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HELEN J. WOOD BA Hons, MSc

THE EXPERIENCE OF COGNITIVE FUNCTIONING  
DIFFICULTIES IN PSYCHOSIS

Section A:

Cognitive Functioning in Psychosis:  
A Review of the Literature  
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Section B:

The Experience of Cognitive Functioning Difficulties in People with  
Psychosis: An Investigation  
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## **Summary of portfolio**

Section A is a review of the literature on cognitive functioning difficulties in psychosis. It focuses on these difficulties as they relate to cognitive models of psychosis. After outlining relevant cognitive models, the literature on cognitive functioning is critically reviewed. The review highlights methodological limitations; gaps in our understanding; and a need for research exploring people's experiences of cognitive functioning difficulties.

Section B describes a qualitative study investigating the experience of cognitive difficulties in people with psychosis. Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009) was used to analyse interview data from eight men. Cognitive impairment was understood in terms of five master themes. Results are discussed with reference to existing literature, with clinical implications for psychoeducation and formulation. Future research is recommended on interventions for metacognition and on staff understanding of cognitive difficulties in psychosis.

Section C is a critical appraisal of the qualitative study 'The experience of cognitive functioning difficulties in people with psychosis: An investigation' described in section B. It provides critical and reflective answers to four questions on the following topic areas: research skills acquired; what one would do differently if repeating the study; clinical consequences of the study; and future research projects.

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**Helen Wood**

**Section A:**

**Cognitive Functioning in Psychosis:**

**A Review of the Literature**

**Word count: 5500**

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### Section A:

#### **Cognitive Functioning in Psychosis: A Review of the Literature**

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### **Abstract**

This review evaluates research on cognitive functioning in the context of psychosis. It focuses on cognitive functioning as it relates to cognitive models for psychosis, given their relevance to psychological interventions. Following definition of key concepts, cognitive models for psychosis are outlined. The literature on cognitive functioning in psychosis is then critically reviewed, examining neurocognition; social cognition; neurobiology; psychotic experiences; the impact of cognitive functioning difficulties; interventions; and the experience of cognitive functioning difficulties. Priority was given to reviewing meta-analyses. Gaps in the literature will be considered in the light of cognitive models, and shortcomings highlighted as regards government directives to take into account what matters to service users (Department of Health, 2011).

The review reveals gaps in the understanding of cognitive functioning difficulties, particularly how they relate to cognitive models for psychosis. There is also a lack of information about the impact of these difficulties on people's lives and about coping strategies. Quantitative approaches used to study cognitive functioning show methodological limitations, while rigorous qualitative accounts are lacking. The review concludes by highlighting a need for research on people's experiences of cognitive functioning difficulties, in line with developments in other areas of psychosis.

## **Introduction**

This review aims to critically evaluate the state of research on cognitive functioning in the context of psychosis. No comparable reviews exist on this broad subject area, which encompasses the role of cognitive functioning in both neurodevelopmental (Nuechterlein & Dawson, 1984; Murray et al., 2006; Reichenberg et al., 2010; Silverstein, Mavrolefteros, & Turnbull, 2003) and cognitive models (Frith, 1979; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Hemsley, 1977) for psychosis (Appendix A: literature search strategy).

Following an introduction to the concepts of psychosis and cognitive functioning, this review will focus on the role of cognitive functioning in cognitive models that have been developed for understanding psychosis. These models have informed psychological interventions, such as Cognitive Behavioural Therapy (CBT) (Fowler, Garety, & Kuipers, 1995). The literature on cognitive functioning will then be critically reviewed with reference to these cognitive models, with a focus on the following relevant areas: neurocognition; social cognition; neurobiology; psychotic experiences; the impact of cognitive functioning difficulties; interventions; and the experience of cognitive functioning in psychosis. Gaps in the literature will be highlighted as a result of this critique, with particular attention to cognitive models and shortcomings as regards government directives to consider what matters to service users (Department of Health, DoH, 2011). The implications of these gaps for clinical psychology and future research will then be outlined.

## **Psychosis**

Psychosis may include perceptual experiences, such as hearing or sensing things that others do not; holding unusual beliefs; and holding beliefs about others' malicious intentions that seem unwarranted (Thornhill, Clare, & May, 2004). Components implicated in the

development of psychosis include vulnerability factors like genetics, and stressors, such as major life events or drugs use (The Sainsbury Centre for Mental Health, SCMH, 2003). The experience of psychosis occurs within a number of diagnostic categories. The category of schizophrenia (American Psychiatric Association, APA, 2000) informed the search strategy for this review (Appendix A). Criteria for diagnosis with schizophrenia include ‘positive symptoms’ (hallucinations, delusions, disorganised or catatonic behaviour, and disorganised speech) and ‘negative symptoms’ (low mood and low motivation), as well as decreased social and occupational functioning (APA, 2000). One in a hundred British men and women will receive a diagnosis of schizophrenia in their lifetime (British Psychological Society, BPS, 2000).

The term ‘schizophrenia’ is fiercely debated (e.g. BPS, 2000), given concerns about its specificity, reliability, validity, and associated stigma (e.g. Bentall, 2003; Boyle, 2007; May, 2007; Moncrieff, 2007). Psychosis can also be understood to be caused by impaired reality testing, affecting a person’s ability to produce judgments about their internal and external experiences (Frosch, 1964; Kaplan & Sadock, 2007). It has been suggested that psychotic experiences are better understood as lying on a continuum (Esterberg & Compton, 2009; Strauss, 1969) or as dimensional (Bentall, Claridge, & Slade, 1989; Esterberg & Compton, 2009), rather than a categorical pathological state.

Psychosis is associated with a number of secondary difficulties, including anxiety (Huppert & Smith, 2001); self-harm (Haw, Hawton, Sutton, Sinclair, & Deeks, 2005); stigmatisation (Dinos, Stevens, Serfaty, Weich & King, 2004); social exclusion (BPS, 2000; Sayce, 1998; SCMH, 2003); and low self-esteem (Barrowclough et al., 2003). Current treatment focuses on early intervention, long-term recovery, and therapeutic approaches, including medication,

CBT, art therapy, and family interventions (National Institute for Health and Clinical Excellence, 2011).

### **Cognitive Functioning**

For more than a century, cognitive functioning has been a recurrent theme in research seeking to understand psychotic experiences. Cognitive functioning involves both basic neurocognitive processes, such as memory, executive functioning (related to problem solving and planning), and attention, and more sophisticated cognitive processes, such as social cognition. Social cognition includes theory of mind (ToM), i.e. the ability to hold in mind what another person is saying and understand what their thoughts might be (Premack & Woodruff, 1978). It also involves metacognition, or the reflexive ability to think about one's own thoughts, affecting a person's ability to use, for example, memory, or select other strategies where necessary (Wykes & Reeder, 2005). Cognitive functioning difficulties are experienced by many people who are given a diagnosis of schizophrenia (BPS, 2000) and may be included in the new Diagnostic and Statistical Manual-V (Bora, Yücel, & Pantelis, 2010).

### **The Role of Cognitive Functioning in Cognitive Models of Psychosis**

#### **Early Foundations for Future Models**

Difficulties with cognitive functioning in people with psychosis were first documented by Kraepelin (1910), who noted his patients' inability "on their own initiative to keep their attention fixed for any length of time" (Kraepelin, 1919/1971, pp. 5-6). Bleuler (1950/1911) also observed ongoing difficulties with attention. He documented people's weak active attention, regarding directing thoughts or senses. Secondly, he noticed people's overactive passive attention, or information that is registered regardless of any action on the part of the

subject. Bleuler suggested that such attentional difficulties could explain aspects of psychotic experiences, such as catatonic states, since they resulted in sensory information overload due to difficulties in both directing and inhibiting attention. Bleuler (1976/1924) additionally considered that distraction, due to poor attention, explained people's forgetfulness.

Chapman and colleagues (Freedman & Chapman, 1973; McGhie & Chapman, 1961; McGhie, Chapman, & Lawson, 1964) subsequently noted patients' own accounts of cognitive functioning: "Patient 14: Things are coming in too fast. I lose my grip of it and get lost. I am attending to everything at once and as a result I do not really attend to anything" (p. 104). Such early accounts have formed the basis for evolving cognitive models of psychosis.

### **Hemsley: Memory and Context**

Hemsley (1975; 1977; 1994; 2005) (Appendix B) built on early accounts to develop a model suggesting that psychotic experiences are explained by cognitive functioning difficulties related to a collapse in the separation of material stored in memory and incoming sensory data. Thus, response biases or expectancies, established by existing stored memories, fail to operate to enable an efficient processing of incoming new data from the person's temporal and spatial context. This onslaught of unstructured, new sensory data could result in unusual perceptual experiences, such as hallucinations. Abnormal causal relationships might also be inferred between external events, resulting in delusional experiences (Hemsley, 1994). In line with the suggestion that this incoming information from environmental stimuli has greater influence (Hemsley, 1994), people with psychosis have been found to require less information before arriving at a conclusion compared to controls (jumping to conclusions, JTC), as well as being more likely to change their mind in response to contradictory information (Garety, Hemsley & Wessely, 1991). This reasoning bias is understood as an

example of dysfunctional social cognition. Hemsley's (1977) model additionally explains negative symptomatology, such as poverty of speech, as a way of adapting to the impact of this cognitive functioning impairment and resultant flooding with information. Finally, Hemsley (1998; 2005) suggests that a person's 'normal' sense of self is affected, since conscious experience is altered due to the disruption of the balance in influence of stored material in memory versus new sensory input.

### **Frith: Metarepresentation and Executive Control**

Hemsley's model understands cognitive functioning difficulties as impairments stemming from 'bottom-up' or basic automatic cognitive processes. In contrast, Frith posits that impaired top-down, conscious control is at fault (Wykes & Reeder, 2005) (Appendix C). Frith (1979; 1992) suggests cognitive functioning difficulties are based on impaired metarepresentation, the ability to represent or think about perceptions or thoughts about the world (Wykes & Reeder, 2005). Drawing on Shallice's (1972) understanding of consciousness as a higher-order executive system, Frith (1979) suggests that a collapse in this system results in a breakdown between preconscious and conscious awareness, affecting both material entering consciousness and the selection of responses. Stimuli normally filtered from consciousness as being irrelevant may then linger in consciousness, resulting in delusions, while stored multiple alternative meanings or associations with words present in consciousness could affect both speech understanding and production. Thus, Frith's model (Frith, 1992; Doody, Gotz, Johnstone, Frith, & Cunningham-Owens, 1998) evolved to suggest that psychotic experiences are not due to a global reasoning problem, but, more specifically, an impairment in self-awareness. This would then lead to a lack of awareness of willed (intended) actions; difficulties with self monitoring; and difficulties in understanding the intentions of others, i.e. ToM.

Psychotic experiences, such as thought insertion or alien control, can then be understood as difficulties monitoring one's intended actions (Frith & Done, 1989; Frith et al., 1998). Perceptual experiences, such as hearing voices, can be seen as a misattribution of internal thoughts to an external source (Frith et al., 1998). Finally, difficulties with social interactions can be understood as deriving from difficulties with ToM (Doody et al., 1998).

### **Garety: Social Factors and Emotion**

More recently, Garety and colleagues (Garety, Bebbington, Fowler, Freeman & Kuipers, 2007; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001) (Appendix D) have proposed a multi-factorial cognitive model that gives weight to social factors, including deprivation and emotion. In Garety et al.'s model, a person developing psychosis is assumed to have a pre-morbid vulnerability based on biopsychosocial factors. Stressors, such as drugs use or life events, may trigger emotional and cognitive processing changes. Garety et al. (2001) acknowledge both Hemsley's (1977; 1994) and Frith's (1992) accounts of the role of cognitive functioning difficulties, highlighting their common conclusion that changes in cognitive functioning, both neurocognitive and social-cognitive, contribute to anomalous conscious experiences: for example, unconnected events appearing linked or thoughts being experienced as external voices. Emotional changes, in response to both the triggering event and anomalous experiences, are suggested to affect the content of these anomalous experiences: for example, the emotional blow of job loss may contribute to critical voices (Garety et al., 2001). These emotional changes may also affect the interpretation of these experiences as personally significant, and the ensuing search to explain the cause of anomalous experiences. Biases in cognitive appraisal, such as difficulties understanding social situations (Doody et al., 1998) or increased influence of environmental stimuli (Hemsley, 1994), contribute to an understanding of these experiences as externally caused.

Pre-existing negative beliefs, linked to early adverse experiences (e.g. social marginalisation, childhood trauma), could also affect the interpretation of anomalous experiences (e.g. contributing to externalised attributions of persecution by others) (Garety et al., 2001).

### **Cognitive Functioning: A Critique of the Literature**

#### **Neurocognition and Neuropsychological Testing**

The literature on neurocognition provides a variety of evidence consistent with aspects of the above models, including impairments in working memory, long-term memory, executive functioning, attention, and processing speed in people with psychosis relative to the normal population. However, not everyone with psychosis experiences such difficulties; confounding factors may influence outcomes; and there are problems with measurement of neurocognition.

Research on working memory – a system of short term information storage and manipulation (Forbes, Carrick, McIntosh, & Lawrie, 2009) – is complicated by working memory’s range of definitions. Meta-analyses have addressed this complexity by including measures of all hypothesised working memory domains, such as Baddeley and Hitch’s (1974) verbal, visuospatial, and central executive domains. Lee and Park (2005) found significant impairments on all working memory tasks in people with a diagnosis of schizophrenia, with no significant differences between domains. Forbes et al. (2009) also report significant deficits compared to healthy controls across these working memory domains.

Long-term memory is also seen as multimodal. It involves conscious recollection of explicit memories; unconscious storage of information forming implicit memories; and a semantic organisational structure, whereby information is stored according to relevant schemas

(Wykes & Reeder, 2005). Mesholam-Gately, Giuliano, Faraone, Goff and Seidman (2009) found significant effects for delayed verbal memory and list learning, supporting the hypothesis of impaired explicit memory. Studies using verbal fluency tasks, which require word generation within semantic clusters, have provided some evidence for impaired semantic abilities (Dickinson, Ramsey, & Gold, 2007; Holthausen et al., 2003; Mesholam-Gately et al., 2009). However, studies using semantic memory tasks have shown only small effect sizes in people with a diagnosis of schizophrenia (Doughty & Done, 2009).

The executive system is understood as directing voluntary, controlled behaviour towards internally driven aims (Norman & Shallice, 1986). General evidence of a deficit in executive processes has been found using the Wisconsin Card Sort Test (Polgar et al., 2010). Joshua, Gogos and Rossell (2009) compared people with schizophrenia to healthy controls and people with a diagnosis of bipolar disorder using the Hayling Sentence Completion Task (Burgess & Shallice, 1997). They found evidence for impairment of a specific subcomponent of executive functioning, namely response inhibition.

Attention – towards environmental stimuli – may be under central executive control, or automatic in the absence of external stimuli. Attentional impairments are commonly found in Trail Making Task performance compared to healthy controls (Heinrichs & Zakzanis, 1998; Mesholam-Gately et al., 2009). Poor performance on the Continuous Performance Task provides evidence for sustained attention difficulties (Heinrichs & Zakzanis, 1998; Mesholam-Gately et al., 2009).

Finally, studies using tasks measuring processing speed – time to process information – such as Digit-Symbol Coding, have provided evidence for impairments in people with psychosis compared to healthy controls (Dickinson et al., 2007; Mesholam-Gately et al., 2009)

These impairments are relevant to areas of cognitive functioning highlighted in cognitive models of psychosis: for example, executive dysfunction is significant for Frith (1992), and attention and memory difficulties’ are important to Hemsley (1994). However, there are a range of limitations to these findings.

Firstly, although significant neurocognitive functioning difficulties occur for many people with a diagnosis of schizophrenia, evidence suggests that neurocognitive impairment may not affect each person with psychosis: for example, 27.5% of Palmer et al.’s (1997) sample (N = 171) were ‘neuropsychologically normal.’ Indeed, a schizophrenia subgroup defined by a cognitive ‘deficit syndrome’ has been proposed (Mesholam-Gately et al., 2009). It is unclear whether people without apparent neurocognitive impairment have nevertheless experienced a decline compared to their premorbid functioning (Kremen, Seidman, Faraone, Toomey, & Tsuang, 2000), or whether degree of decline exists on a continuum (Heinrichs & Zakzanis, 1998). This possible heterogeneity raises questions about the best way in which to define the samples used in empirical research.

Secondly, a number of confounding factors may influence the outcomes of neuropsychological testing. Antipsychotic medications may have differing effects on cognitive functioning (Lee & Park, 2005): for example, Stip (2006) found differential effects of Clozapine, Haloperidol, and Risperidone on the Tower of Toronto task that is used to

assess executive functioning. The impact on cognitive functioning of institutionalisation, chronicity of psychosis, and number of acute episodes is also unclear (Johnstone et al., 1992).

The nature of neurocognitive difficulties has also been found to vary according to age of onset: for example, people with youth-onset psychosis have been shown to have greater difficulties in arithmetic, executive function, IQ, speed of processing, and verbal memory (Rajji, Ismail, & Mulsant, 2009). People with later-onset psychosis show difficulties more in attention, fluency, 'global cognition', IQ, and visuospatial skills (Rajji et al., 2009).

A further confounding factor is the question of how cognitive functioning varies with time and according to fluctuations in psychotic experiences. Both individual accounts (Tucker, Harrow, Dedre, & Hoffman, 1969) and empirical studies (Fagerlund, Anderson, Oranje, Gade & Glenthøj, 2010; Forbes et al., 2009; Hoff, Svetina, Shields, Stewart, & Deisi, 2005; Leeson et al., 2010; Sponheim et al., 2010) suggest that after an initial drop neurocognitive impairments are stable over time, whilst others suggest decline in specific areas of functioning (Chan, Chen, & Law, 2006). Evidence for improvement over time is documented both in an individual account (Leete, 1989) and empirical research (Szöke et al., 2008; Zabala et al., 2009). However, it is inconclusive since empirically determined improvement could be explained by a practice effect due to repeated testing. This fluctuation in cognitive functioning complicates sampling for measurement of cognitive functioning, and undermines the assumption of stable neurocognitive functioning difficulties in the models outlined.

Thirdly, problems exist in the measurement of neurocognitive functioning. Assumptions may be made about task comparability (Bentall, 2003) and repeatability (Kremen et al., 2000). Studies measuring separate areas of functioning assume it is possible to know what each task

measures, and that they measure discrete areas of functioning (Forbes et al., 2009; Lee & Park, 2005; Mesholam-Gately et al., 2009). Related to this dilemma, debate continues as to whether cognitive impairment in psychosis is specific or general. Forbes et al.'s (2009) meta-analysis found no association between IQ and working memory in psychosis, suggesting memory may be a specific deficit. In contrast, according to Dickinson and Harvey (2009), the existence of cognitive impairments across a range of ability areas, both pre- and post-onset of psychosis, indicates a general, rather than specific cognitive deficit.

The ecological validity of neuropsychological measurements - the extent to which tests replicate people's everyday difficulties - is also questionable. No rigorous analysis of subjective accounts of cognitive functioning exists to examine this further. Interviews with 40 psychiatrists about their perception of cognitive deficits in people with a diagnosis of schizophrenia yielded the following qualitative themes: "lack of follow through on the big picture;" "attention and concentration;" "emptiness;" "functioning;" and "learning and remembering" (Bromley, 2007, p. 649). Given that the psychiatrists interviewed were at a Measurement And Treatment To Improve Cognition In Schizophrenia (MATRICS) conference, and thus likely to be familiar with the research literature, it is striking that their answers only partially match the areas of neurocognitive functioning identified through neuropsychological testing.

Empirical research provides some evidence for the existence of neurocognitive functioning difficulties. However, no studies conclusively map the whole range of known neurocognitive functioning difficulties to the outlined cognitive models, and there are a number of limitations with approaches to measurement. No rigorous service-user focused qualitative approaches

have followed from early patient accounts, restricting our understanding of service users' experiences and possibly hindering refinement of cognitive models.

### **Social Cognition and Experimental Paradigms**

Two aspects of social cognition proposed by cognitive models are considered here: the reasoning bias, JTC (Garety et al., 1991), and ToM (Doody et al., 1998). JTC has typically been investigated using the 'beads task' paradigm. This involves participants judging from which of two previously presented but then hidden jars red and white beads are successively being drawn. People with a diagnosis of schizophrenia tend to base their decision on fewer draws of beads (Fine, Gardner, Craigie, & Gold, 2007).

However, further evidence suggests the JTC bias has a complex relationship to psychosis. Some studies, using other paradigms (e.g. Mouselab computer program, Glöckner & Moritz, 2009), do not show the JTC bias. Also, people in remission take fewer draws of beads before a decision, compared to those with present delusions, contradicting the proposed connection of JTC to delusions (Lincoln, Ziegler, Mehl, & Rief, 2010). The JTC bias has also been shown to be heightened under emotional stress (Moritz et al., 2009). Additionally, the relationship between JTC and neurocognitive functioning has yet to be clarified (Bentall et al., 2009; Lincoln et al., 2010). More research is needed to elucidate these factors, as well as the connection between JTC and service users' psychotic experiences.

The 'false belief task' is the most common paradigm used to explore ToM. This measures first order false beliefs, i.e. a participant's ability to understand that someone else may act on the basis of beliefs that misrepresent reality. It also measures second order false beliefs, or the participant's inference of the false belief of one person about the beliefs of a second person.

Bora, Yucel, and Pantelis (2009) and Sprong, Vos, Hox, and van Engeland (2007) found large effect sizes for ToM performance in people with schizophrenia, both on this task and combining other paradigms. Impairment was less strong but still significant for people in remission ( $d=.80$ ) compared to non-remitted participants ( $d=1.21$ ). This decrease in impaired ToM supports Doody et al.'s (1998) proposal that delusions may be related to ToM difficulties. However, ongoing low-level ToM difficulties are inconsistent with this hypothesis. It is possible that low-level ToM difficulties are a form of stable trait in psychosis. Alternatively, ToM difficulties may interact with neurocognitive difficulties at different points of psychosis. Bora et al. (2009) found a non-significant correlation between lower IQ and greater ToM deficit, which became significant only when confined to 'remitted' patients. In addition, illness duration and memory impairment were positively correlated with ToM deficit (Bora et al., 2009; Harrington, Sigurt, & McClure, 2005). However, further studies are needed to clarify the relationship between ToM and neurocognition.

The extent to which social-cognitive deficits (e.g. JTC and ToM) are distinct subcomponents or one deficit is debated (van Hooren et al., 2008). Irrespective of whether they are two separate dimensions or one, their relationship to neurocognitive functioning and psychotic experiences has not yet been decisively mapped out.

### **Neurobiology**

Neurobiological approaches to investigating cognitive functioning in psychosis have had varying success. Research has sought to match cognitive models to neurobiology (Gray, Feldon, Rawlins, Hemsley & Smith, 1991; Garety et al., 2007) and specific brain regions have been posited as linked to cognitive processing difficulties. Hemsley (1994; 2005) proposes that the hippocampus, which forms associations, plays a role supporting context-

driven interpretations. Frith (1992; Doody et al., 1998) also proposes neurobiological underpinnings for his model, suggesting that disconnections between prefrontal parts of the brain that manage willed intentions and posterior brain areas concerned with perception are responsible for cognitive processing impairments.

Experimental approaches examine both brain structure and activity. Schobel et al. (2009) found that the volumes of the left anterior hippocampus and left orbitofrontal cortex, areas linked to verbal and executive functioning, were slightly reduced in people with psychosis. Meanwhile, Thomann et al. (2009) ascertained a significant association between neuropsychological soft signs, motor and sensory deficits, and decreased white or grey matter density in the central gyrus, middle and inferior frontal gyri, cerebellum, caudate nucleus, and thalamus. Hill et al. (2006) found small effect sizes for decreased overall brain blood flow and brain metabolism, and medium effect sizes for decreased blood flow/metabolism in frontal areas (hypofrontality) in people with psychosis, both at rest and when active.

There are, however, some difficulties with these studies. Neurobiological changes may be due to medication (Hill et al., 2004), with particular implications for studies with long mean illness durations (e.g. 10 years: Schobel et al., 2009). It is also unclear how structural changes relate to changes in brain activity (Hill et al., 2004). Where structural differences exist compared to controls, their causative role in psychosis is questionable: ventricular size can vary with time, alcohol and water consumption, and pregnancy, while structural changes may post-date psychosis as a response to psychological experiences (Bentall, 2003). Further research is needed to understand the relationship of physiological changes to cognitive functioning difficulties.

