had done with her belongings.

In addition to these small scale studies, there is also evidence of effectiveness from an RCT that a protocol-driven approach which allows individual goals to be addressed can produce benefits (Clare et al., 2010). This study compared a group of people with mild dementia who received 8 sessions of goal-oriented cognitive rehabilitation, with an 'attention' control group who received relaxation therapy and a treatment as usual group. Self-rated goal performance and satisfaction were significantly improved in the cognitive rehabilitation group following intervention compared with the other two groups, and attention, memory, quality of life and mood were also better in the cognitive rehabilitation group. Following this, a larger scale study is being conducted (Clare et al., 2013).

13.4 A Person-Centred Approach to Cognitive Interventions

This section will introduce some of the different dialogues which have dominated dementia care, and informed today's conceptualisation of a *person-centred* approach. It is now accepted that it is important to take a person-centred approach to the care and support provided to people with dementia (DoH, 2009). Therefore cognitive interventions should strive to be person-centred in nature, and not focus on neurological impairments in isolation to other factors which influence the lived experience of the person.

Chapter 13: Living well with dementia

The biopsychosocial approach to healthcare is the precursor to the development of person-centred care. A seminal paper by Engel (1977) made a clear and convincing case for treating an individual with any health condition within the full biological, psychological and social context of their life. This was subsequently applied to the treatment of people with dementia, and contrasted with the predominant approach of the time, which was very much embedded in a medicalised model. The biomedical model focuses on the treatment of the neurological symptoms of dementia in isolation to other factors. Whilst it is recognised that people with dementia have difficulties related to memory, language and orientation in time and place, these do, of course, vary from one person to another and over time. A purely medical model can struggle to account for these variations in experience; given the disease process may not vary greatly across individuals.

Where the biomedical model of dementia focuses on changes to the brain alone, the biopsychosocial model recognises that biological changes interact with psychological and social factors. Biological factors also include health related issues: a person with dementia is no less likely than anyone else in their age group to experience, for example, pain related to arthritis, cardio-vascular disease or problems with sight and hearing. Recognising biological factors is critical for supporting the well-being of people with dementia. For example, people with dementia may need, but not receive, appropriate analgesia if their ‘aggression’ is viewed as a symptom of dementia when it is caused by an alternative condition.

The psychological component relates to the factors associated with the mind and emotions of the person with dementia, such as personality and sense of self. The social component encompasses aspects of the person’s lived experience which are significantly influenced by the broader social context, including relationships, and external environment, including cultural, historical, economic and political factors. There are overlaps and interconnections

between all three dimensions of the biopsychosocial approach, and some of the important aspects of the experience of people with dementia still do not sit easily within any of these categories.

One of the proponents of person-centred care for people with dementia was Tom Kitwood. Kitwood contrasted the person-centred approach with the biomedical model, and argued that psychological and social factors make a significant contribution to the experience and presentation of dementia. Kitwood (1993) explained his theory of dementia using the following 'equation': D = P + B + H + NI + SP. In this equation, D – the presentation of dementia in any one person – is influenced by: P – Personality; B – Biography, or life history; H – Health (including other physical or mental health problems, sensory deficits, etc); NI – Neurological impairment (the extent of difficulty with memory and other cognitive skills); and SP – Social psychology (the extent to which the social environment meets, or fails to meet, the person's needs).

Person-centred cognitive interventions therefore need to take account of all of these factors, meaning that a thorough assessment of people's needs is therefore required before embarking on an intervention (see the section below). Addressing people's needs in the context of the biopsychosocial framework is consistent with taking a holistic approach that addresses the physical health, psychological and social needs of an individual. Most cognitive interventions will aim to slow down neurological symptoms of changes, impacting on the biological level. In addition, cognitive rehabilitation paradigms may introduce goals aimed at enhancing activity or understanding about its importance, also acting on the biological level. At the psychological level, cognitive interventions might address recent changes in personality and behaviour, anxiety and depression, catastrophic reactions, coping and defensive mechanisms.

Interventions may, to different extents, also have a social component to address issues associated with isolation, lack of social contact or lack of meaningful social engagement.

13.5 Selecting an Appropriate Cognitive Intervention

In this section we draw together the information about evidence-informed approaches to improving cognitive functioning in dementia with the tenets of person-centred approaches to suggest how to apply knowledge in the human context of living with dementia. As we have seen above, albeit still limited, there is a growing body of evidence about how different aspects of cognition, such as autobiographical memory, prospective memory and metamemory work and are affected by dementia; and there is also evidence that each of the 'big three' approaches to cognitive intervention can have positive benefits for people with dementia. Cognitive training is most likely to have discrete effects on the domains that are the focus of practice, cognitive stimulation has a wider impact across cognition possibly through reducing excess disability and improving confidence, and cognitive rehabilitation is suited to addressing specific difficulties in everyday living through its tailored use of restorative and compensatory strategies based on refined understanding of everyday memory.