### **Psychotic Experiences**

Cognitive models for psychosis posit a link between cognitive dysfunction and psychotic experiences. Negative symptoms have been found to be related to poorer working memory and verbal fluency (Ayres et al., 2007); attentional functioning (Chan et al., 2007); processing speed (Leeson et al., 2010); and executive functioning (Dibben et al., 2009). Research has also found a positive correlation between executive functioning impairment and positive symptoms (Guilem, Rinaldi, Pampoulova, & Stip, 2008).

As regards social cognition, cognitive models have linked impairments in ToM to paranoia and delusions. Experimental studies have shown a relationship between ToM difficulties and negative symptoms (Sprong et al., 2007; Woodward, Mizrahi, Menon, & Christensen, 2009).

An association between psychotic symptoms and cognitive functioning does not mean they are causally related, however. Other evidence appears to contradict the connection between cognitive functioning and psychotic symptoms, or at least suggests it may only be related to particular areas of functioning. Forbes et al.'s (2009) meta-analysis did not find that the extent of either positive or negative symptoms affected performance on working memory tasks. Meanwhile, Hughes et al. (2003) found that improvements in symptom ratings did not predict improvements in cognitive functioning, except motor speed, suggesting that the course of symptoms does not affect the course of cognitive functioning. Indeed, the persistence of cognitive difficulties in people who have recovered from psychosis also indicates that the relationship between cognitive functioning and symptomatology may not be straightforward (BPS, 2000). Alternative research methodologies, building on early patient interviews, may enhance understanding of this relationship or clarify directions for further empirical research.

### **Impact on General Functioning**

Cognitive impairment has been shown to have a significant association with impaired quality of life (Yamauchi et al., 2008). As suggested by the cognitive models, cognitive functioning difficulties have a variety of impacts on every-day functioning, particularly work and social functioning.

Some studies have shown that impaired neurocognitive functioning (e.g. memory) is associated with impaired social functioning (Mueser et al., 1991). This connection is not universal: combined measures of neurocognitive functioning have been shown not to predict interpersonal functioning (Holthausen et al., 2007), nor to explain greater variance than symptomatology on combined measures of quality of life and days worked (Perlick, Rosenheck, Kaczynski, Bingham, & Collins, 2008). Aspects of social cognitive functioning (ToM and metacognition) are suggested to be mediators in the relationship between neurocognition and social functioning (Couture, Granholm, & Fish, 2011; Lysaker et al., 2010). However, the definition of social functioning and its measurement varies across these studies (Cohen, Forbes, Mann, & Blanchard, 2006; Yager & Ehmann, 2006), making findings hard to summarise or compare.

As regards work, poorer executive functioning has been linked to unemployment (McGurk & Meltzer, 2000) and worse functioning at work (Holthausen et al., 2007), including personal presentation, work quality, and cooperativeness (Bell & Bryson, 2001). Cognitive functioning has also been found to better predict work capacity (Christensen, 2007) and employment status (Kaneda, Jayathilak, & Meltzer, 2009) than other psychotic symptoms, with verbal working memory being a particularly strong predictor (Kaneda et al., 2009; Vauth, Corrigan, Clauss, Dietl, & Dreher-Rudolph, 2005). However, this relationship is not necessarily

causative, since negative symptoms and education may also play a role (McGurk & Meltzer, 2000). As with social functioning, there is also no standard agreement of what ‘work functioning’ consists of across studies.

The impact of cognitive functioning difficulties is observed by professionals, who note that people with psychosis “really have a hard time with basic daily function, such as organising their apartment ... cooking ... managing finances,” and who suggest cognitive functioning difficulties are the “major reason people couldn’t return to work” (Bromley, 2005, p. 956). However, no research exists into how people with psychosis understand these difficulties. This gap contrasts starkly to studies looking at service-users’ perspectives on the impact of cognitive functioning difficulties in other contexts (e.g. dementia, head injury, post-chemotherapy) on social relationships (Boykoff, Moieni, & Subramanian, 2009); previous habits and routines (Erikson, Karlsson, Borell, & Tham, 2007); sense of self (Medved & Brockmeier, 2008); and shopping (Smith & Adkins, 2006). The significance of cognitive functioning to such areas suggests clinicians may lack understanding of the impact of cognitive functioning difficulties for people with psychosis, limiting interventions and recovery.

### **Interventions and Coping**

There is a range of interventions for cognitive difficulties. As indicated by cognitive models, these have implications not only for cognitive functioning but also for related psychotic experiences. Drug treatment, a focus of the MATRICS project (Green, Kern, & Heaton, 2004), has yet to demonstrate conclusive benefits. Typical antipsychotic medication has been found to have a modest-to-moderate effect size across areas of cognitive functioning

(Mishara & Goldberg, 2004). However, motor function showed a negative impact and medication dose did not correlate with effect size (Mishara & Goldberg, 2004).

Cognitive Remediation Therapy (CRT) aims to rehabilitate cognitive functioning through tasks exercising cognitive functioning areas. CRT has had some positive outcomes, with a moderate effect size (0.41) for cognitive functioning (attention, speed of processing, problem solving, and social cognition) and for longevity of effects (0.66) (McGurk, Twamley, Sitzer, McHugo, & Mueser, 2007). Wykes, Huddy, Cellard, McGurk and Czobor's (2011) meta-analysis reports similar findings. It may also protect against grey matter loss (Eack et al., 2010) and may boost self-esteem (McGrath & Hayes, 2009). However, results remain inconclusive, compared to occupational therapy (McGrath & Hayes, 2009) and it seems to be most effective in combination with a vocational focus (Bell, Zito, Greig, & Wexler, 2008; Wykes & Huddy, 2009) or psychosocial rehabilitation (McGurk et al., 2007). Some variability in outcomes may be due to the variety of remediation approaches (Wykes et al., 2011).

From a participant perspective, participants within a research context suggest they noticed improvements in their thinking after CRT, yet also became more aware of their difficulties; there was a drop in self-esteem in those who perceived no improvement (Rose et al., 2008). However, Rose et al. (2008) did not interview clients who dropped out of therapy. Outcomes of cognitive rehabilitation are hard to appraise, given the variety of interventions used, and it is possible that assessment outcomes reflect practice effects due to their similarity to remediation tasks. Cognitive remediation is also difficult to implement within a non-research context due to sessions occurring several times per week (Cupitt, Byrne, & Thompson, 2004).

It is clear from the literature that people with psychosis have developed a variety of strategies for coping with their experiences. These range from smoking as possible self-medication (Zabala et al., 2009) to strategies documented in a first-person account for reducing distraction, and lists to support memory (Leete, 1989). Participants have also suggested that tiredness and task importance affect attention (Freedman & Chapman, 1973). However, there is a lack of research into coping methods by ‘experts by experience,’ which might be limiting the development of psychological interventions.

### **Individual Experience**

Subjective experience has long been a concern in the field of psychology (e.g. James, 1890). Cognitive models for psychosis originated with observations of patients’ experience of cognitive difficulties (Bleuler, 1911; Kraepelin, 1910) and accounts by patients themselves (Freedman & Chapman, 1973; McGhie & Chapman, 1964). However, these early studies have a number of limitations. Neither Bleuler (1911) nor McGhie and Chapman (1961) explained their methodology of collecting data on people’s experiences of cognitive difficulties. In addition, leading questions in some studies may have biased participants’ responses (e.g. Bowers, 1968; Freedman & Chapman, 1973). These accounts also lack reliability/credibility checks, discussion of participants’ context, consideration of transferability of findings to other contexts, and reflexive consideration of the interviewers’ influence on findings (Elliott, Fischer, & Rennie, 1999; Mays & Pope, 2010). Apart from these studies, there have only been occasional single person accounts, though none focused on cognitive functioning (e.g. Leete, 1989).

In accordance with government directives (DoH, 2011), emphasis on self-definition (Rose, 2001; Wallcraft, 2003), and the growing body of research exploring service users’

experiences, this review has highlighted subjective accounts where possible. However, the scarcity of such accounts, along with the limitations of existing ones, reveals a gap in the current literature. This void reflects the dominance of traditional quantitative methodologies in this area, as well as concerns about the generalisability of qualitative research. Alternatively, first-person accounts may have been overlooked due to assumptions about the impact of cognitive functioning difficulties on a sense of self (Frith, 1992; Hemsley, 2005); on so-called ‘insight’ (Quee et al., 2011), and on ‘sealing over’ (Bell & Zito, 2005).

### **Conclusions: Implications For Clinical Psychology and Research**

This review illustrates the significance of cognitive functioning to understanding psychosis, and demonstrates the range of approaches used to investigate this relationship. Empirical evidence has been established for the existence of cognitive functioning difficulties in people with psychosis. However, these difficulties have not been comprehensively mapped to relevant cognitive models of psychosis. The relationship between neurocognitive and social-cognitive functioning has not been fully established. There is, as yet, no clear understanding of aetiology as regards physiological changes. Furthermore, there remain ambiguities concerning the relationship of cognitive functioning to psychotic experiences and to people’s daily functioning. Approaches used to study cognitive functioning show limitations regarding ecological validity and confounding factors. Finally, current interventions need to improve understanding of their ‘side-effects’ and acceptability (Wykes et al., 2011). CRT may be enhanced by further examining the coping strategies and expertise of people with psychosis.

The lack of rigorous research into the experience of cognitive difficulties in psychosis is striking, particularly given early documentation of experiences. Strauss (1989) proposes that neglecting to attend to subjective experience may lead to the omission of information that

does not fit with pre-existing theories. This could potentially result in a gap between theory and clinical application, or in a lack of meaning of findings to clients or clinicians (Lieberman, 1989). Seeking to understand such experience is central to certain psychological approaches, such as community psychology (May, 2007), as well as to therapeutic stances, like the therapeutic importance of working with a client's reality (Campbell, 2007) and their related distress, as opposed to focusing on belief modification (Knight, 2005).

Idiographic approaches aim to enhance understanding of what is universal or common, through uncovering individuals' particular experiences (e.g. Husserl, 1927). Such approaches have been used in qualitative methodologies for investigating many areas of psychosis: for example, to look at psychosis both generally (Thornhill et al., 2004) and with attention to more specific areas, such as cultural perceptions of illness (Sanseeha, Chontawn, Sethabouppha, & Disayavanish, 2009); communication (Fatouros Bergman, Preisler, & Werbart, 2006); stigma (Knight, Wykes, Hayward, 2003); delusions (Rhodes and Jakes, 2000); perceptions of identity and cause of problems (Phillips, Cooke, Cooke, & Peters, 2006); hearing voices (Knudson and Coyle, 2002); experiences of group therapy (Newton, Larkin, Melhuish, & Wykes, 2007); first episode psychosis (Perry, Taylor, & Shaw, 2007); and social relationships (MacDonald, Sauer, Howie, & Albiston, 2005; Mackrell & Lavender, 2004). No studies have used rigorous qualitative approaches to investigate cognitive functioning in psychosis. Such studies would improve our existing understanding of cognitive functioning, enhance clinical practice, and draw our attention to new areas for investigation.

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## Appendix A

### Literature Search Strategy

The following databases were searched up to 31<sup>st</sup> May, 2011:

PsycInfo

Cochrane

Medline

The following search terms were used:

1. Psychosis OR Schizophrenia

AND

2. Cognitive functioning OR cognitive difficulties OR cognitive impairment OR cognitive dysfunction

AND

A: neurodevelopmental

B: cognitive model

C: neurobiology OR physiology OR brain functioning OR anatomy

D: neurocognitive functioning OR neurocognition

D1: memory

D2: executive functioning

D3: attention

D4: processing speed

E: social cognition OR theory of mind OR jumping to conclusions

F: impact OR work functioning OR employment

G: impact OR social functioning

H: treatment OR intervention OR medication OR cognitive remediation OR cognitive rehabilitation OR coping

Section A Cognitive functioning in psychosis: A review of the literature

I: experience

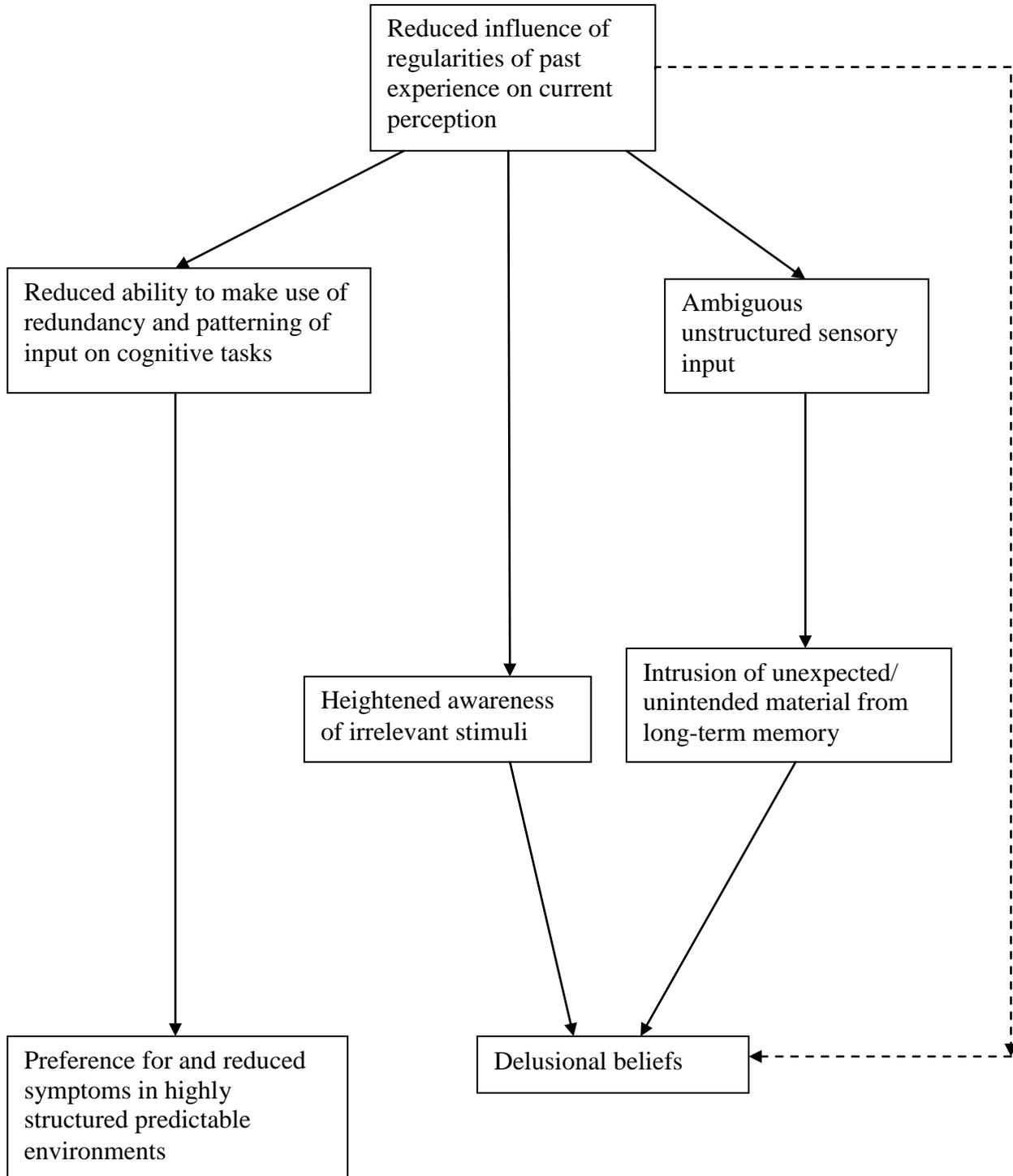
English language, peer reviewed journals were included.

References were scanned for further relevant literature.

In the review, priority was given to high impact rating journals and the most recent meta-analyses, where they existed and where they were appropriate to the area of review.

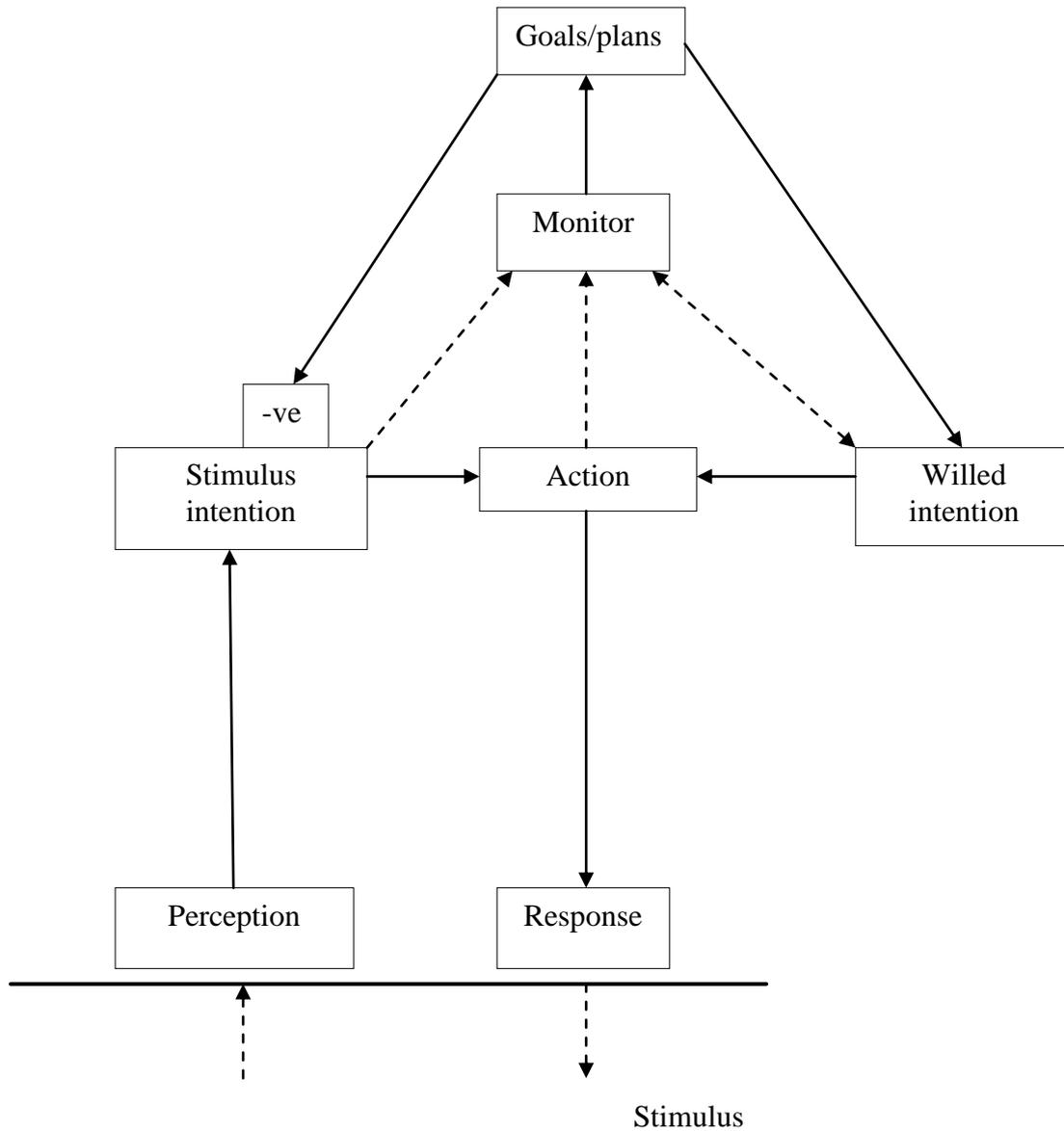
**Appendix B**

**Hemsley (1994): Model of the Cognitive Abnormalities and Symptoms of Schizophrenia**



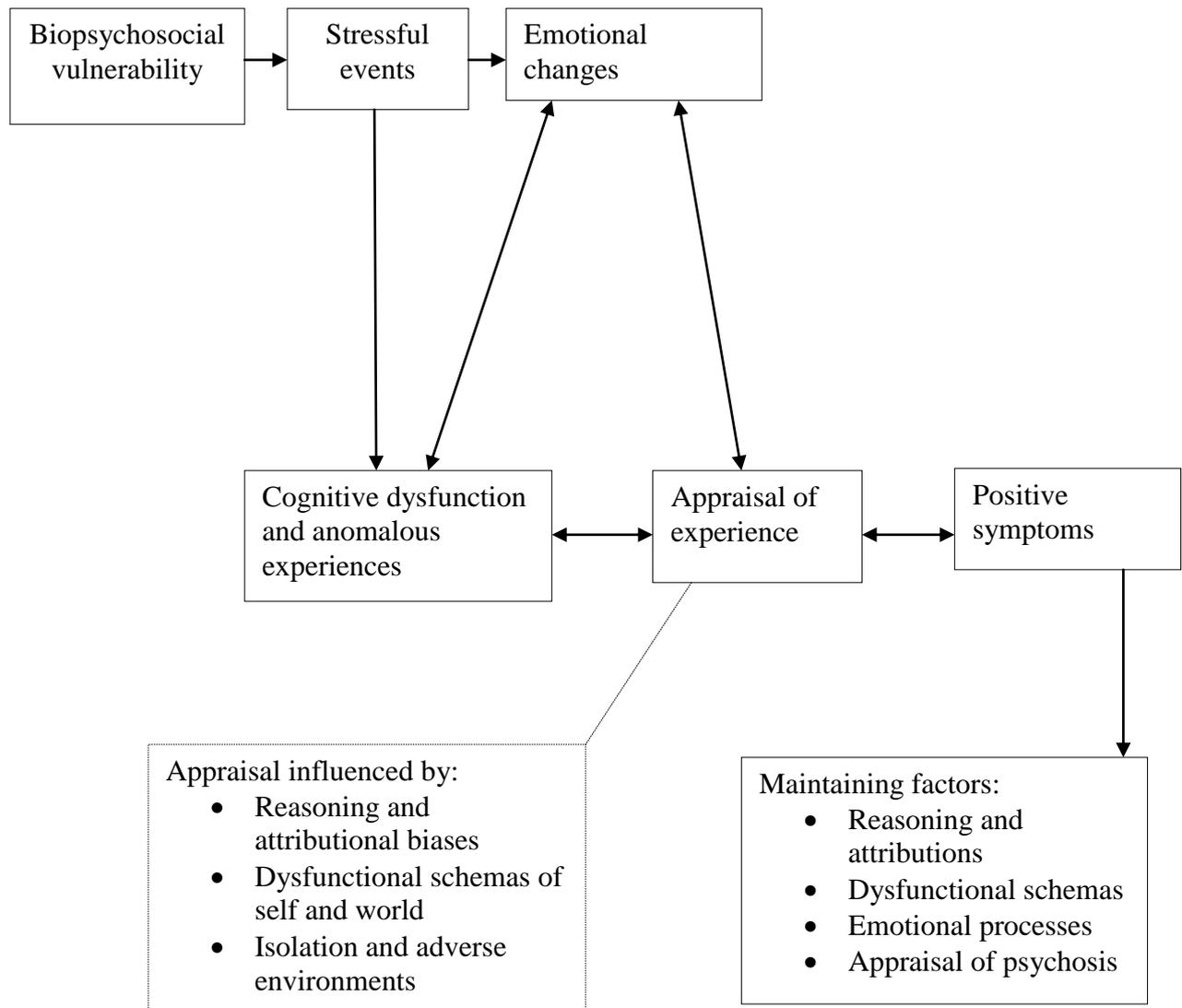
### Appendix C

**Frith (1992): The Monitoring of Action: Positive Symptoms of Schizophrenia**  
The monitor receives information about willed intentions, stimulus intentions, and selected actions. One disconnection is shown: information about willed intentions fails to reach the monitor leading to positive symptoms of schizophrenia.



Appendix D

**Garety, Bebbington, Fowler, Freeman, & Kuipers (2007):  
Schematic Representation of a Cognitive Model of the Positive Symptoms of Psychosis  
(As originally presented in Garety et al., 2001)**





**Helen Wood**

**Section B:**

**The Experience of Cognitive Functioning Difficulties in  
People with Psychosis: An Investigation**

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### **Abstract**

**Background:** An overview of research on cognitive functioning in psychosis reveals limitations in existing understandings, including the absence of a rigorous account of how people with psychosis experience cognitive functioning difficulties.

**Aims:** This study aimed to provide an account of the experience of cognitive functioning difficulties in people with psychosis, including how these difficulties are perceived and understood, how people respond to these difficulties, and what people's perceptions are of others' views of these difficulties.