Deciding which approach might be helpful for a particular person with dementia involves undertaking a holistic assessment. This needs to include careful assessment of the nature of the difficulties arising from the dementia from the perspective of the person as well as others who are closely involved. We need to consider the context and environment in which the person lives, their cognitive and social resources, their awareness of their problems and their ways of coping with them, i.e., we need to take a biopsychosocial approach. Broad discussion of the needs of the person with dementia, which considers the impact of dementia on life in

general, is essential, and much preferable over a narrow assessment of level of dementia or of cognitive functioning per se. A biopsychosocial assessment would normally begin with a semi-structured interview(s) with the person themselves, as well as any close relative(s) who are also affected by the dementia, and would then be supplemented by further behavioural, cognitive or biomedical tests as necessary. Where dementia is advanced and it is hard for the person to communicate their needs verbally, then observation rather than conversation will take a more central place. In this context, an approach such as Dementia Care Mapping can be used (Brooker, 2005). A person-centred, biopsychosocial formulation can then inform the prioritisation of needs and the best approach to employ to address them. Some of the key aspects are briefly outlined below.

13.5.1 Cognitive functioning

The need for cognitive intervention depends on the way cognitive impairment is affecting the person's day-to-day life. This sounds simple but necessitates development of a reflective, informed consideration of the interplay between cognitive functions and everyday activity in the life of the person with dementia. It means that the clinician conducting cognitive assessment should be guided by motivation in relation to intervention rather than intellectual curiosity or a disengaged wish to provide comprehensive information.

Despite these caveats, in-depth cognitive assessment, based on knowledge of information processing, is invaluable in outlining areas of impaired and conserved functioning. This informs areas that could be a focus of intervention and strategies that may be successfully implemented. The assessment needs to go beyond simple cognitive screening to test functioning in a more sophisticated way in each relevant cognitive domain. Exploration of memory, for example, should include assessment of long-term and working memory,

retrospective, prospective and meta-memory, consideration of visual and orally presented material, learning across trials in addition to single trial assessment, and free and cued recall as well as recognition. Where possible, standardised tests should be used but need to be chosen with the overall level of dementia in mind. Detailed discussion of selection of tests is beyond the scope of this chapter (see Lezak et al., 2012).

Many people with dementia find standardised testing of cognitive functioning uncomfortable, so a clear explanation and justification needs to be presented to the person with dementia and their consent needs to be gained. Attention must be paid to rapport and motivation, with breaks if the person becomes fatigues or discouraged, and time needs to be given to de-briefing and explanation of the outcomes.

13.5.2 Relational considerations and resources

It is widely acknowledged both that dementia affects not only the individual but also the family, and that family members are hugely instrumental in supporting relatives with dementia in the community. In considering cognitive approaches, service providers therefore should consider carers' needs in their own right, and not only think about them as a helpful resource to assist the person with dementia.

Carer stress is quite widespread and multi-determined. It may be associated with changes in the balance of the relationship related to responsibility (e.g., for household finances) or extra work (e.g., extra washing), frustration about the impact of memory problems (e.g., repetitive questions), tiredness (e.g., from interrupted sleep), worry (e.g., the person with dementia being at risk) or loneliness (e.g., change in the relationship). Primary sources of stress are often related to issues with a cognitive dimension that could be a focus of cognitive

intervention. Where using a cognitive rehabilitation approach it will be important to consider the carer's priorities in balance with those of the person with dementia.

Where a core dyad is involved, typically spouses, but also sometimes parent and adult-child, a relational perspective is helpful in prompting exploration of whether there is convergence or divergence between understanding, priorities and goals. Providing care in the context of a wider and longer-term relationship means that long established patterns of interaction and perceptions influence reactions to the changes brought about by dementia. Some couples may work constructively together to face dementia whereas others may 'work apart' or may come to diverge over time (Keady & Nolan, 2003). Where there are differences, it may be that preliminary steps need to be taken before cognitive interventions can be used, to assist person-centred understanding of dementia and to generate some optimism that the approach is worth trying.