**Method:** A semi-structured interview was carried out with eight participants, focusing on participants' experience of cognitive difficulties, how they respond to these, how participants perceive others' understandings, and available support. Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009) was used.

**Results:** Cognitive impairment was understood in terms of master themes focusing on controlled and reflective thinking; physical experiences; explaining the origins of impairment; identity; and anticipating the future with fear and hope.

**Conclusions:** The findings had significant implications for clinical psychology, including staff and client education about cognitive difficulties, and the importance of cognitive functioning to formulation. New areas for research include interventions stimulating metacognition; managing identity changes in response to cognitive difficulties; and ascertaining staff understanding of cognitive difficulties.

**Declaration of interest:** None

**Key words:** IPA, schizophrenia, cognitive functioning

## **Introduction**

### **Psychosis and Cognitive Functioning**

Psychosis involves perceptual experiences, such as hearing or sensing things that others do not; holding unusual beliefs, or unwarranted beliefs about others (Perry, Taylor, & Shaw, 2007; Thornhill, Clare, & May, 2001). The experience of psychosis occurs within a number of diagnostic categories, including schizophrenia (American Psychiatric Association, APA, 2000). Diagnostic criteria for schizophrenia include ‘positive symptoms’ (hallucinations, delusions, disorganised or catatonic behaviour) and ‘negative symptoms’ (low mood and motivation) (APA, 2000). The term ‘schizophrenia’ is fiercely debated, given concerns about its specificity, reliability, validity, and associated stigma (Bentall, 2003; Boyle, 2007; May, 2007; Moncrieff, 2007).

Cognitive functioning difficulties are not yet included in diagnostic criteria (Bora, Yucel, & Pantelis, 2010). Nevertheless, they are a crucial component in explanatory cognitive models for psychotic experiences (Frith, 1992; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Hemsley, 1994), which have shaped psychological interventions (Fowler, Garety, & Kuipers, 1995). Early observations and patient accounts of cognitive functioning (Bleuler, 1911/1950; 1924/1976; Freedman & Chapman, 1973; Kraepelin, 1910; McGhie & Chapman, 1961; McGhie, Chapman, & Lawson, 1964) were a foundation for cognitive models. Cognitive functioning is now understood to encompass basic neurocognitive processes (e.g. memory, executive functioning and attention) and more sophisticated cognitive processes, such as social cognition, entailing abilities like theory of mind (ToM) (Premack & Woodruff, 1978) and metacognition (Wykes & Reeder, 2005).

### **Cognitive Models of Psychosis**

Hemsley's (1975; 1977; 1994; 2005; Garety, Hemsley, & Wessely, 1991) model posits a collapse in the separation of material stored in memory and incoming sensory data in people with psychosis. Consequently, incoming information from environmental stimuli has increased influence (Hemsley, 1994). This contributes to difficulties with social cognition, including reasoning biases, such as jumping to conclusions (JTC). For example, people with psychosis require less information than controls before arriving at a conclusion (Garety et al., 1991), which is thought to contribute to psychotic experiences such as delusions.

Frith (1979) presents a model of psychosis as a breakdown of the higher-order executive system (Shallice, 1972), understood as consciousness. The breakdown between conscious and pre-conscious awareness leads to difficulties monitoring one's actions and understanding information derived externally compared to internally. This is also thought to contribute to social cognitive difficulties, for example with ToM (Frith, 1992; Frith & Done, 1989; Frith, Rees, & Friston, 1998) and misinterpretations of others' intentions.

More recently, Garety et al. (2001; Garety & Hemsley, 1994) have proposed a multifactorial cognitive model, giving weight to social factors, like deprivation. Garety et al. (2001) emphasise Frith's (1992) and Hemsley's (1994) common conclusions that changes in cognitive functioning affect anomalous conscious experiences and their appraisal. Garety et al. (2001) additionally propose that emotions and pre-existing negative beliefs contribute to the content of anomalous experiences.

### **The Literature on Cognitive Functioning: An Overview and Critique**

Neurocognitive functioning difficulties have been found in people with a diagnosis of schizophrenia, compared to healthy controls (Dickinson, Ramsey, & Gold, 2007; Forbes, Carrick, McIntosh, & Lawries, 2009; Heinrichs & Zakzanis, 1998; Lee & Park, 2005; Mesholam-Gately, Giuliano, Goff, & Seidman, 2009; Polgar et al., 2010). Although such difficulties are relevant to cognitive models (Frith, 1992; Garety et al., 2001; Hemsley, 1994), no study conclusively maps the range of known neurocognitive difficulties to the models outlined above. Moreover, not everyone with psychosis experiences such difficulties (Heinrichs & Zakzanis, 1998; Palmer et al., 1997), and confounding factors, such as medication, may influence results (Lee & Park, 2005; Stip, 2006). Neurocognitive functioning measurement is also limited methodologically by assumptions about tests' comparability (Bentall, 2003), repeatability (Kremen, Seidman, Faraone, Toomey, & Tsuang, 2000), specificity (Forbes et al., 2009; Lee & Park, 2005), and ecological validity – the extent to which tests replicate people's everyday experiences.

Social cognition has also been explored experimentally, with contradictory evidence for the reasoning bias, JTC, and ToM difficulties (Bora, Yucel, & Pantelis, 2009; Fine, Gardner, Craigie, & Gold, 2007; Glöckner & Moritz, 2009). Moreover, the role of emotion and relationship of these difficulties to psychotic experiences and neurocognitive functioning is not yet clear (Bentall et al., 2009; Bora et al., 2009; Harrington et al., 2005; Lincoln, Ziegler, Mehl, & Reif, 2010; Moritz et al., 2009).

As regards psychotic experiences, some evidence exists for the cognitive models' proposed link between poor cognitive functioning and worse negative and positive symptoms (Ayres et al., 2007; Guilem, Rinaldi, Pampoulova, & Stip, 2008). Nevertheless, other studies contradict

Section B      The experience of cognitive functioning difficulties in people with psychosis

these findings (Forbes et al., 2009) whilst the persistence of cognitive difficulties in people who have recovered from psychosis (British Psychological Society, 2000) suggests this relationship is not straightforward.

Poor cognitive functioning relates to difficulties with social functioning (Couture, Graham, & Fish, 2011; Lysaker et al., 2010; Mueser, Bellack, Douglas, & Wade, 1991) and work functioning (Bell & Bryson, 2001; Holthausen et al., 2007; Kaneda, Jayathilak, & Meltzer, 2009). However, these relationships are not necessarily causative, given the possible contribution of factors such as psychotic experiences and education (McGurk & Meltzer, 2000). Qualitative studies on the impact of cognitive functioning difficulties in other populations hint at a broader range of affected areas, such as sense of self (Medved & Brockmeier, 2008) and shopping (Smith & Adkins, 2006), but none explore the broader impact for people with psychosis.

Current treatment for cognitive functioning difficulties includes medication, without conclusive outcomes (Mishara & Goldberg, 2004). Cognitive Remediation Therapy (CRT) – rehabilitating cognitive functioning through tasks exercising cognitive functioning areas – has had some success (McGurk, Twamley, Sitzer, McHugo, & Mueser, 2007; Wykes, Huddy, Cellard, McGurk, & Czobor, 2011). However, it is hard to implement (Cupitt, Byrne, & Thompson, 2004) and negatively affects some service-users' self-esteem (Rose et al., 2008; Wykes et al., 2011). Little is known about service-users' own coping strategies, possibly limiting the development of further interventions.

## **Summary**

Cognitive functioning in psychosis has a significant position in cognitive models of psychosis and has been widely studied. However, gaps remain in the understanding of how cognitive functioning maps onto proposed models, its impact and treatment.

Research into cognitive functioning in psychosis began with patients' experiences (Bleuler, 1911/1950; 1924/1976; Kraepelin, 1910), but early qualitative studies (Freedman & Chapman, 1973; McGhie & Chapman, 1961; McGhie, Chapman, & Lawson, 1964) lack methodological rigour (Elliot, Fischer, & Rennie, 1999) (e.g. unclear methodology; leading interview questions; no authorial reflexivity). Research has since been dominated by empirical approaches and important information may have been missed (Strauss, 1989). With the exception of studies interviewing non-service-users (Bromley, 2005; 2007), no studies have since used qualitative approaches to explore cognitive functioning, despite qualitative methodologies being used to investigate a range of other experiences in the context of psychosis: stigmatisation, delusions, hearing voices, group therapy, and social relationships (Knight, Wykes, & Hayward, 2003; Rhodes & Jakes, 2000; Knudson & Coyle, 2002; Newton, Larkin, Melhuish, & Wykes, 2007; MacDonald, Sauer, Howie, & Albiston, 2005). Attending again to service-user experiences would match government directives (Department of Health, DoH, 2011), service-user initiatives (Rose, 2001; Wallcraft, 2003), and current research trends.

## **Aims**

This study aims to enrich understanding of cognitive difficulties in psychosis, through gathering information about subjective experiences. The study aims to answer the following questions:

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- (1) What cognitive functioning difficulties do people with psychosis experience and what is this experience like?
- (2) How are these difficulties perceived and understood?
- (3) How do people respond to these difficulties?
- (4) How do people perceive others' views of these difficulties?

It is hoped that increasing clarity in these areas will guide developments in clinical interventions and further research.

### **Interpretative Phenomenological Analysis (IPA)**

The most appropriate methods to explore human experiences and their meaning idiographically are qualitative approaches (Smith, Flowers, & Larkin, 2009; Strauss, & Corbin, 1998). To explore the phenomenology of an ongoing event - cognitive difficulties - within the context of psychosis, IPA was chosen (Smith et al., 2009). This allows for the study of individuals' relationships to cognitive difficulties with respect to their cognitions (thoughts, sense-making, meaning), emotions, and actions. The choice of IPA parallels successful studies of experiences of other areas of psychosis listed earlier. Its philosophical roots (Husserl, 1927; Baker, Wuest, & Stern, 1992) and 'double hermeneutic' (Smith et al., 2009) fit the project's aim to improve the understanding of individuals' experiences and of individuals' relationships to the subject of cognitive difficulties. In line with this project's objective to enrich understanding of existing theory, IPA requires that individuals' experiences are both explored within the data and illuminated by theory.

## **Methodology**

### **Participants**

Eleven participants were recruited from mental health teams in an urban NHS Trust and eight participants completed the study (Table 1; Table 2). Sample size was guided by Smith et al. (2009) and comparable recent studies. Inclusion criteria were: diagnosis of schizophrenia (World Health Organisation, 2005); aged 18-65; assessed presence of cognitive impairment; good spoken English. Exclusion criteria were: evidence of possible learning disability (IQ <70), or organic cause of cognitive difficulty (e.g. brain lesion); excessive drugs or alcohol use (APA, 2000); distressing present psychotic experiences or recent life events.

### **Measures**

#### **Cognitive assessment.**

Participants completed a cognitive screening assessment (Table 1), since not everyone with a schizophrenia diagnosis experiences cognitive decline (Heinrichs & Zakzanis, 1998). This ensured the sample matched previous empirical studies (e.g. Reeder, Newton, Frangou, & Wykes, 2004), improving results' transferability (Lincoln & Guba, 1985; Mays & Pope, 2000). Assessment results were also used to enrich discussion of findings.

To ascertain objectively-measured evidence of cognitive functioning difficulties, participants needed to score more than one standard deviation below the norm in two areas of cognitive functioning (Lezak, Howieson, Loring, Hannay, & Fischer, 2004; Reeder et al., 2004). The following measures were used to efficiently assess cognitive functioning with minimum participant burden (Appendix B):

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Working memory. This was tested using the Digit Span, Wechsler Adult Memory Scale – III (WMS-III) (Psychological Corporation, PC, 1997), which involves repeating back increasing strings of numbers. This was standardised on a British sample (PC, 1997). Test-retest reliability ranges from  $r = .66$  to  $r = .89$  (Matarazzo & Herman, 1984; Snow, Tierney, Zorzitto, Fischer, & Reid, 1989). An age-scaled score of less than eight was used as a cut-off for inclusion (PC, 1997).

Verbal memory. Participants completed the Controlled Oral Word Association (COWA) Task (Benton & Hamsher, 1989), which involves listing words beginning with a given letter in one minute. This was standardised on an American non-clinical sample (Spren & Benton, 1969). Test-retest reliability is  $r = .88$  on adults after 19 to 42 days (des Rosiers & Kavanagh, 1987). Concurrent validity with WAIS Verbal IQ = .14, Performance IQ = .29 (Yeudall, Fromm, Reddon, & Stefanyk, 1986). Low word production is associated with frontal lesions (Benton, 1968). An education-adjusted score for total number of words below the 16<sup>th</sup> percentile was used as a cut-off for inclusion.

Memory (short and long-term). Participants completed Logical Memory I and II, measures of short-term and long-term memory respectively (WMS-III, PC, 1997). This involves recalling details of two orally presented stories. It was standardised on a UK sample (PC, 1997). Reliability coefficients range from  $r = .82$  to  $r = .93$  (Lezak et al., 2004). WMS-III is sensitive to mild traumatic brain injury (Fisher, Ledbetter, Cohen, Marmor, & Tulskey, 2000). An age-scaled score of less than eight was used as a cut-off for inclusion.

Cognitive flexibility. This was tested using the Trail Making Test (TMT) (Army Individual Test Battery, AITB, 1944), which involves connecting numbers and letters on a page. The

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TMT was standardised on American non-clinical samples (Strauss, Sherman, & Spring, 2006). It has moderate internal reliability, ranging from  $r = .3$  to  $r = .6$  (Heilbronner, Henry, Buck, Adams, & Fogle, 1991; Pineda & Merchan, 2003; Royan, Tombaugh, Rees, & Francis, 2004). It has concurrent validity with the Wisconsin Card Sorting Test (Kortte, Homer, & Windham, 2002). An age-adjusted score for time taken falling below the 16<sup>th</sup> percentile was used as the cut-off for inclusion.

Response inhibition. Participants were tested using Sentence Completion (The Hayling and Brixton Test) (Burgess & Shallice, 1997). This was standardised on a UK non-clinical sample. Split-half reliability coefficients range from  $r = .35$  to  $r = .83$ . Test-retest reliability for overall score is  $r = .76$ . (Burgess & Shallice, 1997). It has moderate correlation with other tests of executive functioning (Clark, Prior, & Kinsella, 2000). Performance on this test has been shown to be impaired for individuals with a schizophrenia diagnosis (Marczewski, van den Linden, & Laroi, 2001). An overall scaled score of less than five was used as a cut-off for inclusion (Burgess & Shallice, 1997).

Table 1

Participant assessment information

Participant name	Areas of cognitive functioning meeting inclusion criterion
David	Working memory, verbal memory, cognitive flexibility
Don	Working memory, verbal memory, short-term memory, long-term memory, response inhibition
Gerald	Working memory, verbal memory, short-term memory, long-term memory, cognitive flexibility, response inhibition
Harry	Verbal memory, Short-term memory, cognitive flexibility, response inhibition
Jim	Working memory, short-term memory, long-term memory, cognitive flexibility, response inhibition
Jonathan	Long-term memory, cognitive flexibility
Tom	Verbal memory, short-term memory, cognitive flexibility, response inhibition
Will	Working memory, verbal memory, short-term memory, long-term memory, response inhibition

**Interview.**

Semi-structured interview questions (Appendix C) were guided by the study’s aims (Smith et al., 2009). Interview questions covered the following topics: the experience of and responses to cognitive difficulties, perceptions of others’ understandings, and available support. The interview was discussed with a Salomons Advisory Group expert, and piloted on two colleagues.

### **Ethics**

Ethical approval was obtained from an NHS Research and Ethics Committee, and Research and Development approval from the relevant NHS trust (Appendix D; see Appendix E for summary of findings and declaration of end of study).

### **Procedure**

Potential participants were purposively identified by care coordinators and given information (Appendix F). Participants either contacted, or gave consent to be contacted by, the researcher. Participants, who were seen within their service's setting, gave written informed consent to take part in the study prior to the cognitive assessment and interview (Appendix G).

Three participants were excluded from participation: two did not meet the assessment inclusion criterion and one participant's ongoing capacity to consent was judged to be lacking during testing.

Demographic information (Table 2) and interview data were collected from eight participants. Interviews lasted 30-60 minutes and were recorded. Interviews were transcribed and anonymised for analysis. A summary of findings was given to all participants (Appendix H) and services (Appendix I).

Table 2

Participant demographic information

Demographic information	Demographic sub-categories	Number of participants
Gender	Male	8
	Female	0
Age (years)	Range	29-61
	Mean	44
Ethnicity	White British	6
	British Asian	1
	Other	1
Education (years)	Range	9-18
	Mean	14
Contact with mental health services (years)	Range	7-35
	Mean	20
Current service status	Outpatient	4
	Inpatient	4
Living situation	Inpatient-rehabilitation service	4
	Living independently with support	3
	Living with family	1
Employment status	Unemployed	8
Relationship status	Single	8

### **Data Analysis**

According to IPA techniques (Smith et al., 2009), themes were searched for one participant at a time (Appendix J sample transcript). Themes were collated, master themes selected, and patterns, connections, and tensions examined (Appendix K for data).

### **Quality Assurance**

The researcher kept a reflexive diary (Appendix L) to facilitate bracketing of prior assumptions (e.g. related to experience delivering CRT ) and minimise their influence on data gathering and interpretation (Fischer, 2009). A supervisor's independent analysis of a transcript helped audit data coding (Turpin et al., 1997). Elliot et al.'s (1999) guidelines informed grounding data in examples, and sample contextualisation through providing demographic and assessment information.

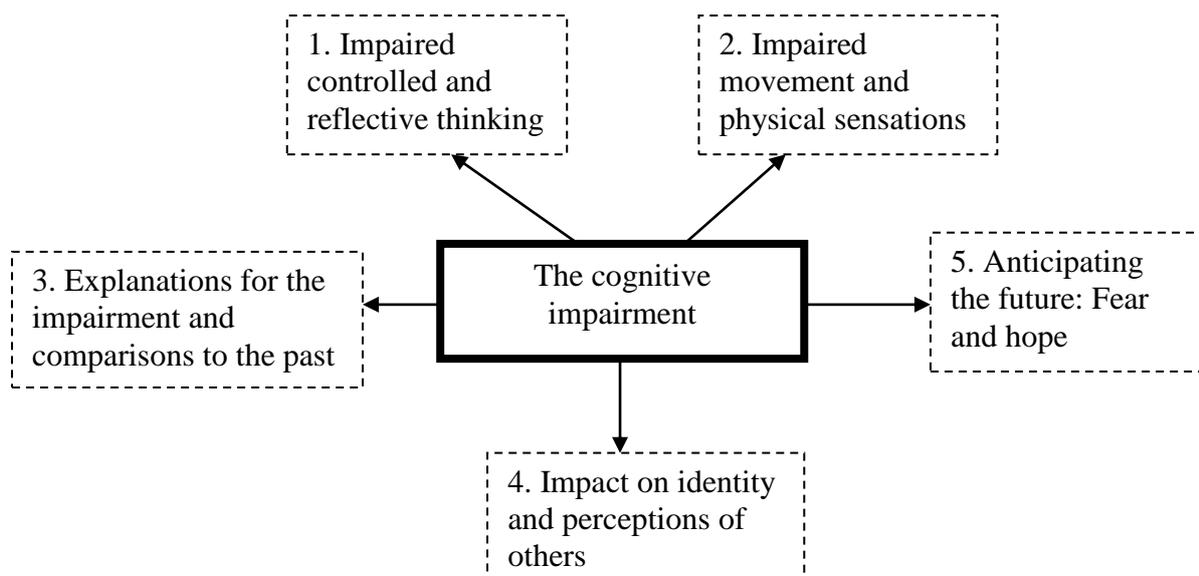
## **Results**

This research aimed to understand people with psychosis' experience of cognitive functioning difficulties. Interview analysis yielded an organising structure based around a central 'cognitive impairment' (Figure 1). The following account explores this impairment in terms of its component master themes: 'impaired controlled and reflective thinking;' 'impaired movement and physical sensations;' 'explanations for the impairment and comparisons to the past;' 'impact on identity and others' observations;' and 'anticipating the future: fear and hope.'

A table is not provided since diagrams were thought to best display the meaning IPA is concerned with uncovering. Master themes will be broken down into subthemes supported by

verbatim extracts.<sup>1</sup> The number of participants included per theme is indicated after the theme's title.

Figure 1. The cognitive impairment.



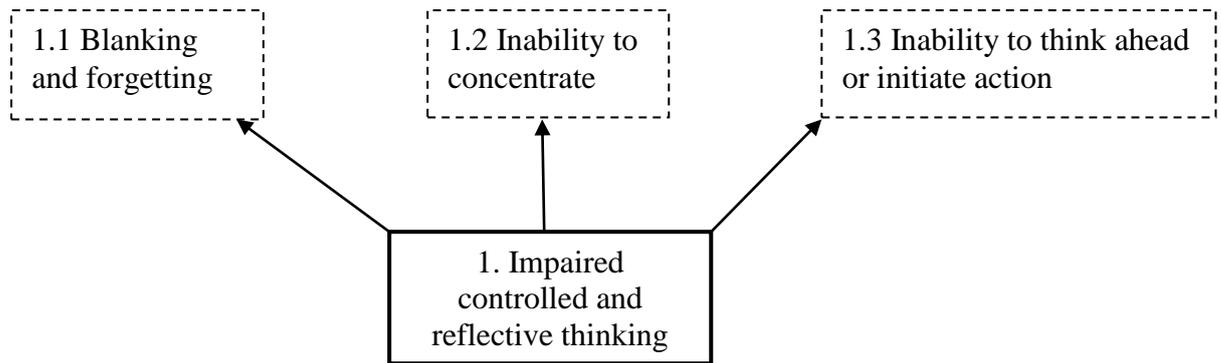
## The Cognitive Impairment

### 1. Impaired controlled and reflective thinking.

This first master theme describes the cognitive impairment (Figure 2). It contains three subthemes, illustrating components of the cognitive impairment that are affected by controlled and reflective thinking.

<sup>1</sup> ... elision in quotation section removed for clarity  
[ ] interpolation added by author for clarity  
Hmm italics represent the interviewer's words  
Names and identifying details have been altered: to protect anonymity these do not reflect ethnicity

Figure 2. Impaired controlled and reflective thinking.



### **1.1 Blanking and forgetting (8/8).**

This theme revealed the parameters of forgetting, including examples of things that participants forget:

The food: I try to remember what I ate ... *I don't remember many days before.* (Harry)

For Will and Don forgetting was not a static state, but varied according to day and context:

I might something forgot one day, and remember the next. (Don)

David described using reflection to help his memory. Recall required effortful thinking, sifting through information as if searching for the missing pages of memory:

You can remember bits of the book ... *Some bits you can't so you can find it through your thinking.* (David)

Section B      The experience of cognitive functioning difficulties in people with psychosis

The interviewer used a voice recorder to ensure none of the interview was missed. In contrast, David's brain only appeared to record intermittently:

*Like this little voice recorder thing ... sometimes you can remember all of it, sometimes you can't . ... I think it just, just slips my mind ... when you talk to someone it doesn't really register.* (David)

Will described how it would be good if he could '*keep track of what's gone on.*' It is as if information at most leaves a skid mark, but no identifying track, as it slips away. Jonathan said his '*memory is like a sieve. I lose it. Unless I write it down.*' Again, the information seems to slip through the mind, as if not thick or elaborate enough to be caught.

For some participants, '*going blank*' (Gerald) seemed to overlap with an inability to recall information. When Gerald went blank in the interview, he described this as, '*you just can't think.*' Other participants' descriptions of 'blinking' seemed more complex. On the one hand it was related to experiences of blanks of information being searched for, '*like a missing, missing bit of a sentence*' (David), a simile also used by Tom. On the other hand, paradoxically, the 'blank' seemed defined by its content:

*The world is a blank that I'm thinking in my mind, and it's a struggle to get back into reality again.* (David)

Derrida (1968/1982) suggested that words can never fully signify meaning, being defined only in relation to words to which they differ. It is as if the content of David's thinking is best defined by its difference to a 'blank,' since it appears to captivate. Blanking, or forgetting,

Section B      The experience of cognitive functioning difficulties in people with psychosis could be the result of focus on a rich inner world, and the difficulty of exercising control to bring the mind ‘back into reality’ (David). The blanks are gaps in the experience of the outer world, rather than in experience per se.

### **1. 2 Inability to concentrate (7/8).**

This theme is closely linked to ‘blinking and forgetting,’ as Gerald pointed out:

*I guess, um, yeah, if I go blank, really blank, then I can't concentrate ... if you can concentrate, you're going to be able to take it in, which means you'll probably remember it.*

(Gerald)

Inability to concentrate prevents the registering of information, and thus remembering.

However, some participants seemed to have good concentration, if using it for unusual purposes. Harry described monitoring whether or not people are ‘*goodies or baddies*,’ which was important for discerning their relationship to alien abductors:

And it was through my concentration, I saw the doorman, *the guy, he's not too bad, I look at his face, the degree of love.* (Harry)

A third person interacting with Harry might judge him to have poor concentration at this moment.

Poor concentration could be understood, therefore, as having poor control of focus, rather than as a global inability to attend. Don described it as ‘*can't try and control my thoughts.*’

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Tom, meanwhile, indicates concentration is *'being able to keep your mind on something.'* This is exactly what Will is unable to do when his mind *'gets bored'* and seems rebelliously separate from himself:

*It's like, I get distracted, if I'm doing the same thing, um, then my mind tends to wander.*  
(Will)

### **1.3 Inability to think ahead or initiate action (5/8).**

Gerald reported difficulty *'thinking ahead:'*

Recently I find it hard, um, harder to think, trying to work out ... the time going, not the time going backwards, but the er, how to work it out as you go, as you go. (Gerald)

The confusion of how to embark on what Gerald additionally described as *'planning'* is evident in his muddled syntax. Don also explained how *'just planning things is difficult. Trying to meet people.'*

The participants understood these difficulties with thinking ahead in different ways. Jonathan saw the absence of memory as critical to initial planning. His memories formed stepping stones, enabling movement towards a plan:

With a plan, really, you need *a flow diagram, don't you? With a plan, one thing leads to another, but if you've forgotten what the first thing is, you can't move on to the other.*  
(Jonathan)

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In contrast, Jim related his inability *'to perceive the future'* to difficulties with *'higher level thinking.'* The latter consisted of reflective imperatives that enabled the initiation of actions:

*I've lost my ability to think on higher levels ... Things like ... 'oh, I've got to give up smoking' ... 'what's the next thing I've got to do?'* (Jim)

## **2. Impaired movement and physical sensations (4/8).**

This master theme also acted as a subtheme for analysing data, capturing the bodily experience of cognitive impairment.

Harry described his difficulties as encompassing *'coordination, concentration, and memory.'* He seemed to find movement in relation to others hard, possibly related to poor concentration or poor relating of his own movement to that of others:

*I look. You are moving your right hand. And I try to concentrate. Your right hand is my right hand ... It's a mirror, mirror image.* (Harry)

Jim described how *'navigation really is a bit of a problem,'* linking memory to poor agility:

*If I was to take a walk through the local woods, probably forget about things, paths and trails ... I'm not that agile now.* (Jim)

Others reported the physical sensations of cognitive functioning difficulties. When asked to describe *'going blank,'* Gerald shared panic-like sensations:

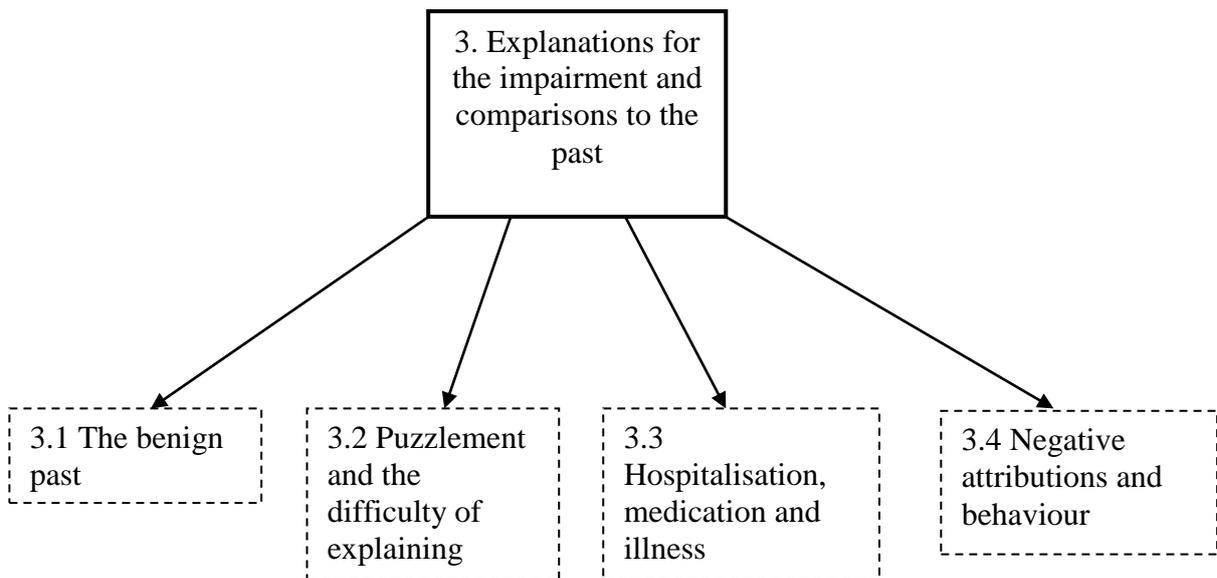
*You feel you're going to collapse, really dizzy and that. (Gerald)*

Finally, Jim's description of how his head feels '*rough inside*' alluded to the discomfort of cognitive impairment.

### 3. Explanations for the impairment and comparisons to the past.

Participants gave rich detail on the nature of their cognitive impairment. In contrast, this master theme conveys participants' struggle to pinpoint the impairment's origin, as well as their view of a benign past compared to the complexity of the present (Figure 3).

Figure 3. Explanations for the impairment and comparisons to the past.



#### 3.1 The benign past (8/8).

It was hard to discern whether participants' past was characterised by normality or utopian perfection regarding mental health, intellectual ability, or social belonging. For example,

Section B      The experience of cognitive functioning difficulties in people with psychosis

Gerald had *'perfect health;'* and Jonathan *'could memorise anything.'* Participants' comments hinted at how things may be different now:

My mind was well ... I was another one of the boys ... I fitted in, everything. (Will)

*Well, that's when I was pretty normal ... I could concentrate ... stuff like that: knew what I was doing.* (David)

Don shared David's sense of knowing what he was doing, as if the past contained hope for the future:

I used to want to own a *home, didn't I?* (Don)

Tom, however, indicated that his awareness of his memory's limits started in childhood. His description seems a playful view of cognitive functioning:

*It was, when I was little, right ... I counted up how many things I could remember, then I couldn't even remember [LAUGHS].* (Tom)

### **3.2 Puzzlement and the difficulty of explaining (7/8).**

The interview prompted new cognitive experiences, providing an occasion for first thoughts on the origin of impairment. David had *'never really thought, thought about looking back on my thoughts,'* while Gerald simply said, *'no, not really.'* For others an explanation seemed possible, but elusive, somehow puzzling:

Section B      The experience of cognitive functioning difficulties in people with psychosis

*I couldn't say ... something's changed it.* (Don)

No way of explaining that sort of thing. (Tom)

Contradictions in some accounts also suggest it was hard to explain the difficulties. Jonathan initially said he first noticed the difficulties '*quite recently*', but also reported noticing them at university, some 30 years earlier.

### **3.3 Hospitalisation, medication, and illness (8/8).**

Some participants associated hospitalisation, medication or illness with the origins of their cognitive functioning difficulties:

I started having this, this trouble when I come to Foxton House. (Don)

Jim's account went further, suggesting hospitalisation was causative, not just coincidental:

*I've lost a lot in hospital, which I wouldn't have lost if I hadn't been admitted to hospital ... [PAUSE]. Actually, I've lost the higher thinking.* (Jim)

Harry stated that pills '*make it worse.*' However, others were ambivalent about the role of medication:

*Sometimes they're [the tablets] good, and sometimes there are side-effects. And I think that um, it's like, part of the side-effects.* (Will)

## Section B      The experience of cognitive functioning difficulties in people with psychosis

Some participants saw themselves as resigned victims or passive patients. For Gerald, these difficulties are *'part and parcel of me illness;'* David suggested mental illness could play a role:

But as mental health you can be, one day could be a good day and one day could be a bad day. (David)

Jonathan held a *'brain disease'* or *'learning disabilities'* responsible, sharing his perspective that *'memory loss is a symptom, not a ... It's not a cause of my illness, it is.'* Meanwhile, Tom's joke that the difference between the past and present was that he was *'just older!'* hinted at ageing, or even dementia, as an explanation.

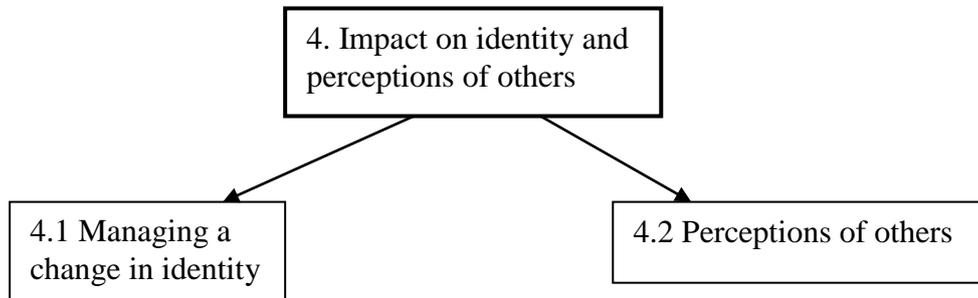
### **3.4 Negative attributions and behaviour (4/8).**

Participants also seemed to hold themselves responsible for their difficulties. Two men saw these difficulties as inherent: Harry suggested, *'maybe I was born like that,'* and Will said, *'it could be to do with me.'* Tom's suggestion—*'I think it's just laziness'*—indicated he could avoid these difficulties if he was more motivated. Others suggested that if they got more sleep their difficulties would be alleviated: Gerald indicated that it is *'really difficult ... to think when you're tired.'* Don also wondered if it *'could be sleep pattern.'*

### **4. Impact on identity and perceptions of others.**

Participants' descriptions of the impairment suggested how they had had to manage a change in their identity, as well as how they understood others' perspectives of the impairment (Figure 4). These two areas formed superordinate themes, which were derived from a number of subthemes.

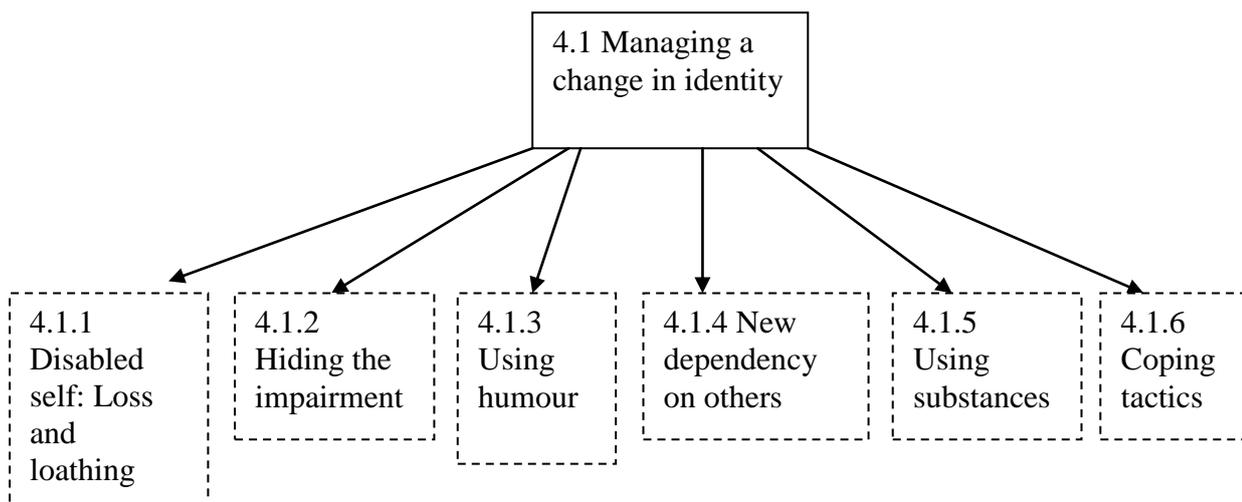
Figure 4. Impact on identity and perceptions of others.



**4.1 Managing a change in identity.**

Participants managed their change in identity using a variety of psychological and practical coping methods (Figure 5).

Figure 5. Managing a change in identity.



Section B      The experience of cognitive functioning difficulties in people with psychosis

4.1.1 The disabled self: loss and loathing (7/8).

Cognitive functioning difficulties were described as '*learning disabilities*' (Jonathan), being '*handicapped*' (Jim), or as a complete absence of ability: '*I don't know what I could do*' (Don). Some compared themselves to others, possibly alluding to a sense of social exclusion: Harry described his memory as '*lousy*' in contrast to the assumed abilities of the interviewer; Will worried, '*I'm not going to fit in or something;*' and Jim's description of '*grovelling around in the dirt*' suggested he felt a significant loss of status.

The extent of loss was revealed by Jonathan, whose poor memory was '*the biggest loss I ever had.*' The consequent '*negative mark*' for his university finals seems a permanent scar.

These descriptions conveyed a sense of self-doubt, extending to explicit self-loathing:

*I've become more and more like the people I hated.* (Jim)

4.1.2 Hiding the impairment (6/8).

Some men revealed the interview was the first time they had '*really gone into it, forgetting things and stuff like that*' (Don). Others seemed alone because '*nobody talked to me about memory*' (Harry).

In contrast, Jim seemed to actively choose to '*kind of hide it. I kind of pretend that I can. Higher-level conversation.*' Perhaps this was a way of managing the changes in his abilities in relation to others. Indeed, Will seemed to see being alone as a coping strategy:

I tend to deal with it in my own way, a bit more easier that I am alone sometimes. (Will)

4.1.3 Using humour (4/8).

Humour emerged as a way for participants to manage their identity before the interviewer. Laughter acted as a possible psychological defence, seeming to minimise the extent of the impairment. However, it is unclear whom it was meant to protect. If protecting the interviewer, it was ambiguous as to whether it was to protect them from seeing the extent of the impairment or to veil the extent to which the interviewer was responsible for the discomfort of the impairment being unveiled:

Er. [PAUSE] [LAUGHS] This is really testing my thoughts and that and that. [LAUGHS].  
(Gerald)

However, at other times it seemed more clearly to protect the participant from their own fear:

*I hope I don't end up like that with Alzheimer's ... some people put the cooker on and they forget about it and can be quite, quite a dangerous illness ... I have left the oven on before*  
[LAUGHS]. (David)

4.1.4 New dependency on others (7/8).

In tension with the social exclusion of disability and hiding, dependency on others was also expressed. Sometimes it seemed others might not be aware of how they were depended on:

*Now when my mind goes blank ... that's a bit scary, but then I just sort of go, errrr, I dunno, see someone I know and say hello and then I'm alright.* (Tom)

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However, Don more explicitly found *'asking the staff questions about explaining it'* helpful.

Gerald relied on someone accompanying him shopping, his dependency extending to the support worker choosing the day:

*She gives me a day and I'm like, 'ok' and we go then or whatever.* (Gerald)

Others were also relied on as memory prompts: *'jogs'* (David) or *'environmental signals'* (Jim):

*It happened to me in Foxton House. I ask the inmates, 'what did we eat?'* (Harry)

The use of 'inmate' conveys passive dependence, as if relying on others for freedom, perhaps the freedom and independence that being able to remember affords. For Jim, however, the situation is more complex, one of co-dependence between him and *'psychiatric services'*:

*I have to extract myself from the system because the system just um ... f-feeds on the weak and vulnerable people who can't think for themselves.* (Jim)

#### 4.1.5 Using substances (2/8).

Participants talked about using substances to manage their difficulties, perhaps as an extension of their dependent patient status:

*I wondered if I have to take ginkgo biloba ... I heard about it, it's good for the memory.* (Harry)

Jim found alcohol, cannabis and coffee act as starter motors, for example:

*Caffeine explosion ... That gets my brain whizzing, thinking.* (Jim)

#### 4.1.6 Coping tactics (7/8).

An array of more independent means of coping with cognitive functioning difficulties was also revealed. David seemed able to use his own reflexivity or metacognition:

*In order to jog my memory you just have to think back and think, 'now, what was I thinking there?'* (David)

The participants also shared their expertise. Breaking down tasks seemed useful: Harry said '*not many tasks, very little tasks*' were easier, and Will said:

And—short stories ... it just seems easier for my mind to take. (Will)

Both perhaps help occupy the '*wandering mind*' and support poor concentration.

David found that '*reading the bible ... a few times ... gradually you get to remember stuff you know,*' possibly experiencing the benefits of rehearsal for encoding memories. Jonathan also shared an understanding of the importance of mental activity, perhaps drawing on media reporting on brain-gyms (e.g. British Broadcasting Corporation, 2009):

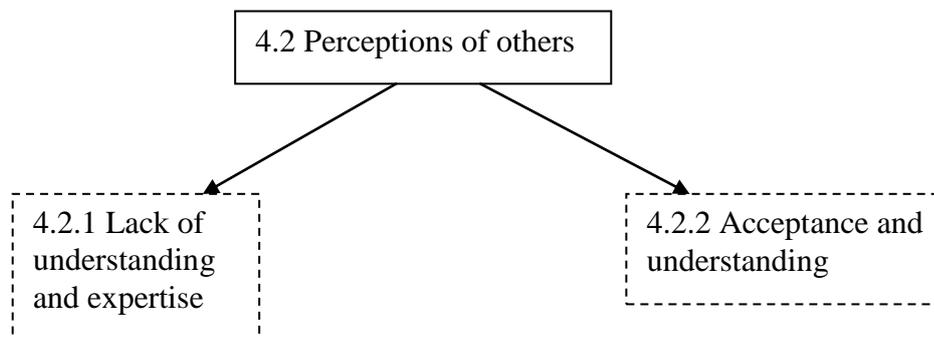
I do, do crosswords with my mum every Sunday afternoon, the Times crossword, and it keeps us both mentally agile it does. (Jonathan)

Tom, Will, and David all found keeping notes helpful to remember appointments or events. This was best exemplified, however, by Jonathan, who brought his diaries to the interview, as if ensuring his full self, including his memories, was present.

#### 4.2 Perceptions of others.

Participants' perspectives of how others perceive the impairment revealed contrasting themes of presence and absence of understanding (Figure 6).

Figure 6. Perceptions of others.



##### 4.2.1 Lack of understanding and expertise (6/8).

Don was puzzled even to be asked about others' understandings, since he was *'not sure. That's why we're talking about it.'* David described a general absence of mental health expertise:

*Well, with people with Alzheimer's, there is help for them, yeah, I've read it ... But for mental health, I've never really heard of people, not really.* (David)

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Several participants identified a lack of understanding in others. Jim's earlier description of staff support was contradicted by his suggestion that they do not know what he needs:

*They'd probably wouldn't understand them [difficulties] at all ... They'd have to prompt me to do things and I don't want to be that kind of person. (Jim)*

Harry's suggestion that *'nobody helps me because the extraterrestrials wouldn't want'* could be a delusional explanation for the lack of help from others.

#### 4.2.2 Acceptance and understanding (6/8).

In contrast to this lack of understanding, some participants described others' perceptions of the impairment more positively. Harry had a psychologist—*'the first person that had helped me was Ben'*—who did a test which *'helped me recognise my difficulties.'* Gerald found people generally sympathetic: *'they must think just how terrible it is for me,'* whilst others experienced acceptance:

*Everyone's ok, yeah. They coped with it, yeah. (Don)*

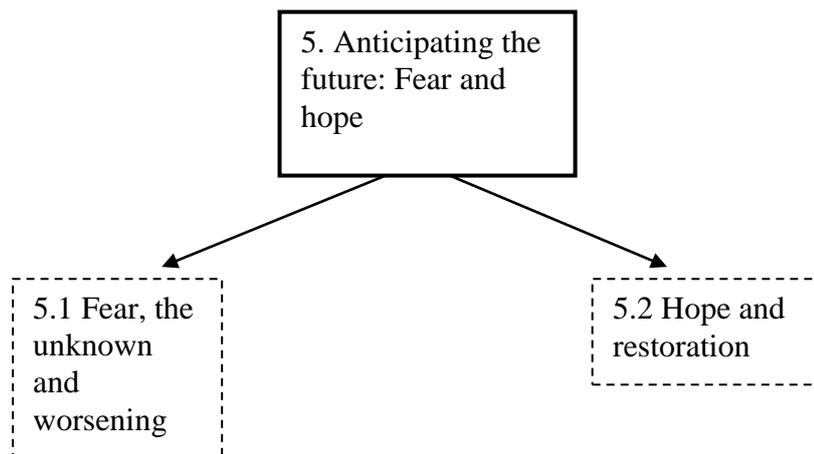
Jonathan suggested that this understanding may stem from memory difficulties being *'all part and parcel of life these days ... er, more people have got dementia, and, er memory loss.'* However, his portrayal of others' acceptance suggests that the difficulties have been subsumed into his identity:

*I think they, they think it's all part and parcel of being Jonny. (Jonathan)*

### 5. Anticipating the future: fear and hope.

The final master theme encompasses the confusion present in participants' understandings of what their future holds (Figure 7).

Figure 7. Anticipating the future: Fear and hope.



#### 5.1 Fear, the unknown, and worsening (8/8).

Participants expressed a sense of bleakness regarding the impairment and the future.

Jim's difficulties with planning ahead prevented him from seeing a future:

*I've lost my ability to perceive the future a hundred percent ... I used to think ahead and into the future, but now I can't do it at all. (Jonathan)*

Several men experienced fear when imagining the future, as if only able to see it in terms of their experiences now. Harry 'get[s] afraid' when unable to understand an instruction manual. David hoped he does not 'end up' like people with Alzheimer's disease, while Jonathan described trying to pre-empt 'the time when we're going to be sort of diagnosed

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*with a memory loss,* ' as if the memory loss will become the primary diagnosable state.

Meanwhile, Gerald's fear of the future contributed to current anxiety:

*If I'm trying to work things out and, you know, just getting worse and worse and worse, just say to myself, you know, what's it going to be in the future, you know. It is a worry.* (Gerald)

## **5.2 Hope and restoration (5/8).**

In contrast to the desolation of the above perspectives, participants also expressed optimism.