Cognitive rehabilitation is usually carried out in the domestic setting and has to be supported by others in the household to be successful. If compensatory adaptations are to be made, for example, labelling kitchen cupboard doors to assist with finding items, then the carer needs to understand and agree to this approach. If restorative approaches are used, then a carer is often key in prompting the person with dementia to put strategies in place, and might be closely involved in assisting with fading cues, or spaced rehearsal. Cognitive training is more often a solitary activity so could be carried out without assistance, although where a person with dementia needs a prompt to do training then it is helpful to have understanding and commitment also from the carer. Cognitive stimulation, on the other hand, is usually carried out in a service setting and so could give a stressed carer some time to themselves, whilst also allowing the person with dementia to combat excess disability. This approach may therefore

be possible even when differences in perspective exist between carer and the person with dementia.

People with more advanced dementia may be living in care home settings where the context is of communal living and care is provided by care assistant staff. In these settings and with greater levels of cognitive impairment, interventions will need to be differently applied. Some key considerations would be: adapting cognitive stimulation to the levels of functioning (e.g. appealing to emotional memories triggered through the senses); and focusing on compensatory and environmental strategies.

13.5.3 Awareness and Coping

Aside from the profile and relational issues, levels of awareness and usual coping strategies of the person with dementia also need to be taken into account in considering cognitive interventions. Awareness is a complex construct. It is influenced by neuro-degeneration but also by the social milieu and the individual's psychology, and is undoubtedly altered in dementia. Awareness is not global but related to its object, and it occurs at different levels, from the explicit which can often be voiced, to the implicit which is shown in behaviour (Agnew & Morris, 1998). Early in dementia, there is varying awareness between individuals in how well they seem to recognise changes in their cognition. It may be that someone does not show a high level of reflective meta-awareness, but is aware of on-line difficulties in memory, for example, as they carry out a task. Not only are there individual differences in awareness but there may also be differences associated with the type of dementia. Those with behavioural variant fronto-temporal dementia, for example, may be less likely to have rounded awareness (Eslinger et al, 2005), yet those with semantic dementia may be acutely aware of their expressive difficulties (Gorno-Tempini et al.,2011).

Explicit strategies involving behavioural goals for the person with dementia are far easier to implement if a person is aware of their cognitive problems and prepared to tackle them in a problem-focused way, than if they have less full awareness and/or prefer to cope by using emotion-focused strategies. Where awareness is limited, it may still be possible to put cognitive stimulation in place, as its social medium may still be acceptable to the person. Similarly, environmental adaptations or passive compensatory strategies can still be implemented and may provide benefit where explicit and active cognitive rehabilitation cannot be employed.

Awareness is a phenomenon that includes automatic and unconscious processes as well as conscious ones, and it forms the backdrop to coping. Coping, in psychological parlance, usually refers to the efforts, both cognitive and behavioural, a person makes to respond in a situation where there are demands that exceed their usual resources (Lazarus & Folkman, 1984). Like awareness, coping occurs in reference to its object, thus someone with dementia may be coping with memory problems, or coping with changes in a relationship. An individual can be seen as having a coping repertoire that may be narrow or broad, and rigid or flexible. There is, not surprisingly, some research that indicates that flexibility is important to adaptation. Although individual coping differs from one situation (‘object’) to another, individuals often have a general coping style, which can be characterised as approach (or problem-solving) or avoidant (or emotion-focused). Approach coping tends to be pro-active and involves the person trying to find ways of stopping the source of the stress, either behaviourally (e.g., finding a way not to get lost, or finding a strategy to re-learn forgotten names) or cognitively (e.g., blaming embarrassment on the dementia rather than the self), whereas an avoidant coping strategy tends to be less direct and does not tackle the source

(e.g., ceasing to go out so as not to have the stress of getting lost; or turning to alcohol or relaxation tapes to overcome the embarrassment of forgetting someone's name). Studies of coping with a diagnosis of dementia have found these broad styles are echoed in the way a person responds to diagnosis (Clare, 2003) with some accommodating the diagnosis into their sense of self (self-adjusting) and others fending it off (self-maintaining), and that both problem-focused and avoidant coping are demonstrated through the actions of people with mild to moderate dementia when they are confronted by their memory problems (Oyebode et al., 2009).

The three approaches to cognitive intervention would seem to fit differently with different coping styles. Cognitive training might appeal to a person who has a problem-focused approach where they like to feel they have mastery and control over a situation; and similarly cognitive rehabilitation might also better suit someone who has a problem-focussed approach; whereas cognitive stimulation might be amenable to those with approach or avoidant styles.

13.6 Summary

In summary, there are a range of cognitive based interventions designed to enhance the everyday function of people with different types of dementia. However, in order for the intervention to succeed it is essential that a person-centred approach is taken to assessing the suitability and implementation of the intervention. Person-centred approaches are known to best support the well-being of people with dementia. The development of person-centred cognitive based interventions is in line with national and international policy, in a landscape where pharmaceutical interventions for people with dementia are limited.

Chapter 13: Living well with dementia

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