Will identified that *'it's [thinking too much] not as much as it used to be'*, noticing an improvement. Harry also stated that he had *'been remembering better this month once or twice.'*

For others, the interview experience seemed to prompt resolutions, as if the interviewer unwittingly provided a 'nudge,' or the interaction had stimulated new thoughts:

In the first place, I should like, er, what I want to do is make more of an attempt, at like writing things down. (Tom)

Jim was unique in describing a possibility for healing or regeneration, recovering a sense of himself as victorious and powerful:

*You know like in this film 'Terminator', he gets stabbed in the heart by a spear, and his power goes off 'cause he's a robot, and then he, er, finds another power-source from somewhere in his body, and it re-, and it reconnects to his main source. That's like my brain.*

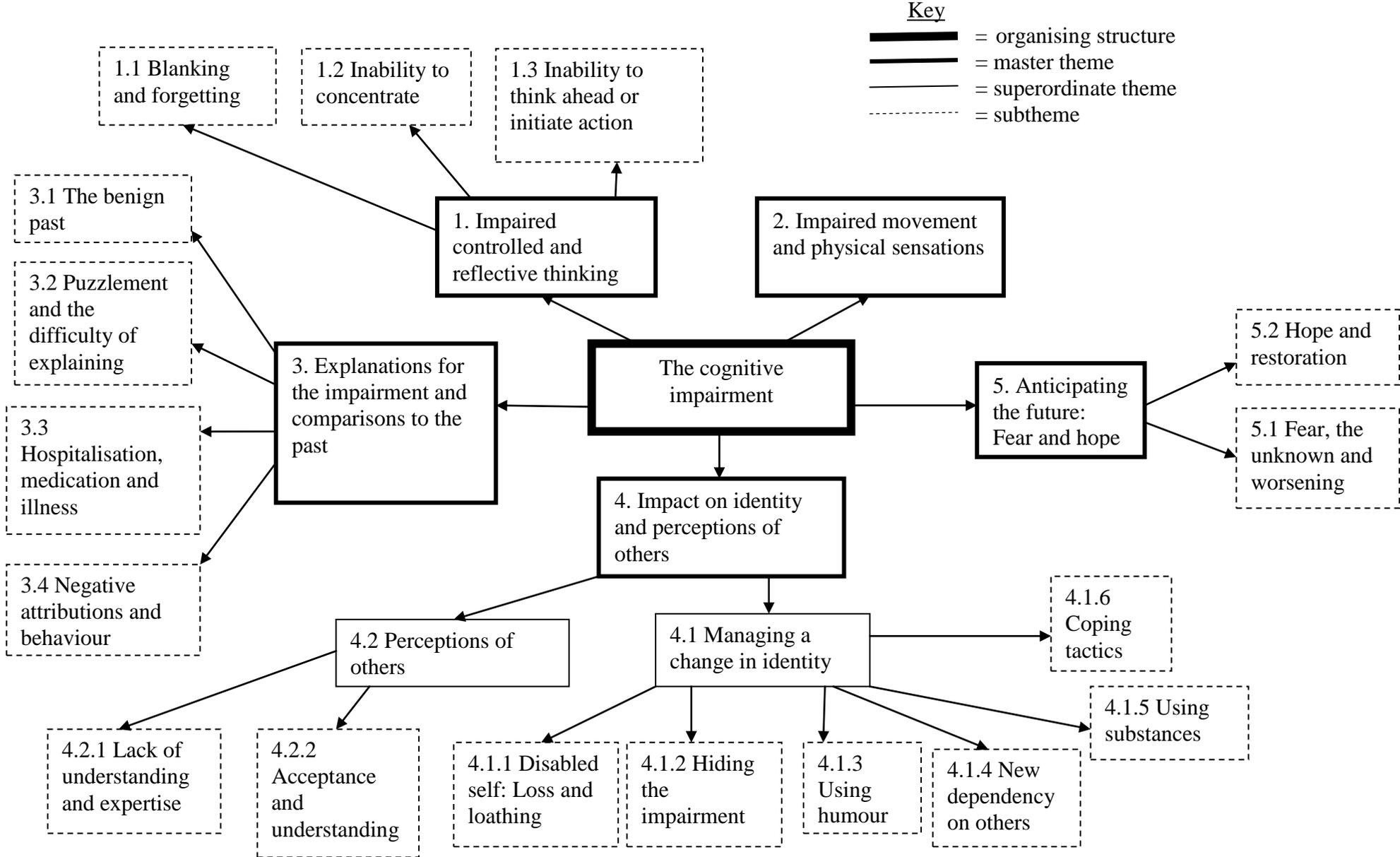
(Jim)

## **Discussion**

### **The Cognitive Impairment**

IPA led to results being structured around a general experience of cognitive impairment, understood in a variety of ways (Figure 8).

Figure 8. The cognitive impairment.



**Impaired controlled and reflective thinking.**

The significance of ‘controlled and reflective thinking’ matches emphasis on impaired top-down conscious control (Frith, 1979) and impaired metacognition (Moritz & Woodward, 2007) in psychosis. Participants’ difficulties seemed to result from an inability to direct cognitive resources, rather than a cognitive deficit per se.

The theme ‘blinking and forgetting’ echoes memory difficulties identified in people with psychosis (Forbes et al., 2009; Heinrich & Zakzanis, 1998) and in the screening assessment. Participants’ meta-memory seemed impaired (Izaute & Bacon, 2010): although they tried to use their thinking to retrieve memories, they were often unsuccessful. Inability to control attention also limited initial registering of information ( Craik & Lockhart, 1972), with the ‘voice-recorder’ mind working intermittently.

Descriptions of ‘blanks’ support the suggestion that memory difficulties may also result from retrieval or storage failures (Baddeley & Hitch, 1974), possibly explaining long-term memory difficulties in the initial assessment. Jonathan’s description of his sieve-like mind, and others’ faint memory traces, can be understood as a result of poorly elaborated information encoding (Craik & Lockhart, 1972). These memory blanks may also be significant for understanding so-called positive symptoms. Dodgson and Gordon (2009) describe how conceptually driven processing biases fill gaps in auditory information. It is possible that blanks in memory may be completed with information related to a person’s conceptual biases or psychotic experiences, such as their negative appraisal of themselves or others.

Controlled thinking was also significant to concentration, as in models of attentional control (Norman & Shallice, 1986). Concentration was not poor per se, but was directed to people’s

Section B      The experience of cognitive functioning difficulties in people with psychosis most salient needs. Harry seemed to describe a perceptual bias, adaptively using concentration to check perceived threats from aliens. However, this could simultaneously contribute to processing errors, false-positive threats being identified, and important information, such as an appointment time, being missed.

Participants struggled with planning or thinking ahead, which Jonathan attributed to memory difficulties. Indeed, impaired memory has been linked to foreshortened future perspective (d'Argembeau et al., 2008; Heerey, Matveeva, & Gold, 2011; Szpunar, 2010), with implications for planning and functional recovery (Eack & Keshavan, 2008; Heerey et al., 2011).

#### **Impaired movement and physical sensations.**

Empirical literature links poor motor control in psychosis to cognitive functioning changes (e.g. difficulties with planning) (Destoop, de Bruijn, Hulstijn, & Sabbe, 2010). Motor control was required in the cognitive flexibility test, TMT (AITB, 1944) that several participants struggled with. Participants' physical experiences of cognitive functioning difficulties could also represent alterations in the relationship between self and body (Gipps, 2010; Laing, 1990; Merleau-Ponty, 1962).

#### **Explanations for the impairment and comparisons to the past.**

Participants' tendency to locate the origins of cognitive impairment with themselves is commensurate with self-blame post-psychotic episode (Birchwood, Iqbal, & Chadwick, 2000). Significantly, no participants mentioned psychosis or schizophrenia in explaining their difficulties, though some associated cognitive functioning difficulties with their 'illness.' This may link to sealed-over recovery style (McGlashen, 1987; McGlashen, Levy, & Carpenter,

Section B      The experience of cognitive functioning difficulties in people with psychosis (1975). However, lack of education about the connection between cognitive functioning difficulties and psychosis may also be relevant. Equally, from a social constructionist viewpoint, psychosis is not generally spoken of as encompassing cognitive difficulties, meaning participants' understandings of psychosis were not linguistically predefined as including cognitive difficulties (Willig, 2001).

Participants identified hospitalisation and medication with the start of their difficulties. This may represent the point at which psychotic experiences, including accompanying cognitive difficulties, became most problematic. However, it could also represent the links identified between institutionalisation and loss of cognitive functioning skills (Lapornik et al., 1996; Johnstone et al., 1992), and between medication side-effects and cognitive slowing (McEvoy & Brown, 1999).

#### **Managing a change in identity.**

Results demonstrated how coping tactics occur 'naturalistically' (Tarrier, 2002, p. 80). Participants' use of practice and repetition resonates with the theory of maintenance rehearsal to support memory (Atkinson & Shiffrin, 1968; Craik & Tulving, 1975), while 'dependency on others' for 'jogs' involved cued recall (Craik & Tulving, 1975).

In comparison, coping tactics such as caffeine or cannabis use, are poorly understood. Though caffeine is maligned for inducing psychosis (de Freitas & Schwartz, 1979), affecting medication (Dratcu, Grandison, McKay, Bamidele, & Vasuvden, 2007) and sleep, Jim may have enjoyed caffeine's stimulating effect on attention (Bolton & Null, 1981) or its compensation for medication side-effects (Hughes, McHugh, & Holtzmann, 1998). Cannabis is linked to psychosis-onset (Forti et al., 2009). However, cannabis' appeal could be

Section B      The experience of cognitive functioning difficulties in people with psychosis understood if it gave Jim the experience of thinking ably, possibly through increased introspection and enhanced sensory experiences.

Overall, the challenges to participants' identities were prominent. Participants had moved from being able to disabled. This had implications for their relationships to themselves, to others, and to substances, such as caffeine, on whom they depended for support. 'Hiding' resonates with social exclusion or stigmatisation related to psychosis (Hayward & Bright, 1997). Alternatively, the cognitive functioning impairment may itself stigmatise, as with learning disabilities (Ali, Strydom, Hassiotis, Williams, & King, 2008) or when Jonathan described the wound of 'negative marks.' It is possible this altered identity compounds or is compounded by 'bad me' or punishment paranoia (Trower & Chadwick, 1995).

#### **How others perceive the impairment.**

Participants saw people as accepting their cognitive impairment, but there was little sense of others having expertise. In some instances, participants suggested that others' views of them were such that their identity was subsumed by the cognitive impairment. Perceptions of identity sublimation may have been augmented by a decreased sense of self (Doody et al., 1998; Hemsley, 1998; 2005).

#### **Anticipating the future.**

Participants feared the progression of their difficulties, though empirical research suggests cognitive functioning difficulties are stable (Fagerlund, Andersen, Oranje, Gade, & Glenthøj, 2010; Hoff, Svetina, Shields, Stewart, & DeLisi, 2005). The subjective experience of deterioration may be due to a selection bias based on prevalent public understanding that adult cognitive decline is generally due to progressive illness (e.g. dementia). Consequently,

Section B      The experience of cognitive functioning difficulties in people with psychosis experiences of worsening may have been noted over improvements. Equally, self-labelling—as dementing or disabled—may also have impacted on their intentions and consequent behaviours (Fishbein & Ajzen, 1975; Penn & Nowlin-Drummond, 2001). Participants may have limited their range of cognitively stimulating activities, compounding their experience of cognitive decline. Finally, cognitive functioning difficulties (‘inability to think ahead’) may limit the ability to perceive a future.

Deterioration was held in tension with ‘hope and restoration.’ There was a sense of the brain’s capacity to heal and participants voiced new intentions. This seemed due to the stimulus of the interview, the result of demands placed on reflective thinking. Participant optimism also mirrors their positioning as experts whose experiences were being listened to. However, from a psychodynamic perspective, hope could be seen as a form of denial, a psychological defence against the fear of cognitive deterioration (Gabbard, 2010).

### **Methodological Critique**

This study grounds empirical findings in people’s experiences. Its rigorous qualitative approach also compensates for early qualitative studies’ limitations (Freedman & Chapman, 1973; McGhie & Chapman, 1961). Bearing in mind these limitations, early studies nevertheless function as a form of credibility check (Elliott et al., 1999), supporting, for example, findings about fear, changes in mobility (McGhie & Chapman, 1961) and distraction (Freedman & Chapman, 1973).

The phenomenological methodology did not aim for generalisability. Instead, the aim was to improve understanding of human experience (Husserl, 1927). Nevertheless, any transferability (Lincoln & Guba, 1985; Mays & Pope, 2000) of findings may be limited, since

Section B      The experience of cognitive functioning difficulties in people with psychosis participants were all male, predominantly white British, from a suburban area, and four lived in rehabilitation units.

Sampling was purposive, seeking the experiences of those with an objectively defined level of cognitive impairment. However, the discrepancy between self-assessed and objectively assessed cognitive functioning is acknowledged (Prouteau et al., 2003). This study did not aim to compare the two. Instead, it sought to understand the experiences of a group of people. To minimise predetermination of experience, the question ‘can you tell me about your experiences of thinking difficulties?’ was used to open interviews. However, arguably, this still biased content in presupposing such difficulties existed or were problematic. The interview’s questions were sometimes shorter than in other qualitative studies to compensate for cognitive functioning difficulties (Booth & Booth, 1996; Fatouros-Bergman, Preisler, & Webart, 2006).

### **Clinical Implications**

Findings have implications for psychosis formulation; service-user and carer education; and support offered by services to clients. As regards formulation, clients’ fears about their cognitive functioning may affect mood, and their sense of being ‘disabled’ may affect core beliefs. Participants’ ‘inability to think ahead’ suggests people with psychosis may need more support in planning intentions if a theory of planned behaviour approach is used (Ajzen, 1987), for example, in smoking cessation.

In terms of carer and service-user education, existing US models could be drawn on (Medalia, 2010; Revheim & Medalia, 2004). This study could also inform coping strategies and accessible language used in client psychoeducation groups that are due to be piloted in

London (T. Wykes, personal communication, June 21, 2011). Finally, results suggest a need for staff to develop expertise in understanding and supporting cognitive functioning. In residential settings, encouraging stimulating and reflective conversation may benefit clients. Rather than fostering dependency, staff could also help clients move to less stigmatising forms of support, such as mobile phone reminders.

### **Research Implications**

This study's findings elucidate a number of research directions, including how people with cognitive functioning difficulties manage changes in relation to their identity; staff understandings of cognitive functioning; and interventions for metacognition. It is possible, though not clear from this study, that particular ways of managing changes in identity, such as coping tactics, facilitate more positive future perspectives and future levels of functioning in people with psychosis. This relationship needs investigating. Additionally, there is a need to establish staffs' levels of understanding of cognitive functioning difficulties to inform further training, building on Bromley's (2005; 2007) studies. The interview seemed to have a positive impact on participants' experiences of cognitive functioning. Although metacognitive training is being pioneered (Moritz et al., 2011), this study suggests increasing reflective conversational style in residential settings could also be measured as a preliminary intervention for metacognitive difficulties.

### **Conclusion**

This is the first rigorous qualitative study looking at experiences of cognitive functioning difficulties in psychosis. It matches the the DoH's (2011) directive to take into account what matters to service-users. Results answered the project's aims of understanding what cognitive functioning difficulties people experience; how they are understood; how people respond to

Section B      The experience of cognitive functioning difficulties in people with psychosis these difficulties; and how others' views of these difficulties are perceived. The findings highlight a wide range of new directions, both for research and clinical interventions. These will enhance theoretical understandings of cognitive functioning in psychosis and contribute to alleviating some of its associated distress.

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**Section C: Critical Appraisal**

**Word count: 2000**

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**1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to develop further?**

Prior to undertaking this research project, I worked as a research assistant on an exploratory empirical study looking at the efficacy of Cognitive Remediation Therapy (CRT) when combined with supported employment. I gained experience of recruitment, taking consent, and carrying out cognitive assessments. Undertaking my first research project as Principal Investigator, I learned about proposal development, budgeting, and applying for ethical approval, including the value and challenges of seeking ethical approval by a committee of non-experts in psychosis. This type of scrutiny prompted me to consider with particular thoroughness the process of taking consent from people with cognitive functioning difficulties.

This project has allowed me to develop my qualitative research abilities. Despite giving careful attention to interview development through service-user consultation, it was sometimes challenging to get rich interview data from participants who were less verbally articulate and reflective. The very cognitive functioning difficulties I was interested in learning about sometimes seemed to impede data collection. At times, I noticed myself wanting to ask questions I might use therapeutically; I wished to support the participants' development of understanding alongside my own. However, previous research on interviewing people with cognitive disabilities, and on communication style with people with psychosis, helped me develop the ability to use briefer, more frequent questions and prompts, without biasing the data (Booth & Booth, 1996; Fatouros Bergman, Preisler, & Werbart, 2006). Meanwhile, I learnt to recognise that live examples of the difficulties being investigated, such as Gerald forgetting what I had asked him, enhanced my findings. These incidents afforded an opportunity to enquire about the experience in the moment.

As regards data analysis, I initially found it challenging to move from a first order descriptive level of analysis to the second order level of interpretation (Larkin, Watts, & Clifton, 2006). I had to learn this particularly at the point of synthesising my interview analyses, when considering what meaning and new understanding I was discovering.

Finally, I learnt about the conscious effort necessary in meeting quality assurance requirements in qualitative research (Yardley, 2000). The ongoing requirement to ‘bracket’ (Fischer, 2009) one’s own experiences is challenging when past experiences work at unconscious levels. Talking to colleagues helped make the influence of these experiences more conscious, such as caring for a relative with dementia or my work using CRT.

Research skills I would like to develop further encompass consolidating my Interpretative Phenomenological Analysis (IPA) skills, using other qualitative approaches, and developing my empirical research skills. As regards other qualitative approaches, during this project I was aware of discourses related to gender and power: for example, my position as a white British female clinical psychologist, and the position of participants as unemployed, mentally ill men. This has given me an interest in developing skills in Foucauldian discourse analysis (Andersen, 2003). Building on previous experience with small-scale service evaluations and MSc research projects, I would also like to develop skills in more complex quantitative data analysis.

**2. If you were to do this project again, what would you do differently and why?**

Recruitment was initially difficult for this project. If doing this project again, I would concentrate on rehabilitation units from the beginning of the recruitment process. I started by approaching early intervention (EI) teams and assertive outreach teams. In EI teams, clients' diagnoses were generally not clear enough for my inclusion criteria. In both EI and assertive outreach contexts I had the impression that the teams' need to focus on engaging clients left little scope for care coordinators additionally trying to engage clients to take part in research. In contrast, within rehabilitation teams or units, I was less reliant on care coordinators as 'gatekeepers' to recruitment. I was more easily able to meet clients, who were often resident. I became familiar to them, meaning trust could be established and they were more likely to want to take part in my study.

It is possible that not offering remuneration also hindered recruitment. I would consider this in the future, though it raises ethical issues of its own. Additionally, I wonder if staff's own lack of awareness of the significance of cognitive difficulties impeded their role as 'gatekeepers.' Clinical psychologists and occupational therapists (OTs) were most helpful, suggesting they were either more sympathetic to my training needs, or considered my project's focus significant. I hoped that the cognitive screening assessment would help teams by informing participants' care. A brief education session for teams on cognitive functioning difficulties in psychosis might have improved the staff's sense that they benefited from the study, and thus enhanced recruitment further.

If doing this project again, I would now have more awareness of data that might not be captured. Sometimes my initial conversations with participants yielded information that might have been rich data, but which they did not mention in interviews. For example, two

men described the importance of art and music to them, but barely touched on these topics in interview. I am now curious about how music or art might support a 'disability of controlled and reflective thinking,' perhaps strengthening the ability to train focus externally. On the one hand, an interview should be recognised as containing material the participant judges to be relevant to their experiences in that moment. On the other hand, I wonder if there would be scope for me to express curiosity about topics mentioned prior to interview without biasing content. Alternatively, particularly given possible difficulties with paranoia and trust, I wonder if meeting for a second interview would have naturally brought up further material for some participants.

More generally, there may be value in a further encounter post-interview. Participants often rushed off as the interview ended, as if having reached the limits of their concentration, stamina, or tolerance for 1:1 interaction. However, based on what they shared, I was aware that the interview could have aroused painful realisations about their cognitive functioning levels. Where possible, I provided brief psychoeducation at the end of the interview, addressing, for example, the difference between these cognitive difficulties and dementia. All participants seemed to have OTs or clinical psychologists sympathetic to their cognitive difficulties. However, if setting up this study again, I would consider including the option of a follow-up phone call or appointment in my ethics application. Simultaneously, I am aware that sustained contact could have been misleading as to the nature of our relationship.

Finally, I would like to give more attention to the role of language and interpretation. Though I designed interview questions to minimise bias, I question the extent to which I was constructing cognitive functioning difficulties through the language I was using to interact with people who had never previously articulated their experiences of cognitive functioning.

IPA relies on the representational validity of language as a way of capturing the essence of human experience (Willig, 2001), yet language may also precede experience and predefine it. On the other hand, first utterances of experiences may be the purest articulation of experience we can hope to get within the limits of language and its construction of reality.

**3. Clinically, as a consequence of doing this study, would you do anything differently and why?**

When working 1:1 with clients, I would now pay more attention to the role of cognitive functioning difficulties in cognitive behavioural formulation. My results suggest that cognitive functioning difficulties may play a greater role in anxiety than is usually acknowledged. Participants shared their fears about the future, particularly if they had misattributed their difficulties to a dementia-like syndrome. Cognitive dysfunction in the form of Jim's expressed inability to see the future might also affect anxiety, motivation, or low mood if the future felt impossible to conceive. Cognitive functioning difficulties may further affect core beliefs, particularly given participants' descriptions of themselves as 'disabled.' In addition, I would consider the possibility that cognitive biases in psychosis may influence not only how blanks in memory are viewed, but how they are filled in, for example with information related to a person's conceptual biases or negative self-appraisal.

My results suggest a place for educating clients about cognitive functioning, which could also serve as an intervention. Clients could be educated about the coping strategies elicited in this study, such as breaking down tasks. Medalia's (2010) model of psychoeducation groups could be used, but psychoeducation could also take place at assessment. Accessible language observed in this study, such as 'blanking,' would facilitate these interactions.

More widely, when supervising others and in team discussion, I could draw people's attention to cognitive functioning difficulties. I imagine there will be opportunities also to gently challenge staff's misunderstanding of their clients. Clients described as 'unmotivated' or 'lazy' may in fact be experiencing 'blinking and forgetting' or difficulties 'thinking ahead.' In a team context, I would draw on the theme 'dependency on others' to foster awareness of how we may need to support people. I would suggest we function as an external memory store, for example by providing reminder phone calls, letters, or, text message prompts (Pijnenborg, Withaar, Evans, van den Bosch, & Brouwer, 2007). Simultaneously, however, following Jim's comments suggesting services foster clients' dependency, I would encourage colleagues to work with clients to achieve greater independence. This might involve choice about the type of reminders provided, in line with policy emphasis on service-user choice (Department of Health, 2010). It could also be achieved by a graded intervention, whereby clients are increasingly encouraged to use their own reminder systems, such as their mobile phone calendars, which may be less stigmatising than asking others for help.

It seemed that the experience of being interviewed stimulated cognitive functioning. In the future, I would like to draw on this to promote more cognitive stimulation in residential mental health settings, for example through the style of staff-patient conversations.

In addition to staff education, Revheim and Medalia (2004) suggest a role for educating families about cognitive functioning difficulties. While my results suggested that family and friends were supportive, it is possible that specific information would foster more appropriate support, perhaps lessening the extent to which difficulties are subsumed into a person's identity and seen as just 'part of being Jonny' (Jonathan).

**4. If you were to undertake further research in this area what would the research project seek to answer and how would you go about doing it?**

My results suggest a research project is needed to answer the question, ‘what are staff understandings of cognitive functioning difficulties in psychosis?’ This would broaden the existing information from Bromley’s (2007) account of psychiatrists’ perspectives. A new research project would seek to understand the perspectives of a range of professions in a given service context, such as a rehabilitation unit. An IPA methodology would fit well, since it would leave staff’s understandings open to discovery. A selection of vignettes could be presented describing hypothetical clients’ behaviour and tasks they find challenging (e.g. being on time for meals). These vignettes could be used as prompts for a semi-structured interview around how participants’ understood these clients. Care would be taken to ensure the vignettes did not contain descriptors that would bias participants’ attributions. The results would be used to develop a survey to measure the understandings of a larger number of staff from a range of settings. The results of this survey would inform plans for further staff training on cognitive functioning in psychosis.

My findings suggest that the stimulus of the interview interaction may have been beneficial to participants. If delivered in a residential unit, the proposed staff training programme could include a component on how to create a cognitively stimulating environment, and teach residents cognitive strategies. Such a milieu could be based on CRT-type strategies (Wykes & Reeder, 2005), e.g. scaffolding clients’ abilities by providing just enough support, or by encouraging clients to use strategies such as written notes or reminders. Clients would be helped to ‘thicken’ or elaborate memories in order to deepen encoding, for example by repeating back an appointment time they needed to remember. Staff would encourage a

reflective conversational style, to help clients notice the focus of their attention and stimulate their metacognitive abilities.

The impact of this staff training on clients' cognitive functioning could be measured via an initial series of case studies. Clients' cognitive functioning would be assessed pre-staff training and at time points post-staff training, across a range of areas. This assessment could include objective measures from Section B; subjective measures (Keefe et al., 2006) of cognitive functioning; and measures of metacognitive ability (Broadbent, Cooper, Fitzgerald, & Parkes, 1982). Mood changes could also be assessed (Beck & Steer, 1990; Beck, Ward, Mendelsohn, & Erbaugh, 1961).

These research proposals for investigations of staff understandings of cognitive functioning difficulties in psychosis, the staff training programme, and case studies, could pave the way for a larger randomised control trial (RCT) and the development of a new type of intervention for cognitive functioning in psychosis.

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**Section D: Appendix of Supporting Material**

## **Section D**

### **Appendix of Supporting Material**

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## **Appendix A**

### **Copies of Measures**

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## Appendix B

### **Semi-structured interview schedule** **Allow 40 minutes to one hour**

(Second level questions denote probe questions).

Remind participants of voluntary nature of participation, option of taking breaks during the interview or of stopping at any time. Remind participants also of purpose of interview and limits of confidentiality.

Explain role of researcher not therapist.

#### **Demographic information**

Participant number:

Gender:

Ethnicity:

Living circumstances:

Partnership status

Employment:

Length of time in contact with mental health services:

Order of question areas is flexible to suit participants

#### **NB remember:**

##### **Prompts and probes:**

**Can you tell me a bit more about that?**

**Why?**

**How?**

**How did you feel?**

**What were you thinking?**

**Sorry if this is a stupid question, but what do you mean by xxxxx?**

**Was there anything you did in response to that?**

**I'm interested in how...**

## **1. Experiences of cognitive difficulties.**

**Can you tell me a bit about your experience of thinking difficulties?**

**Can you tell me a bit about what thinking difficulties you experience?**

- Give concrete examples if necessary e.g. some people find it hard to remember what someone said.... some people find it hard to concentrate when watching TV... some people find it hard to do several things at once...

Possible prompts:

- Can you give me an example of.... (whatever difficulty mentioned)?
- Can you tell me about a recent time when....?
- What happens?/happened?
- How do you feel?/did you feel?
- How do you respond?/What did you do in response?
- Can you tell me what it is like when...?

## **2. Time**

**Can you say when these difficulties/when X first happened?**

Prompt: What was going on in your life at the time?

**Past: How were things before that/what was different about before? /Has it always been like this?**

Prompt: did these difficulties affect things at school/were they present at school?

What were the main differences between then and now?

How did it make you feel/does it make you feel?

**Future: What do you think will happen to these difficulties in the future?**

What might help?

What would be a positive development for you? what would be a negative development?

How could your situation improve? What would it feel like?

**Present: are their times when it's better/worse?**

- Concrete e.g.s: how is it when you're tired? How is it when you're feeling well?

*Prompt: what are the main differences between times when it's easier/more difficult?*

How does it make you feel? How do you respond? What happens?

## **3. Attribution/understanding**

**What do you think has caused these difficulties?/Do you have a sense of what has caused these difficulties?/ How do you explain?**

Prompts: what was going on in your life when they started?

How does it make you feel?... have you always felt that way about the difficulties? What do you notice?

## **4. Impact**

**How do you think your life would be if you didn't have these thinking difficulties?**

**How do they (thinking difficulties) affect your day?**

**How do they affect your relationships?**

For all: how does it make you feel? What do you think when that happens? How do you respond?

Can you tell me what it is like when...?

**5. Feelings re self – if not already covered.**

**You've mentioned x, x and x. I wondered if you could tell me a bit more about how it makes you feel when....?/how x makes you feel**

**Has it changed how you feel about yourself?**

- Concrete example e.g. how does it make you feel when you forget an appointment?

Can you tell me what it is like when...?

**6. What do you think other people make of it?**

What do you think your friends make of these difficulties/of x?

What do you think your family make of these difficulties?

What do you think your psychiatrist/Care Coordinator makes of these difficulties?

*What do you think people who don't know you make of these difficulties?*

How does it make you feel? How do you respond? What do you say? What do you/were you thinking? Can you tell me what it is like when....?

**7. Coping (idea of interviewees as experts, naturally occurring therapeutic strategies)**

**We've talked about xxxxx. How do you cope with xxxxxx?**

*I wondered if there's anything that you find helpful?*

Can you describe a recent example?

What makes xxxxx better?

*I wonder if there's anything you find unhelpful?*

What makes xxxxx worse?

Have you changed the way you respond over time?

How do you feel about these changes?

Can you tell me what that is like? What it is like when....? How does it make you feel? How do you respond?

**8. Help that's available?**

**Do you know whether there's any help available?**

*Does you xx (care coordinator/family/friend etc) think that there's any help available?/anything that can help?*

**9. Relationship of cognitive difficulties to psychotic experiences**

**You mentioned you've been unwell... I wondered how that affects the thinking difficulties?**

*Some people hear voices when they're unwell, is that something you experience... I wondered how that affects.... louder/quieter voices*

*Some people feel low... is that something you experience... I wondered how that affects...*

Thank participants for their time and cooperation.

**Appendix C**

**NHS Research and Ethics Committee (REC)**

**&**

**NHS Research and Development (R&D) Approval**

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## **Appendix D**

### **Summary of findings for REC and R&D**

#### **Declaration of the end of study**

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**Appendix E**  
**Participant information sheet**

## Participant information sheet

### **The experience of cognitive (thinking) difficulties in people with psychosis**

I would like to invite you to take part in a research study. Before you decide whether or not to take part, I would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

If we meet, I will also go through this information sheet with you and answer any questions you have. Ask if there is anything that is not clear.

#### **What is the purpose of the study?**

I am a trainee clinical psychologist. This study is part of my doctoral degree.

People who have been given a diagnosis of Schizophrenia or Schizoaffective Disorder sometimes experience thinking difficulties: for example, difficulties with remembering things, concentrating, doing several things at once, or switching from one activity to another. This study aims to understand this experience better. This type of research is called 'qualitative research'. I am interested in interviewing people about their experiences of thinking difficulties. I hope this will improve the support people are given and guide further research.

#### **Why have I been invited to take part?**

You have been invited to take part in this study because at some point you have been given a diagnosis of Schizophrenia or Schizoaffective Disorder. A member of your NHS team thought you might be interested in this study's focus on thinking difficulties (e.g. difficulties with remembering things, concentrating, doing several things at once, or switching from one activity to another). I will be interviewing a maximum of 12 people about their experiences.

#### **Do I have to take part?**

It is up to you to decide whether or not to join the study. When we meet, I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

**What will happen to me if I take part?**

The accompanying diagram shows what will happen if you agree to take part. If you agree to take part, we can talk about when it is best for you to do each stage. Your involvement in the study will end after the interview and feedback of the test results (stages 3 and 4). If you wish, you can comment on the results of the study (stage 5). Your normal treatment will not be affected by taking part.

Stage 1. Thinking skills tests. **We will do some short tests with you. This is to ensure that you have the sort of thinking difficulties we are interested in. You will complete some short exercises using thinking skills that will help us understand your strengths and weaknesses. This should take about 30 minutes. You will be able to take breaks if you need to.** If you have already completed thinking skills tests with someone in your team it may not be necessary for you to do all of this assessment.

No further participation required: **if the tests show that your thinking skills are not the sort we are interested in, we will not need you to continue with the study. However, we will share the test results with you & your Care Coordinator.**

Further participation:  
Stage 2. **If you have the sort of thinking difficulties we are interested in, we will invite you to take part in Stage 3. We will share the results of the thinking skills tests with you after Stage 3 (an interview). We do the interview first because we would like to hear about your experience of thinking difficulties, without this conversation being influenced by the results of the tests.**

Stage 3. Interview. **We will ask you some basic questions about yourself & then some questions about your experiences of thinking difficulties: e.g. what you notice, what's hard/easy, when they are worse/better. However, we hope this can take the form of a conversation and that you will feel free to talk. This will take about 40 minutes-1 hour and will be tape-recorded. You will be able to take breaks if you need to.**

Stage 4. Feedback of results from thinking skills tests. **We will let you know what the tests showed about areas of strength or difficulty. These results will be shared with your Care Coordinator.**

Stage 5. Sharing thoughts about the outcome of the study. **We will send you a copy of the results of the study. If you would be happy to share your thoughts about these results, please let us know.**

### **Expenses and payment**

Unfortunately, I am not able to offer money for expenses or as payment.

### **What will I have to do?**

All meetings will take place at your usual team base. The flow diagram shows what you will need to do. I can answer any questions you have about this.

### **What are the possible disadvantages and risks of taking part?**

You will need to travel to your team's base to meet me. It is possible that receiving the results of the thinking skills tests may feel difficult. It is also possible that during the course of the interview you may find yourself talking about something that brings up difficult feelings. If this happens, we can decide whether you want to take a break, stop, or talk about something different.

### **What are the side effects of treatment received when taking part?**

There is no treatment received by taking part in this study. If you do become distressed, the researcher will do their best to help you with these feelings at the time. You should contact your care coordinator if you experience on-going distress. Or, if you wish, the researcher can contact your care coordinator on your behalf.

### **What are the possible benefits of taking part?**

There is no intended clinical benefit to taking part, but I hope that the experience of sharing your experiences will be positive one. It is possible that the results of the thinking skills tests will help you understand your difficulties better. I hope the information I get from this study will improve the support offered to people with psychosis.

### **What happens when the research study stops?**

All data collected will be stored securely for 10 years at Canterbury Christ Church University. This is in accordance with the Data Protection Act, 1998. Before the study ends, I will send you a summary of the results. You can comment on these results if you wish.

### **Will my taking part in the study be kept confidential?**

You have been approached by your care coordinator or a member of your team with information about the study. They will know about your participation and the results of the thinking skills tests. They will not know about the content of the interview, unless during the course of the interview you reveal something that causes me to be concerned for your safety or the safety of others, I will

then need to inform your care coordinator immediately. I will let you know if this is necessary.

Recordings of interviews will be saved anonymously and securely. The recordings will be used to make a written version of the interviews. All names will be changed and identifying information will be removed from these written versions. Only myself, my supervisors and you will have access to these recorded and written interviews.

Your words may be quoted in the final write-up of the study and future publications. However, every care will be taken to ensure these quotations are anonymous.

The forms that are filled out for the thinking skills tests will not have your name on. Only myself, my supervisors, you and your care coordinator will have access to these results.

All of this information will be stored securely for 10 years at Canterbury Christ Church University. This is in accordance with the Data Protection Act, 1998.

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

If you withdraw from the study, we will not use any data collected. If you wish, we can destroy data collected, or store it securely with other data for 10 years at Canterbury Christ Church University.

### **What if there is a problem or I wish to complain about the study?**

If you have any concern about any aspect of this study, you can contact me and I will do my best to answer your questions (Tel. [REDACTED] - please leave a message and I will return your call). You can also talk to your care coordinator.

For further advice, you can talk to a member of the Patient Advice and Liaison Service (PALS) on [REDACTED].

If the problem is not resolved, you can contact the [REDACTED] Trust Complaints department on [REDACTED].

### **What will happen to the results of the research study?**

The results will be written up as a doctoral thesis. They will also be submitted for publication in a peer reviewed journal and may be presented at academic

conferences. You will not be identified in any report or publication, although your words may be quoted anonymously.

**Who is funding the research?**

The study is being funded by Canterbury Christ Church University.

**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 West Central London REC 3 Research Ethics Committee.

**Further information and contact details.**

For further information about the study and taking part please contact:

**Helen Wood**

Tel. [REDACTED] - please leave a message and I will return your call.

**Appendix F**  
**Participant consent form**

Centre number:

Participant information number:

## CONSENT FORM

**Title of project:** The experience of cognitive (thinking) difficulties in people with psychosis

**Name of researchers leading the study:** Helen Wood

1. I confirm that I have read and understand the information sheet dated.....  
(version.....) for the above study. I have had the opportunity to consider the  
information and ask questions. I have had these questions answered satisfactorily.
2. I understand that my participation is voluntary, that I am free to withhold personal  
information and that I am free to withdraw at any time without giving any reason and  
without my medical or mental health care or legal rights being affected.
3. I agree to the Chief Investigator (Helen Wood) accessing my past cognitive  
assessment results, if they exist. I understand that these results will be used to make a  
decision about how much of the study's assessment of cognitive (thinking) skills and  
difficulties I need to carry out.
4. If it is judged to be necessary, I agree to an assessment of my cognitive (thinking)  
skills and difficulties (e.g. memory skills). I understand that the results of this  
assessment will be shared with my Care Coordinator. I understand that the results of  
this assessment will be stored securely at Salomons for 10 years.
5. If my cognitive difficulties meet the levels required for further participation in the  
study, I understand I will participate in a one-off interview to explore my experiences  
of cognitive difficulties.
6. I understand that the individual interview will be tape recorded for the purposes of  
this research study. I understand that this recording will be saved with an anonymous  
name and held securely at Salomons for 10 years. The recording will be used to  
create a written copy of the interview, in which all information will be reported  
anonymously. Only members of the research team will have access to the original  
tape recordings and written copies of the interviews. I retain the right to ask for the  
tape to be destroyed, in which case my interview will not be included in the study.
7. I understand that Helen Wood (Trainee Clinical Psychologist) will be using the  
content of these interviews for her research at Canterbury Christ Church University.
8. I agree to quotations from my interview being anonymously written into the research  
of Helen Wood and other articles that may be written about the study.
9. I understand that I will be sent a summary of the major findings of the study.

10. I understand that Helen Wood will inform my Care Coordinator if she has any concerns for my safety or the safety of others. I understand that Helen Wood will inform me if she needs to do this.

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

12. We are interested in hearing people's comments about the results of the study: please tick this box if you are happy to be contacted.

\_\_\_\_\_  
Name of participant:                      Date:                      Signature: \_\_\_\_\_

\_\_\_\_\_  
Name of researcher:                      Date:                      Signature: \_\_\_\_\_

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept sent to care coordinator and kept in electronic patient mental health notes

## **Appendix G**

### **Summary of findings for participants**

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## **Appendix H**

### **Summary of findings for services**

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## **Appendix I**

### **Sample interview transcript**

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**Appendix J: Table of themes, codes and supporting quotes**

<b>Master theme</b>	<b>Code</b>		<b>Definition of master theme</b>
Impaired controlled and reflective thinking	1.		Describes the cognitive (thinking) disability. Contains three subthemes illustrating components of the cognitive disability affected by controlled and reflective thinking.
<b>Subtheme</b>	<b>Code</b>	<b>Participant name</b>	<b>Supporting quotes</b>
Blanking and forgetting	1.1	Harry	The food I try to remember what I ate and Monday, Tuesday I don't remember many days before.
		Harry	I have problems with my watch, [ok] remembering the time. Can you tell me a bit more about that? I don't remember that was in one year ago, or two. So a year ago it was hard to remember the time? Count the days. Now it's twenty past twelve, say it that way. In German you put vier und neunzig. 94. You put first the ninety four.
		Gerald	Er, I can remember simp-, er like, er [PAUSE]. Things like one word things like that. [Mm] Things like one word or, um, anything complicated and things like that, you know, [mm] I just can't remember. [Mm, mm] You know fairly complicated or, you know, really complicated, things like that.
		Gerald	Um, yeah, like I can't remember what people say [LAUGHS] [mm] like this con-, you know, [PAUSE] er, you know things, [PAUSE] you know if you can't, er, remember things people say you going to think um [PAUSE], um.
		Gerald	Right um, um, [PAUSE] can't think at the [moment <i>That's] fine.</i> I've gone blank
		Gerald	Sometimes] I do go blank, you know, just totally out of it.
		Gerald	Er, [PAUSE] you go, but er, I'm trying to [PAUSE], yeah when you go blank you just can't think [yep] your thoughts do that, your thoughts do that, [um

Subtheme	Code	Participant name	Supporting quotes
Blanking and forgetting	1.1	David	I don't know] like sometimes you think stuff like the day before and then, then you think about it the next day and you think, 'oh, what was I thinking, what was it about, um, what did it all mean and what I was thinking?' I was thinking about it the other day, as you go. I was thinking about Jesus and helping him out and then I thought about it the next day [yeah], and I thought, 'what was it?' You know, 'what was I thinking?' And I really couldn't remember what it was and it was really annoying and that's going to bug me like, and er yeah, so yeah, um, sometimes I find it difficult thinking about things
		David	Yeah, it does go blank sometimes, yeah. It's like a missing, missing bit in a sentence. You think, 'I was supposed to be here at...' and... and you think, 'um... what time?'
		David	Jogging my memory? Um, I don't know. I suppose if you, if, if um, like reading a book I suppose. You can remember bits of the book and stuff like that. Some bits you can't so you can find it through your thinking.
		David	Well,] I had, I had a dream and, and I can always remember this dream because it was so, it was so vivid and so in detail and, and there, and there was no [PAUSE] there was, er, three demons and all the people were fighting these demons and there was this red demon and everyone could, no one could beat it and then someone beat it and then this, and there was a lion in it as well and there was these little beings and Jesus is the most gifted, Jesus is most precious gift we've got. I can always remember that. So, so yeah, I can always remember that. And, and yeah [PAUSE] I don't know, the mind's, the mind's like a, er, well, it's like this little voice recorder thing I suppose you can [PAUSE] sometimes you can remember all of it, sometimes you can't remember all of it [yeah] so yeah.
		David	I don't know um, it's, it's, it's like when you read, read a book you can remember parts of it can't you? Some parts you can remember [yeah], some things you can remember and some things you can't so
		David	I think it's just, just, it just slips my mind I suppose. You don't, sometimes when you talk to someone it doesn't really register [yeah] [LAUGHS], doesn't really, if you're busy and you're doing something and they say, 'how's your day go been?' and you go, 'alright, yeah' and if you do something like that, like making something to eat or something like that or I don't know and you think, 'hey a minute, what was your name again?'
		David	But most, yeah, trying to remember people's names and stuff like that, that's what I don't remember, you know, 'what's your name again?' Yeah, so.

Subtheme	Code	Participant name	Supporting quotes
Blanking and forgetting	1.1	David	I think it's just, just, it just slips my mind I suppose. You don't, sometimes when you talk to someone it doesn't really register [yeah] [LAUGHS], doesn't really, if you're busy and you're doing something and they say, 'how's your day go been?' and you go, 'alright, yeah' and if you do something like that, like making something to eat or something like that or I don't know and you think, 'hey a minute, what was your name again?'
		David	Deluding myself, staying in, staying in another world, this imagination world and, and, and sometimes I'm sitting there and I'm just thinking and I'm looking into, you know, blank space [yes] type of thing [LAUGHS] [yeah] and I wake up and I go, 'oh, oh I was in imagination-world again!' So I thought, 'oh!'
		David	So I suppose I've got a disability there I suppose, and, but, trying to keep my mind thinking and imagining, and doing stuff in my mind then, as I said I, I, I, I'm looking into a blank world [yes], world is a blank that I'm thinking in my mind, and it's, it's a struggle to get back into reality again, but yeah, so yeah.
		Don	Forget every day I think [mumbles]
		Don	Yeah. Every day, I might something forgot one day, and remember the next.
		Don	Er...thoughts thoughts they stay in my head then they disappear.
		Don	Yeah. Every day, I might something forgot one day [hm], and remember the next. Mm. And what sort of things? Can you tell me? Um, um, [PAUSE] I don't know, I don't know, sort of thing. Thoughts, go [PAUSE] OK. Thinking about [PAUSE] Yeah, yeah. Yeah. Can you give any examples [er] of that? Er [PAUSE] Sort of, er, er [PAUSE] I might think about something, look at the paper. Packet of fags [PAUSE]. Yeah, yeah. Sure. [Yeah.] Yeah. So, great. And I remember the next day.
		Will	Um, I find it quite hard to remember things sometimes. Um, it's like, I get distracted, if I'm doing the same thing, um, then my mind tends to wander sometimes

Subtheme	Code	Participant name	Supporting quotes
Blanking and forgetting	1:1	Will	<i>And when you said “remembering” – again, another simple or a bit silly-sounding question [yeah] – can you tell me me what you mean by “remembering”, [yeah] Or give me examples?</i> It’s a bit of memory in the mind, like “remembering things”. Um [PAUSE] I <u>can</u> remember, but, but um sometimes I forget, and I find it easier to forget when there’s a lot going on [sure]. There could be quite a lot going on in my, in my life. And um... sometimes I’ll find I’ll misplace things, or I’ll forget [hm, hm]
		Will	And with the remembering [yeah] or the mind wandering or the being distracted... Um... I guess, what would be a positive development for you? Um [PAUSE] [coughs] excuse me. Um... [Pause.] Would be positive to um [PAUSE] to <u>keep track</u> of what’s gone on [hm], yeah.
		Tom	Like, with you, I never, I never even remembered that [laughs] I remembered like I think I remember last week as well [PAUSE]. This <u>morning</u> I had trouble coming up. [hm hm] Having breakfast, had me tablets, and then suddenly it came to me, remembered you were here [hm] Like, I’m grateful for that, I think I would have gone back to sleep!
		Tom	Could you tell me a bit more about not liking it if you <i>can’t remember</i> ? Er, I don’t like it sort of like missing out on it [PAUSE] remembering what the lines to the words to the song that the line’s came from.
		Tom	<i>So: do you mind saying a bit more about what you mean by “forgetting”?</i> I don’t know, just your mind’s blank and er then I something, er, what’s it, something, remember, things like that.
		Jonathan	And um, my memory is like a sieve [hm]. I lose it. Unless I write it down, put it in the book or the diary [hm], it’s, a, I lose it, I do. And erm can’t, can’t get the thought again [yes]. And that goes from one minute to the next.
		Jonathan	Can you give me any examples of things that would feel too difficult or complicated...? Um [PAUSE] Not really, I can’t [laughs, <i>That’s all right</i> ]. My memory [PAUSE] My memory doesn’t bring anything back [ <i>that’s all right!</i> ] to me at that point.
		Jim	Memory [hm] is not too great [hm], it takes me a long time to remember things. And um [PAUSE] thinking’s not too great.

Subtheme	Code	Participant name	Supporting quotes
Blanking and forgetting	1.1	Jim	Could you give me an example, or...? Like, for example, er [PAUSE] I might forget my aunty's [PAUSE] what she said to me when I first, when my parents died and [yeah] I entered into my uncle's and aunty's house [hm], I might forget the things she said to me [hm] to kind of [PAUSE] [hm] Na, I've just completely forgotten, can't remember at all.
Inability to concentrate	1.2	Gerald	Um. [PAUSE] I guess, um, yeah, if I go blank, [mm] really blank, then I can't concentrate [yep] so, er, when I go blank I can't think as well. Because I discovered the two go together somehow.
		Gerald	Er. [PAUSE] I mean, if you can concentrate you're going to be able to take it in, which means you'll probably remember it, [mm, mm] you know.
		Gerald	Yeah. Because conc-, concentrating you can. I, I would have thought if you can concentrate [mm] would be, um, oh, if you can't concentrate then, um - Have I got this straight? I can't think right - you wouldn't be able to remember, [mm] you know, [mm] if you can't concentrate.
		Harry	<i>Ok, do you mind if we go back to concentration? I'm trying to understand...</i> You saw what happened just now [referring to sitting in the entrance foyer waiting to find out what fire alarm was about. Interviewee had pointed out various people to me as we sat there]. Yes, I was sitting there, I was not hearing the voice or nothing. And it was through my concentration, I saw the door man, the guy, he's not too bad, I look at his face, the degree of love.
		Harry	Yes. And supposing, er, so when do you find it hard to concentrate? I look at one face, I look at you for example. And you, your face [mm] relates to me like you would be born again or death [mm] and God brings you back from death, but you've got faith and a lot of love. You're a goody. And there are others who, who, who, who went to death and they come back. But they, they are extraterrestrials who lives [and the baddies] and the goodies and the baddies, and the born again, born... God took them, they were born but then they were... er... God punishes the wicked and rewards the righteous.
		Harry	Every day I get a bad concentration. I get voices.
		David	it's, it's like reading a book or, or, a, you know, when I think, when I'm thinking, um, sometimes I'm thinking, trying to watch TV and thinking as well, and so I do find it... Trying hard to concentrate on, on, on every day, on reality going round instead of my thinking

Subtheme	Code	Participant name	Supporting quotes
Inability to concentrate	1.2	David	Just go in and out, I suppose, like through a door, I suppose, I don't know. Um, but I, I know what I'm thinking about, I can concentrate on what I'm thinking [yeah], but sometimes you've got to be, be, like anybody you've got to be in the mood. You know, I suppose to, to actually try and concentrate on what you read and what you do. Sometimes, when I'm reading a book and thinking as well about something totally different to what the book's telling me [ok], and, and, er, yeah, you know, sometimes I stop and I think, 'am I going back into the book again?' and stuff like that so, so, it can be difficult to concentrate occasionally. It's not all the time, but sometimes it can be, you know, quite difficult to concentrate, yeah [yeah]. Especially when there's things going on around you [ok], you know, and people coming in and out, you know, cos then in the hospital there's loads of people around me and that.
		David	You said it can depend on the moods? On your moods, yeah, um, sometimes when you hear voices you think people are out to get you and stuff like that. And, um, when you hear voices it's, it's tough to concentrate on the real, real world around you
		Don	Mm, mm. Can you tell me... a bit <u>more</u> about it? Er, that's all, all I got[PAUSE] I can't concentrate.[Mm, mm.]
		Don	Er, might be losing your thoughts when you're concentrating, yeah..
		Don	And how, how do you cope with – how do you cope with with, um, with the concentration being harder? Er, can't try and control my thoughts, you know, yeah.
		Will	Um, it's like, I get distracted, if I'm doing the same thing, um, then my mind tends to wander sometimes [Okay] tends to go off, on to um over things [hm]. Yeah, so I'm doing something like painting indoors [Yeah] um [PAUSE] I'll get distracted by like a book or something, and then I'll start reading the book for a while or something.
		Will	<i>So if I was to ask you what you mean by "wander" [yeah], that feeling of your mind "wandering" [yeah], could you describe that more, describe what that's like, when that happens?</i> Yeah, um. I'll be doing the same thing, and then, um, it's like, it'll start to, get distracted or go off it or get bored [mm] it'll get bored of the same thing [hmm], like, it'll be distracted

Subtheme	Code	Participant name	Supporting quotes
Inability to concentrate	1.2	Will	Um, if my mind wanders, um, sometimes I will just um – see, it’s like being, like going out for a drink and having a drink [hm]. I know a lot of people say it’s all fun and everything, but um, that’s sort of how it is, it’s sort of like... You know when you’ve had a drink and your merry [yeah], and you’ll have a little bit more and you’re a little bit drunk [hm], and that’s sometimes – not all the time – but sometimes, late at night, or um... or rarely, that’s, that’s how... that’s how it is [hm]. It’s sort of... It’s like being drunk. I don’t have... as much responsibility over myself [yeah]
		Tom	<i>What does the word “concentration “ mean for you?</i> Er. [PAUSE] Being able to like er keep your mind on something... Hm [PAUSE] As long as it actually needs...
		Tom	I don’t... er... Sometimes books, because I can’t like, you know, er, sort of like, understand all of them, and then I can’t like, sometimes I can’t like, focus on the words and things like that.
		Jonathan	I realised straight away that I had learning disabilities, I did. I wasn’t able to concentrate, I wasn’t able to read and write like I used to [hm, hm]. And as I say, I just can’t read and write properly [yeah]. It was all part of the start of learning... <u>adult learning disabilities</u> ,
Inability to think ahead or initiate action	1.3	Gerald	Recently my thinking’s got pretty worse. You know, thinking ahead.
		Gerald	I work backwards, you know, so buses and er you know recently I find it hard, um, harder to think, trying to work out, trying to work out, you know, the time going, not the time going backwards, but the er, how to work it out as you go, as you go, you know.
		Gerald	Thinking ahead’s sort of like planning, isn’t it, you know, planning things and that, yeah.
		Don	Um, just-just planning things is difficult. Trying to meet people, yeah.

Subtheme	Code	Participant name	Supporting quotes
Inability to think ahead or initiate action	1.3	Jonathan	<p>Yeah, I also have difficulty in concentrating and planning things.</p> <p>Hm! Could you – would you mind telling me a bit more about that?</p> <p>Um, if I, er, I, earlier on this century, I tried to, er, I planned a holiday, I did. And, er, it worked well, but it wasn't planned like it can be [hm]. It was very much, er <u>ad hoc</u>, my plans were. And er they worked out all right. I went to France three times, I did. For the main route [gosh!]. And er, although the plans worked well, they did, er it wasn't planned as far as time was concerned. It was, it was really: “get there, spend your money on whatever's going, and get back and having made it, say ‘I've done the main route’” [hmmm]. Because I can't, I can't really plan activities. I do occupational therapy, I do [hm]. But apart from that I can't actually plan occupations. I don't really plan because I can't.</p>
		Jonathan	<p>Er, unless you actually write it down, you can't put one plan on top of [right]... With a plan, really, you need a sort of flow-diagram, don't you [yes]? With a plan, one thing leads to another [hmmm], but if you've forgotten what the first thing is, you can't move on to the other.</p> <p>I see what you mean, yes...</p> <p>You know what a plan is, it's involved in moving one box to another, To expedite [yes] another, to move to a final result. But if you can't remember your first, you can't move on to your second [yeah, yeah]. So that's why I can't plan, because I can't have the memory [yes] to build on. With with, With memory, memory, you have to have something to build on, for memory.</p>
		Jim	<p>I've lost my ability to perceive the future [right], a hundred per cent, because this higher-level... um, handicapped feeling [yeah] I get [yeah], in my head. I used to think ahead and into the future, but now I can't do it [yeah] at all. Yeah...</p>
		Jim	<p>Er, it just means, um... there's levels of thinking, there's... and I've lost my ability to think on higher levels.</p> <p>Hm [yeah]. So, <i>so um, you feel you've lost your ability to think on a high level</i> [hm]. What would a high level be, what would that be like?</p> <p>I could – I could hear my thoughts UP HERE, and now I can't hear them.</p> <p>Hmmm...</p> <p>Yeah.</p> <p>And what, was that, what sort of thoughts?</p> <p>Things like, erm... “oh, I've got to give up smoking”, “I've got to” er... oh, “what's the next thing I've got to do”, “what's...” er... “what's the...” “what should I...”, “where should I go out to?” .</p>

<b>Subtheme</b>	<b>Code</b>	<b>Participant name</b>	<b>Supporting quotes</b>
Inability to think ahead or initiate action	1.3	Tom	No... well, I was doing it every day, and then I stopped doing it, and I want to start doing it again.
		Tom	I think it's just... In the first place, I should like, er, what I want to do is make more of an attempt, at like writing things down.
<b>Master theme</b>	<b>Code</b>		<b>Definition of master theme</b>
Impaired movement and physical sensations	2.		The bodily experience of cognitive disability
		Harry	Can tell me a bit more about coordination being difficult, can you give me an example? I look. You are moving your right hand. And I try to concentrate. Your right hand is my right hand. It's classes, physics. It's a mirror, mirror image
		Jim	Er,... find it hard to... er... no, that's about it really, just [yeah, yeah]... Mainly... navigati- navigation really is a bit of a problem [OK...?]. I used to be a good navigator [yeah], but now I'm not [yeah], I'm really crap at navigating [hm]. I couldn't... If I was to take a walk through the local woods, probably forget about things, paths and [hm] trails and stuff, [hm] whereas in the past [hm] I could easily get my way through the woods easily [hm, hm].... I'm not that agile now.
		Gerald	Um, so you went, you had an experience just now of going blank [yeah, yeah]. Can you give me or describe another time when that happened, recently? Er. [PAUSE]. Well, about another time, um [PAUSE], yeah I suppose, well, I get dizzy as well you know. [Mm] Er that's not nice as well. [Mm] You feel you're going to collapse, [mm] really dizzy and that [mm] but I don't know whether to do with [PAUSE].
		Gerald	When I go blank I just don't feel right, you know, at all.
		Gerald	Yeah, it's not as much as it used to be [hm], I don't think as much as i used to. Instead i get like rare headaches [hm]... um... um, and [inaudible] and um.. yeah I get rare headaches and stuff. It's not as much as it used to be – thank God!

<b>Subtheme</b>	<b>Code</b>	<b>Participant name</b>	<b>Supporting quotes</b>
Impaired movement and physical sensations	2.	Jim	You said that when you lie for too long you get into a funny mode... Yeah. What do you mean by, by that? Your head starts to feel crunched up [hm], yeah... And... Sorry, <i>I'm going to ask again... Wh-What do you mean by "crunched up", or, wh-what's that like?</i> Kind of... feels like... er...[pause]... kind of... rough inside.
<b>Master theme</b>	<b>Code</b>		<b>Definition of master theme</b>
Explanations for the impairment and comparison to the past	3.		Participants' struggle to pinpoint their disability's origin, as well as their view of a benign past compared to the complexity of their disabled present.
<b>Subtheme</b>	<b>Code</b>	<b>Participant name</b>	<b>Supporting quotes</b>
The benign past	3.1	Gerald	Before that? Oh I just had perfect health, you know. I just had perfect health.
		Harry	Talking about school: It's only for elite, and I got in through a very hard exam, examination. And every year I had to do exams, it was very hard for me.
		David	Well, that's] when I was pretty normal [ok]. Yeah, so, um, yeah I was just happy-go-lucky, just thinking nothing: 'there's a bus or there's a nice car,' ticking over, thinking, thoughts and that, just casual really [yeah].
		David	Yeah, I think it was good, I was always, you know, at school, you know, I could concentrate on what I was doing and stuff like that: knew what I was doing and yeah, things were good, yeah.
		Don	What was different when I left school? I don't know. I used to want to own a home, didn't I? Got a job at 16.

Subtheme	Code	Participant name	Supporting quotes
The benign past	3.1	Will	At school, er [PAUSE] I loved school, school was [PAUSE] all through school, my mind was well, really well [yeah] [PAUSE] I was another one of the boys: I went to an all-boys' school, and I was another one of the boys, you know, I fitted in, everything [yeah, sure], fun.
		Tom	I was wondering: do you have any idea when the sort of forgetting things first started... or? [Sniffs] I can't remember. Yeah... it was, when I was little, right, I can remember some things, I can remember, like, er, er: I counted up how many things I could remember, then I couldn't even remember. [Laughs]
		Jim	<i>And you said ten years it wasn't a problem it's been more in the last...</i> No, nothing was a problem!
		Jonathan	And, and, so... to be clear: how had it been different before that? Because, before, I had no problems memorising: I could memorise <u>anything</u> before that.
Puzzlement and the difficult of explaining	3.2	David	Um, I've never really thought, thought about looking back on my thoughts.
		Gerald	Mm. And do you know what caused your memory to get worse? No, not really, no.
		Will	Um, yeah, yeah. Um [PAUSE] Um [PAUSE] trying to think when it started [hm]. It started happening in [PAUSE] they they, they, they <u>happen</u> , you know [hm]. I'm not sure, really.
		Don	What changed? Um, er, [PAUSE] What changed it? Yeah. I couldn't say. Something's changed it. Mm, mm. Sleep pattern or something.
		Tom	I don't know. I remember experiencing that experience, but I can't explain it any further than that.
		Tom	I can't. I can't discuss it though I can't really understand/think [yeah], no way of explaining it sort of thing [yeah]. [A door closes.]

Subtheme	Code	Participant name	Supporting quotes
Puzzlement and the difficulty of explaining	3.2	Jonathan	<i>How long would you say it's been like that?</i> Er... I think I first noticed, um [PAUSE] quite recently, really. Hm. What, how? No, in fact. Bit strange, it was. I was able – At university, I was able to memorise a lot of things [hm, hm], but um, er, when I finished university and was diagnosed with schizophr-, I'd already realised that I couldn't memorise.
		Jim	OK, yeah. [yeah] And again do you have any explanation for that? It didn't happen all of a sudden... Na: In fact, it <u>did</u> happen all of a sudden. I just woke up one day and found that I couldn't remember things that well [hm, hm]. Yeah. I can't even remember that either [hmmm]. But I know it happened all of a sudden [hm]. 'Cause one day I was all right, and the next day I wasn't [hm, hm]. Yeah.
Hospitalisation, medication and illness	3.3	Harry	I was in Riverside four years. And they let me out. [Yeah] They should have let me out much earlier. So it was when you were in... This, this, this is good what you do. [Ok] What you do is good. What they do is rubbish. They didn't do anything with me.
		Gerald	Why] it's getting worse and worse? [Mm] I don't know. I suppose, I suppose it's just, you know, part and parcel of me illness,
		Don	Didn't used to have the same trouble. Mm. Started having this, this trouble when I came to Foxtan House. Yeah.
		David	yeah, but, um, yeah, but as mental health you can be one day could be a good day and one day could be a bad day
		Will	<i>Okay, I'm going to ask you how do you explain that [yeah] or how do you understand that? (thinking too much)</i> Yeah i think it's something, it might be an anxiety I'm going through in my mind.

Subtheme	Code	Participant name	Supporting quotes
Hospitalisation, medication and illness	3.3	Will	So in terms of then... feeling distracted or your mind wandering [yeah]... how does, how does... does that relate at all when you feel doped up? Yeah, um... I think, in the morning, in the morning, I just feel doped up... but I don't think it's - i think it is all related in ways, but I don't know quite how to work out why or, i think it's just the condition I have or something.
		Will	And then I think the treatment started [mm-hm], and I think amongst the treatment, and the way these tablets deal with what's happening [hm, hm], and sometimes they're good, and sometimes there are side-effects. And I think that um, it's like, part of the side-effects, which, which is that um, I think it <u>could</u> be the side-effects [yeah], or it could be something to do with me [hm]. It's either something to do with me or something to do with the side-effects or the medication that I get this sort of, this sort of, this amnesia, or sort of tired when I wake up, or something [yeah]. It could be with the medication or it could be that I'm not taking the medication [hm] at the, at um, like, I take it in the night before I go to sleep [hm]. It could be that, could be that it's waiting to come on, the medication, [yes] and it could be a side effect I'm having too [yeah, yeah], or something like that.
		Tom	And, um, and what do you say – <i>I don't know, what would be the main differences between then and now?</i> Errr, er. I don't know - just older! [Laughs.]
		Jonathan	I feel it's a symptom, not a cause [hm], of my illness, it is. Memory loss is a symptom, not a- It's not a cause of my illness, it's a cause, and er- [someone coughs] [hm] [pause] I have to just sort of hobble on as best I can with what I've got.
		Jonathan	I mean, more people er, er, more, more people have got dementia and, er, memory loss [hm], er, and er symptoms like that, than ever before [yes]. There's a large proportion of society now, I think 1 in 7 [wow], has dementia [gosh!] with memory loss [gosh!]. I don't know what mine is, I'm not sure, but um, [coughs] mine comes from learning disabilities, mine does [oh, really?]. Yeah, mine comes from learning disabilities.
		Jonathan	<i>Yeah. I wondered, 'cause, I know you have some medical training</i> [yeah], whether you have any explanation or... Probably age. Er, getting old now, I'm losing my er [PAUSE]. Met- I find it difficult to remember things, and thinking-ability's probably gone <u>right</u> down the pan.
		Jonathan	It's all getting a bit difficult these days. I'm getting a bit old.

Subtheme	Code	Participant name	Supporting quotes
Hospitalisation, medication and illness	3.3	Jonathan	No.It's not the disease; it [PAUSE]. Memory loss is not the disease, it's the, it's the effect of the disease, the symptom of the disease
		Jim	And how was the... the higher-levels of thinking then? No, I had all my cognitive abilities back then, That was all OK? and I've lost a few since then [yeah, yeah], which really gets me. Yeah. What, What other ones, what other cognitive abilities, would you say? Er, just various levels, er. The ability to. Not cognitive abilities [mm-hm], I've lost a lot in hospital which I wouldn't have lost if I hadn't have been admitted to hospital [yeah, yeah]. Like the ability to er [PAUSE]. Actually, I've lost the higher thinking [uh-huh],
		Jim	Yeah, it wouldn't have happened if I hadn't have been in hospital, I would've have been a normal person [yeah] walking around. And er, these hospitals have taken it out of me.
		Jim	My life's all a-been, been all about hospital [hm] living out hospital, living [PAUSE] I've spent more time in hospitals than I have been living out [yeah]. And I've just completely and utterly lost the plot [hm, hm], and it's just. Sometimes I don't know why I'm in hospital and it's driven me absolutely round the bend [hm]. My brain is just all mash-up [yeah] through all the medications and everything, and it's just [hm, so being]. Not medications: medications have actually helped sometimes [hm, hm], but um, my head just feels mash-up.
		Jim	Yeah. I just want to divorce myself from psychiatric services now, I'm not [PAUSE] I've regained my er mentalhealth [hm] and I have to extract myself from the system because, the system just um, f-feeds on the weak and vulnerable people [hm] who can't think for themselves.

Subtheme	Code	Participant name	Supporting quotes
Negative attributions and behaviour	3.4	Gerald	Er. [PAUSE] You just find it really, really difficult, you know, to think when you're tired, you know.
		Harry	do you know why it became quite difficult? I didn't practice. <i>Didn't practice, kind of made [it I understand] it, practice, practice, practice.</i>
		Harry	Don't know. Maybe I was born like that.
		Don	Yeah. Yeah. Yeah. What what what changed? Um, er. [PAUSE] What changed it? Yeah. I couldn't say. Something's changed it. Mm, mm. Sleep pattern or something.
		Will	I think it <u>could</u> be the side-effects [yeah], or it could be something to do with me [hm]. It's either something to do with me or something to do with the side-effects or the medication that I get this sort of... this sort of, this amnesia
		Tom	I think it's just laziness, you know, laziness [long pause]. Yeah, sort of thing...
		Tom	I don't know... Sometimes I'm lazy and I feel sort of like, er, guilty of being lazy, sort of thing [hm, hm] or just sort of think "ohhh, what can I do?" [little laugh] or just can't be bothered with anything.

Master and super-ordinate theme	Code		Definition of master theme
Impact on identity and perceptions of others	4.		
Subtheme	Code	Participant name	Supporting quotes
Managing a change in identity	4.1		How participants managed their change in identity (as a result of their ‘cognitive disability’) using a variety of psychological and practical coping methods.
Disabled self: Loss and loathing	4.1.1	Harry	You’re good, you’re good and I’m lousy in memory.
		David	So I suppose it is classed as an illness, thinking too much [ok]. Yeah, thinking, oh I wish I could stop thinking sometimes. It gets annoying sometimes man, yeah, definitely.
		David	Trying hard to concentrate on, on, on every day, on reality going round instead of my thinking [yeah]. So I suppose I’ve got a disability there I suppose,
		Don	Are there – <i>are there things that you’re not able to do</i> because of the forgetting? Things that <i>you can’t</i> do because of forgetting? [Breathes] Er... Most things OK, walking and that, going in the car [mm] [indecipherable] don’t know what I could do...
		Will	Um... and, when your mind wanders or you get distracted, um, and how – how does that make you feel when that happens? Um... that makes me feel – sometimes it’s – um –... sometimes it scares me [hm], that I’m not going to fit in or something [hm].
		Will	...that’s how it feels with all this condition and this phobia [hm] and of losing the memory and stuff and. It feels like “am I losing my marbles here?”

Subtheme	Code	Participant name	Supporting quotes
Disabled self: Loss and loathing	4.1.1	Will	Well if you're losing your memory, sometimes... Then, can you imagine like having a diamond ring and then losing the diamond ring [hm], and that's how it feels sometimes [hm]. Like, "Oh my God I've lost something and I just paid twelve hundred pounds for this ring [yup] and like it's fallen off... and it feels awful, don't it [mm-mm-mm-mm], that um... that you've lost it, just misplaced it for example, like, just get out of the car on a journey to Littleton, and you've dropped the ring, and you've made your way back, and you're like, "Oh my gosh, I've just lost the ring!" [Hm!] And um...
		Tom	Er... it's er... naaaa it's just like... I suppose that, er – in itself, it's good but er [hm] ... I don't know. You can't go round doing that all the time! I suppose you could, couldn't you!
		Jonathan	My memory was so bad, I got a negative mark [hm] on the er on the finals examination [hm], simply because I couldn't remember. That was the <u>biggest</u> loss I'd had. Every year [hm]. That was the biggest loss I've ever had. Actually, I was sitting in my exam, finals exams in medicine, in the hall [hm], in the hall where they're all sitting in rows in, finals, I-I... memorise. I couldn't, my memory couldn't get me anything better than a negative mark [hm... and how?]. That really affected me badly [and how did...?]. That sort of bruised my er... dignity as well [hm, hm]
		Jonathan	I don't know what mine is, I'm not sure, but um, [coughs] mine comes from learning disabilities, mine does [oh, really?]. Yeah, mine comes from learning disabilities. Could you tell me a bit more...? Well, I first realised I had learning disabilities when I left university. I wasn't able to <u>learn</u> properly any more. I think you mentioned that last time... That's when I first realised. And I didn't realise they were called... They weren't really well established [hm]. When I left university, I realised straight away that I had learning disabilities, I did. I wasn't able to concentrate, I wasn't able to read and write like I used to [hm, hm]. And as I say, I just can't read and write properly [yeah]. It was all part of the start of learning, <u>adult</u> learning disabilities
		Jim	The same goes with thoughts: I've lost that power to think things through on a higher level [yeah, yeah], so I'm reduced to just grovelling around in the dirt, kind of thing.
		Jim	but when I reach the end of the road, I just think: "I can't be bothered to... go to London" or "I can't be bothered to do that" [hm], all this, [hm] and then I just go to the newsagents and buy my things [hm, hm] and come back [hm] But it's kind of... I feel almost disabled, really, to tell you the truth.

Subtheme	Code	Participant name	Supporting quotes
Disabled self: Loss and loathing	4.1.1	Jim	<i>Yeah... And what's that</i> like, that change, as a process? It's like, the higher level's gone, I can't... I'll... almost feel handicapped in a way, but it's [hm] like coming from a lower level.
		Jim	I feel like... an invalid because I can't think [yeah] on that level, and everything's slower.
		Jim	I've become more and more like... the people I hated. And I've become like them.
		Jim	They were like dumb idiots, and I became dumb idiot [hm, hm]. Yeah [hm, hm].
Hiding the impairment	4.1.2	Harry	No, nobody talked to me about memory.
		David	First time I've really gone in to it, forgetting things and stuff like that.
		Don	I wondered, um, errr, guess I wondered, um, how the staff here understand, understand it. Er. I haven't told them much. [hm] about...
		Don	And I wondered, would you ever talk to the staff about forgetting things? Um, I don't know. Would – yeah. Or – <i>you talked about feeling 'puzzled' sometimes...</i> [yeah, yeah] I wondered – would you ever talk to the staff about that, or? Not really, no
		Will	But in my own way. I'll deal with things in my own way when I'm on alone as well [yeah]. It's sort of, I tend to cope better [hm]. Like I'm alone and that there's... like... I tend to deal with it in my own way a bit more easier that i am alone sometimes.
		Tom	Yeah... And... when that happens, how does that make you feel, if, if your mind goes blank, or...? I get a bit scared sometimes [laughs]! Okay, sure. Can you explain that a bit more, can you...? I dunno... [laughs] I feel like I'm hiding. [Laughs again.]
		Jim	<i>And has anyone... does anyone else have any ideas about why that's happened to you?</i> No, I haven't told anyone: you're the first person I've told. Okay. Yeah. So, I kind of wondered if any of the staff here had any ideas about... it? Na, I kind of hide it. I kind of I pretend that I can [hm]. Higher level conversation.

Subtheme	Code	Participant name	Supporting quotes
Using humour	4.1.3	Gerald	Um, er, um [PAUSE] can't think [LAUGHING], yeah.
		Gerald	Er. [PAUSE] [LAUGHS] This is really testing my thoughts and that and that. [LAUGHS]
		Gerald	You said when someone told you, sometimes is it when someone tells you something that can be complicated? Yeah, but I can't remember what at the moment. [LAUGHS]
		David	But people sometimes suffer from that stuff. What is it? Alzheimer's. And they forget things and stuff like that. Yeah, one minute they're in the room the next minute they're, yeah, well, I hope I don't end up [LAUGHS] [sorry?]. I hope I don't end up like that [yeah] with Alzheimer's and forget, forget things easily. Yeah, some people put the cooker on and they forget about it [yeah] and can be quite, quite a dangerous illness. Yeah, definitely. Does that ever concern you? I have left the oven on before [LAUGHS]...
		Tom	Positive change [PAUSE] I don't know. [LAUGHS] [LAUGHS] I honestly don't know.
		Tom	Yeah. And when that happens, how does that make you feel, if, if your mind goes blank, or...? I get a bit scared sometimes [laughs]! Okay, sure. Can you explain that a bit more, can you...? I dunno [LAUGHS] I feel like I'm hiding. [LAUGHS]
		Jim	Errr... Recently I've just noticed that I can't think at all. [LAUGHS]
New dependency on others	4.1.4	Gerald	Um, like, er, we go shopping because I like just to, she gives me a day and I'm like, 'ok' and we go then or whatever.
		Harry	I try to ask somebody what did we eat? It happened to me in Foxton House. [Ok] I ask the inmates what did we eat?
		Harry	I wouldn't be frustrated. I read the instruction manual of the radio, read instruction manual of the TV. I always need help, I am not self-sufficient.
		Harry	I could do the thermostat in the living room, turn the, the heating on and off, the, the satellite, put the, the, the wash in the satellite, re- re-set it, that would do me a lot of good because until now I depend on Emily and depend on others.

Subtheme	Code	Participant name	Supporting quotes
New dependency on others	4.1.4	Harry	I've been remembering better this month once or twice. Oh really... With talk to God.
		David	you know, um, if you jogged my memory I probably could remember what I thought [yeah] if I could.
		David	I said, if someone, yeah, er, I don't know, if someone tests you on it, you can, you can, and they can give you a bit, bit of a um, how can I put it? If they tell you a bit about the story you can go, 'oh yeah, I remember that now.' You go, yeah, you can tell them about your story and stuff like that. It's like jogging your memory, kind of thing [yeah, yeah]. If they tell you about the story and you then can go, 'oh yeah, yeah, I read that book.' And they tell you another thing and you go, 'yeah, I remember all that' and you can talk about it and stuff like that, yeah, yeah, yeah.
		David	They'd say, 'oh have you forgotten it have you? Well, we've got it written down for you anyway' or something like that. Sometimes, like a week before or something.
		David	Yeah], it doesn't register, so you have to ask them again and then they just disappear.
		Don	Yeah, I can if I wanted to, yeah [PAUSE]. If I found it difficult [hm] once, If I'm OK [mm-hm], If I'm trouble, I'll talk to staff, and then most of the time I'll be OK.
		Don	Asking the staff questions about explaining it [OK, sure] and how the thoughts [Yeah, yeah, yeah.]... talk to the staff about it, explain the illness or something.
		Tom	Er. I don't know. Now when my mind goes blank, it's a bit whasisname, er, you know, that's a bit scary, but then I just sort of go, errrr, I dunno, see someone I know and say hello and then I'm all right.
		Tom	I see someone I know and then I say hello and that and then I'm all right.
		Jonathan	large planning, large things like planning a move of a house are done by other people, they are [hm]. I'm just, I'm just the pawn that moves from one place to another [hm], and then does as he's told..
		Jonathan	No, it's er... I can't make real proper plans, I can't: they have to be done for me, they do.

Subtheme	Code	Participant name	Supporting quotes
New dependency on others	4.1.4	Jim	Just means um that I can't think about things, like um... Have to wait for kind of... environmental signals [hm] to prompt me to think [hm], "oh yeah I've got to do that, and this", yeah. So wh-wh-what would be an example of... Can you tell me an example of an environmental signal...? Um [PAUSE]. Someone might [PAUSE]/ A staff member might shout loudly, and I might think, and they, they've kind of shouted on a level which is high [uh-huh]. And I don't have that high [hm], and it's kind of... er... almost like, nud- they've nudged me into thinking [uh-huh], and I think "oh yeah, I've got to do this" and "I've got to do that", and then I go and do it...
		Jim	Like, so if I've lost my memory [yeah], people would try to jog my memory, naturally, everyone would try to jog my memory [hm], through... talking to me, and through... body language, and through... erm... birds whistling to me [uh-huh], and people shouting loudly, and... [hm], and I'd think, or what's going on, "oh I've lost my memory", "who am I?" and all this.
		Jim	Yeah... I just want to divorce myself... from... psychiatric services now, I'm not... I've regained my er... mental... health [hm] and I have to extract myself from the system because, the system just um... f-feeds on... the weak and vulnerable people [hm] who can't think for themselves Hm, hm, hm. Jim,... I want to be self-sufficient and... live my own life [yeah] er... look after myself and [hm] not have to worry about people looking after me...
Using substances	4.1.5	Harry	I, I wondered if I have to take ginkgo biloba. What, how can you tell me more about ginkgo biloba? I heard about it, it's good for the memory.
		Jim	Yeah. What do you find helpful? Er... caffeine explosion. Okay...? That gets my brain thinking. Okay. Can you tell me... Coffee. Okay. That gets my brain whizzing, thinking... well, not <u>thinking</u> , but... just gets my brain whizzing and then I might [hm] start thinking later on... and then I might think [hm], 'cause if there's... you're thinking fast, you have to kind of keep up with yourself [yeah]... you try to... you know, catch your thoughts, hold on to them [hm]... think about what's next...

Subtheme	Code	Participant name	Supporting quotes
Using substances	4.1.5	Jim	<p>Actually, what helps is a can of beer or something [OK], 'cause then I get thi-thinking about various... crappy things in life [hm], and I can just kind of mull over them [hm, hm]. I can't really sort them out, 'cause I... Drink just gets used so far but then it just... goes back like a whizzbang [right]. Er, but um... I suppose what would really get me thinking is a... joint or something, but I don't smoke joints anymore.</p> <p>Yeah,[yeah] yeah... yeah. And you – um... so caffeine.</p> <p>No, a joint of cannabis.</p> <p>Sure [yeah], sure.</p> <p>Er, when I smoke a joint of cannabis, then I'd really get thinking [hm]. That was back in my university days, but I wouldn't – I haven't done it for years now,</p>
Coping tactics	4.1.6	Harry	<p>So what helps you concentrate?</p> <p>What helps? Not many tasks [ok], very little tasks.</p>
		Harry	No. I try to put it away from my thoughts. It comes into my thoughts, currencies, and I don't understand them, why I have to practise, understand the nitty gritty the basics.
		David	Um,] um, sometimes the voices can jog your memory. Yeah I suppose, yeah, yeah, um...
		David	in order to jog my memory you just have to think back and think, 'now what was I thinking there?'
		David	I think, 'oh hang on, I must have written it down in something.' You try to find out where you've written it all. 'Where did that letter go?' Rummaging around in the room looking for the, the letter or something, or, yeah, so
		David	Like I was reading the bible, I read it a few times and, and gradually you, you get to remember stuff you know...
		David	Er, yeah, when I, when I, when I read my bible um it's, it's, it's about that teaching, about knowledge and wisdom and stuff like that, and in my life I try and... use that knowledge and wisdom I suppose, so I do remember what I've read and I put it into practise [mm, ok].
		Don	<p>In context of thoughts and concentration:</p> <p>And w-w-w-what happens then?</p> <p>Er, I don't know, I try to rest...</p>

Subtheme	Code	Participant name	Supporting quotes
Coping tactics	4.1.6	Don	When finding it hard to concentrate because of thoughts: Settle, then I'm OK. <i>Yeah, so you settle, and then you're OK. How, how do you settle? What happens when you settle?</i> Er, I don't know, I fall asleep, yeah.
		Will	Or I'll read books, and um... But I can't get into a big, thick book [yeah] Um... I'll be – sometimes... in the past I found it that I'll think about other things, and I'll be reading a big book [yeah] and then it's not as easy or as interesting as when I read... chapters: I find it easier to go through chapters. If I am going to read a big book I'm going to go through chapters [yeah] and it'll have to have to keep me interested [yeah], um. Yeah.
		Will	And – short stories. I know it sounds stupid but it just seems easier for my mind to take, like [hm], short stories and with pictures and short stories – not like, child's books [no, no, sure], but like books like, um... books with chapters and sh-short stories, where there's a story about this in this chapter [yeah], and there's a story about something else [yeah] in the next chapter, where i can keep occupied and not stress myself out.
		Will	Yeah, um. Well, I'd have to be prepared to read a big book [hm], I'd have to be more prepared and um, and... [coughs] sorry, and read chapters in the book [yeah]. I'd have to be more prepared, to sit down and think, like, "I'm going to read <u>this</u> book, so, um, I'm going to have to be more prepared to read it". Right. I might even have to take notes... Yeah, I was going to say... ...to remember what's happening.
		Will	Yeah, sometimes I'll just go on the CD walkman, or I'll put the music on, or just lie under the covers and just listen to music [yeah, yeah]. So it's just a bit more easier to, to cope with [yeah] – um, because the music's distracting enough [yep], like, they're going to have something going on listening to the music [yeah, sure], rather than sitting there thinking.
		Tom	What's good though is write down in me diary all the things that bought during the day and the things that I done... Try and do that...
		Tom	Oh, all I do is just write down little, er, you know, whether I bought my tobacco that day [yeah], so I can work out who, sort of like you know, remember what I've bought, things like that.

Subtheme	Code	Participant name	Supporting quotes
Coping tactics	4.1.6	Jonathan	As I say, loads and loads of diaries I do [walks over] loads and loads of diaries which I've kept over the years, and then I keep a scrapbook as well...
		Jonathan	<p>And you, you were talking about your diaries, <i>which you've brought, or have brought some examples</i> [yeah], your scrapbooks and diaries. And, when did you start using...?</p> <p>Oh, ah, in my late 30s, making diaries. I didn't do the scrapbooks i-i-in those, those days [hm], I had no problem with that...</p> <p><i>Can you tell me the difference between a "diary" and a "scrapbook", for you?</i></p> <p>The diary is just what I've, a list of what I had to do every day [hm] and what I <u>have done</u>, then, every day, and make appointments to do something [yes, yup]. The scrapbooks are thoughts which I've had which I don't want to lose, and might be unable to remember myself... [hm] so I put them in the scrapbook...</p> <p>And what difference does that then make?</p> <p>Just gives me a feeling of erm... being able to cope [hm, hm, hm]. It-It's a way of coping with memory loss.</p>
		Jonathan	I-I've also kept correspondence, which is better than what I've got written in here. You don't <u>really</u> need to, er, see those. I'll go and get some more of my scrapbooks, 'cause there's details of what my life was like for a few years... I'll go and get it, back in a minute.
		Jonathan	I've got very good erm... pic-photo albums as well [ah! And can you tell me...]. I use photos as well. To remember everything that's happened, in photographs, I do, as well.
		Jonathan	Just er the picture sets you into motion a train of thought [yeah]. I remember, "I was in that party", or "we were doing that at that time" [hm, hm, hm], or, er.
		Jonathan	<p>And without that picture, what would it be like, do you think?</p> <p>[Pause.] It would be lost into um... into a nothing, 'cause I haven't got the picture [hm]. It would be lost. The occasion would be lost [hm]. But with the pictures and the camera, it's er saved... for posterity, and er... for memory's sake [yes], you know, I use pictures.</p>
		Jonathan	Well, you see, I do do crosswords with my Mum every Sunday afternoon, the <u>Times</u> crossword [hm], and it keeps us both mentally agile, it does. [Yeah.] My Mum has also got memory loss

<b>Subtheme</b>	<b>Code</b>	<b>Participant name</b>	<b>Supporting quotes</b>
Coping tactics	4.1.6	Jim	And lying on your bed is not bad, as long as it's constructive, you know. [Yeah] If you do it a bit <u>too</u> long [uh-huh], then you start to feel the effects of, erm, slug-sluggishness [yeah] and all that [yeah].[PAUSE] So I do it maybe 15, 20 minutes at a time [OK, OK], maybe for a couple of times a day [yeah, yeah]. I used to [PAUSE] When I was on Blackbird ward, I used to um... lie on my bed all day long [hm], just thinking about things [hm], and, er, I don't like to do that now.
<b>Super-ordinate theme</b>	<b>Code</b>		
Perceptions of others	4.2		How participants perceived others' views of their 'cognitive disability.'
<b>Subtheme</b>	<b>Code</b>	<b>Participant name</b>	<b>Supporting quotes</b>
Lack of understanding and expertise	4.2.1	Harry	No, nobody talked to me about memory. You're good, you're good and I'm lousy in memory.
		Harry	No he just did the tests and went, because he was afraid of the extraterrestrials because the baddies, extraterrestrials, that they would harm him and that's what I feel with you also: that somebody can harm you because you're helping me. Nobody help me because the extraterrestrials wouldn't want.
		David	Um, they'd probably well, it's like if I have an appointment or something, like a job interview and I was there late they'd probably go, 'well, that's no good mate', you know, 'you said you'd be here on this time and you're supposed to do this job' and say, say, 'you're not very reliable.' They'd probably, probably, er, go for another person I suppose, I think at a job interview
		David	Um, well, with people with Alzheimer's, there is help for them, yeah, I've read it, um, doctors, there was help for people like that. But for mental health, I've never really heard of people, not really, [no.
		Don	Mm, mm. So I guess I, I wondered – well: what <u>sort</u> of help is there for this type of difficulty? I don't know, you see. I'm not sure. [Mm, mm.] That's why we're talking about it, I don't know.

Subtheme	Code	Participant name	Supporting quotes
Lack of understanding and expertise	4.2.1	Tom	<p>when your mind might go a bit blank [yeah], or, have one of those moments... um, what do you think other people make of that?</p> <p>What's that, what's that?</p> <p><i>Like the staff or people around, you know... other residents here, if your mind's gone a bit blank for a moment.</i></p> <p>Er, I don't know. I don't think they're... I don't know.</p>
		Jonathan	<p>I, I wondered if you had any sense of how the staff understood the memory loss...</p> <p>Um... I don't know. I don't know how they do, no... [yawns] pardon me. I don't know, to tell you the truth</p>
		Jonathan	<p><i>I was just curious whether anyone's mentioned any type of support...</i></p> <p>There may be one day, pills, that get the memory back, but at the moment there aren't them [hm, hm]</p> <p>We have to get more advanced, before we get memory pills.</p>
		Jim	<p>There's no... no good counselling or um [hm]... [pause] But I just need... there's no drugs are going to help me to think [yeah, yeah], so... I have to kind of do it all myself!</p>
		Jim	<p>About what staff make of difficulties:</p> <p>They'd probably wouldn't understand them at all, they'd probably, er... try to get me... They'd have to prompt me to do things, and I don't want to be that kind of person. [yeah]. So I mean I'll do everything myself anyway [yeah]. But they still have to come and get me when it's dinner-time [right] 'cause I forget when it's dinner-time sometimes, yeah.</p>

Subtheme	Code	Participant name	Supporting quotes
Acceptance and understanding	4.2.2	Gerald	They] must think just how terrible it is for me [mm] to have this, you know, this thing in your head and that you know.
		Gerald	Er yeah, they just say think it's my illness as well [mm] yeah, yeah, they would, yeah.
		Harry	<i>But talking about, um memory, if you're finding it hard to remember something, how do other people react?</i> [Silence] How do? I was thinking of very best friends, my best friends, one of my best friends, name, and he's married to psychologist, name, write it down [gives address] she knows about you. She's 63 she's been forty years in there or 35 years. She's good. Say to her, if you would, you've, you've got that address and I don't know their fax.
		Harry	The first person that did that had [helped me] was Ben[psychologist]. And how did he help? He gave me a good test. I don't know how it came out. And how did the test help? It helped to recognise my difficulties.
		David	Do they understand it? Yeah they would because they've probably experienced it themselves [yeah]. Yeah they would yeah [yeah].
		David	Um, er], well, the staff would because I've always been pretty bad at appointments so the staff would understand, whereas friends would probably go, go, 'have you forgotten that?' and I'd say, 'yeah', and they'd probably go, 'typical.' Staff would say, 'very typical really' and my friends would say, 'don't worry about it' [LAUGHS].
		Don	Or, um, wondered how... your friends... how do your friends respond? Um.... [pause] er... Everyone's OK, yeah. Mm. They coped with it. yeah.

Subtheme	Code	Participant name	Supporting quotes
Acceptance and understanding	4.2.2	Jonathan	Um..., I suppose they think it's all part and parcel of life these days [hm]. I mean, more people er... er, more... more people have got dementia and, er, memory loss [hm], er, and er symptoms like that, than ever before [yes]. There's a large proportion of society now, I think 1 in 7 [wow], has dementia [gosh!]... with memory loss
		Jonathan	Wh-wh-when you ask me now, what do people think of my learning disabilities [yes], and my, er, memory loss, I think they, they think it's all part and parcel of being Jonny [OK], do you know what I mean, of being Jonny, called Jonny I am... just part – all part and parcel of being Jonny, and what that means these days.
		Jim	And how do you think they understand that? ...Um, well, they... My uncle's got his own life but he takes interest in my life [hm], when he can [hm].
Master theme	Code		Definition
Anticipating the future: Fear and hope	5.		Encompasses the confusion and tension present in participants' understanding of what their future holds.
Sub-theme	Code	Participant	Quote
Fear, the unknown and worsening	5.1	Harry	I don't understand everything. I always struggle the manual, the instructions of the things. When I'm reading a manual. My brain. I get afraid.
		David	But people sometimes suffer from that stuff. What is it? Alzheimer's. And they forget things and stuff like that. Yeah, one minute they're in the room the next minute they're, yeah, well, I hope I don't end up [LAUGHS] [sorry?]. I hope I don't end up like that [yeah]
		Gerald	Think um recently my thinking's got pretty worse
		Gerald	I've still got it [difficulty with thinking ahead] now it's getting worse, I think, yeah.
		Gerald	Er [PAUSE], yeah, I suppose just where you're going to end up really, you know. In case it gets worse and worse and worse. I wonder, you know, how, what's going to be like, you know, how bad is it going to be [mm], you know [mm], something like that, you know.

Subtheme	Code	Participant name	Supporting quotes
Fear, the unknown and worsening	5.1	Gerald	Well, yeah, anytime, you know, if I'm trying to work things out and, you know, [mm] just getting worse and worse and worse, just say to myself, you know, what's it like going to be in the future [mm], you know . It is a worry.
		Gerald	I just] couldn't remember what people said [mm] and that's when it got worse and worse and worse.
		Gerald	When they come first they were better then than they are now [mm, mm] . Gradually things got worse you know, [mm] you know, to be honest.
		Gerald	So yeah things just get, things just get worse and worse and worse over the years, you know.
		Don	<i>Um... And... could you tell me anything about how it's got worse, or what's got worse?</i> Er... [pause] er... Er... it's just got worse, [inaudible]
		Will	Um, and sometimes I'll forget, my Mum will say, "Don't you remember when we was going over to um, to um Aunt Jill's this afternoon?", and I'll be like "...are we???", I'll be like, She'll be like, "yeah, I told you yesterday", I'll be like "Oh, I completely forgot!" [hm] And it will be like... And then... And then that phobia, that phobia will come, like, like um... "Oh my God forget everything..." [hm] . And it's like losing something it's a horrible feeling [hm], it's a horrible feeling...
		Will	...that's how it feels with all this condition and this phobia [hm] and of losing the memory and stuff and. It feels like "am I losing my marbles here?" [yeah, yeah] It's like "O MY GOD", like, [hm] I just, I don't want to lose everything [mm-hm?], and it just frightens me and panics me [hm] . This phobia, sort of thing, about it.
		Tom	Er... I don't know. It's not a sort of... er... [Pause.] I dunno... [Pause.] No... it's the sort of thing like, you know, like, er "oh, is it going to get worse?" and sort of things like that, "is it ever going to be a state where it's like really bad or something?", you know?...
		Jonathan	It just means I stay in homes for for learning disabilities [hm], it does. I – I – I can't see anything outside that, I can't [yeah, yup] . I can't see anything outside [yeah] . [Pause.] Can we leave it at that, then?
Jonathan	well, my Mother and I- we're sort of <u>pre-empting</u> the time when we're going to be sort of diagnosed with a memory loss		

Subtheme	Code	Participant name	Supporting quotes
Fear, the unknown and worsening	5.1	Jonathan	Got worse again, yes, it's not just – in those days it was just study, the memory loss was just where study was concerned [yeah], couldn't read or write for study purposes [hm]. It's not until much later on that the memory loss became, um, everyday, became not- the norm rather than the exception [hm]. Everyday there was memory-loss involved [hm], but there wasn't that at the beginning, but it was the beginning of adult learning disabilities. But er, m-mental, er [PAUSE] errrrrrrrrr memory loss [PAUSE] err [PAUSE] errrrr where errrrr [PAUSE] where it affects [PAUSE] your immediate – short-term memory, short-term memory, didn't happen to a while afterwards
		Jonathan	I think - I think it could worse, I do [hm, hm]. I think it's going to get worse [hm]. I'm being absolutely practical, I'm being realistic [hm]. As I get older: I'm now in my 50's [hm], which is still very young [yeah, it is], it is, it's still very young. And to have the diseases that I have – it's only sensible and it's only realistic, to think "it'll get worse, it will".
		Jim	I've lost my ability to perceive the future [right], a hundred per cent, because this higher-level... um, handicapped feeling [yeah] I get [yeah], in my head. I used to think ahead and into the future, but now I can't do it [yeah] at all.
Sub-theme	Code	Participant	Quote
Hope and restoration	5.2	Harry	I've been remembering better this month once or twice.
		David	When I first started hearing voices it was, it was, 'wow', you know, where's all that coming from [yeah, yeah]? So, like I've been, been in the dark, and now I've been shown the light I [suppose.
		Will	Yeah [coughs] well um – excuse me – It's like I can distinguish reality [hm] at the moment, I've been quite well for a long well [yeah], and I can distinguish real-life happenings compared to these sort of mishaps and stuff [yeah], and that's half the battle won, really [yes!], like um I can distinguish reality than when I've been ill [mm-hm] and um... I thought that um... and I was, I couldn't distinguish quite correctly what wasn't, what wasn't real [sure] compared to what was real [sure]. So it would be sort of imitation of things that would be happening to me [hm]. Like I'd be thinking I had pretend friends [hm] and sitting there try and talk to people [hm], like, <u>mad</u> [mm-hm?]. And then I can distinguish now, but, in reality [yep], like, um... real life [yeah], I can distinguish what really happened compared to [yeah] like being ill when I couldn't really distinguish quite what's what.

Subtheme	Code	Participant name	Supporting quotes
Hope and restoration	5.2	Will	Talking about thinking too much: So has that changed now, is that different, now? Yeah, it's not as much as it used to be [hm], I don't think as much as i used to. Instead i get like rare headaches [hm]... um... um, and [inaudible] and um.. yeah I get rare headaches and stuff. It's not as much as it used to be – thank God!
		Tom	I think it's just... In the first place, I should like, er, what I want to do is make more of an attempt, at like writing things down.
		Jonathan	Um... and – <i>in terms of other people's understanding of the planning... difficulties...</i> Er... it was very long ago, and little was understood about it, it was [hm]. It was a very taboo subject, totally, it was [hm, hm, hm] [And now...?] Understanding the pathology of the brain. Yeah, and now... has that changed at all...? Much better understood, it is, and er- Madness has been <u>explained</u> , it has! I don't know if you've read the book, I think you've read the book <u>Madness Explained</u> , ...by Richard Benton... Yeah, have you read it? Yes, I have... Brilliant, isn't it! It's <u>Madness Explained</u> ! My Mother's reading it at the moment.
		Jim	Er... But it's getting better now! My brain is kind of recuperating [yeah, yeah]. Yeah, and I'm beginning to kind of get inklings of...er, things that I can do to... kind of overcome it...

Subtheme	Code	Participant name	Supporting quotes
Hope and restoration	5.2	Jim	<p>Like, little thoughts break out of nowh- out of the back of my mind [hm], it's like a ray of light [hmmmmm]...</p> <p>It's only in the last couple of days [wow!], not in the last month or so...</p> <p>Very recently... [recently]... yeah...</p> <p>It's kind of, filtering through now.</p> <p>Gosh! [Yeah] <i>So, what's filtering through?</i></p> <p>The-The ray of thought, er... the thoughts that feel like rays of light in my head [hm, hm]. And, er, like, tomorrow I'm going to go to the shopping centre [yeah], and erm... [hm] and er... tomorrow I might... yesterday... I would have... I phoned my sister up on my own initiative [wow], I didn't need any kind of external environmental influence to do it [yeah, yeah]... and er... It's kind of all beginning to... reor-, my brain's restructuring itself...</p>
		Jim	<p>my mind started reawakening itself [hm] through.. through kind of err... you know like in this film "Terminator" [mm-hm?], he gets stabbed in the heart by a spear [hm], and his power goes off 'cause he's a robot [hm], and then he, er, finds another power-source from somewhere else in his body, and it rew-, and it reconnects [hm] to his main power-source [hm]. That's like my brain: it's, like, the higher thinking's gone[hm-hm], but it's trying to make up for it another area of my brain [mm-hm], which is kind of, um, um... now, recently, last couple of days, it's throwing thoughts at me [mm-hm], what I can do [mmm] and how to... kind of er bombard myself with thoughts [mm] in my head [mm], which I haven't been having of late [mm] because I've been... engrossed in my own, er... world [mm], as it were, just thinking about how to... er... get out of Robin House [hmmm] and live in Littletown [hm], but now... I've been thinking about that a lot, but only on... through actions [hm], but not thoughts[hm], I've been doing things like talking to the people, nurses and that, telling them I want to move, and... all that, and now it's um... Now I can relax a bit [hm], I find I can relax a bit more [hm]. I'm having good sleeps, sleeping patterns recently [hm]. And I wake up feeling a bit brighter and alert [hm, hm], and er... and I relax a bit more during the day, and my thoughts are all, sort of, coming back from the back of my head [hm] and coming to the forefront[hm] of what I can do, in order to... live a good life [yeah], as it were [yeah, yeah], you know?, kind of experience life a bit more, like how I was [yes].</p>

## **Appendix K**

### **Reflexive research diary**

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