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Who am I? The relationship between the self and memory in psychosis

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Volume I

SYSTEMATIC LITERATURE REVIEW

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EMPIRICAL RESEARCH PROJECT

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Thesis submitted in partial fulfilment of the degree of

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I'd like to thank Clem, I owe you so many thanks for your endless encouragement and support; your friendship is one of the things I'll treasure most from training. Thanks to Helen for allowing me to believe that finishing this was possible, even during the most difficult times; my mum for her constant love and support and my grandad for dedicating his time to reading my last thesis, I hope you enjoy this one, grandad! Finally, I'd like to thank Joe for moving to London and sharing this adventure with me, I can't wait for us to share so many more.

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SYSTEMATIC LITERATURE REVIEW

A SYSTEMATIC REVIEW OF STUDIES EXAMINING AUTOBIOGRAPHICAL MEMORY IN PEOPLE WITH BIPOLAR DISORDER

Supervised by Dr. Vaughan Bell and Dr. Rebecca Kelly

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ABSTRACT

Autobiographical memory (AM) is the aspect of memory concerned with the recollection of personally experienced past events. Recent years have seen an increase in research demonstrating that disruptions to normal autobiographical processes play an important role in the onset and maintenance of emotional disorders. The aim of this review was to systematically identify studies that describe the features of AM in people with bipolar disorder. To the best of our knowledge, this is the first review of its type. A systematic search yielded seventeen studies that met inclusion criteria. Findings suggest that there is a deficit in the specificity of episodic autobiographical memory alongside relative preservation of other AM features, such as, autobiographical knowledge. Findings point towards the potential utility of cognitive remediation interventions to improve AM in people with bipolar disorder, yet additional research is necessary to clarify the mechanisms upon which such interventions would operate.

INTRODUCTION

OVERVIEW

Bipolar disorder (BD) is a chronic, disabling illness associated with disturbances in positive and negative emotion. With regards to negative emotion, BD involves periods of major depression, in which a person experiences depressed mood and loss of interest or pleasure for a period of at least two weeks. Elevated mood is described as mania, or hypomania, depending on its severity and involves "a distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy" (American Psychiatric Association, 2013, p. 787). Common behaviours that present during periods of mania/hypomania include inflated self-esteem or grandiosity, decreased need for sleep and flight of ideas. Psychotic features, such as hallucinations and/or delusions are also common during periods of mania. At least one episode of mania is required for the diagnosis of Bipolar I Disorder, whereas a person will receive a diagnosis of Bipolar II Disorder if they experience depressive and hypomanic episodes in the absence of a manic episode. Disability rates associated with BD are high relative to other mood and anxiety disorders (Pini, de Queiroz, Pagnin, Pezawas, Angst, Cassano et al., 2005); for instance, it has been estimated that 30-50% of people who experience BD fail to achieve premorbid levels of psychosocial functioning (Quinlivan, Dallacker, Renneberg, Strasser, Fiebig & Stamm, 2017). In response, it is crucial for research to uncover mechanisms that underlie poor functioning in BD in order to inform subsequent interventions and improve prognosis.

In recent years, there has been an increase in research investigating neurocognitive dysfunctions in BD, as it has been proposed that they play an important role in maintaining psychosocial dysfunction (Shimizu, Kubota, Mason, Baba, Calabrese and Toichi, 2009). Of all neurocognitive functions, evidence shows that episodic memory is

most severely impaired (e.g. Clark, Iversen & Goodwin, 2001; van Gorp, Altshuler, Theberge, Wilkins & Dixon, 1998; Zubieta, Huguelet, O'Neil & Giordani, 2001). Episodic memory refers to a person's memory of past events (Tulving, 2002) and is closely associated with autobiographical memory (AM). Thus, it can be assumed that people with BD might experience an impairment in AM functioning; indeed, this review provides an opportunity to explore AM disturbance in a unique context, as people with BD experience a spectrum of severe and distinct emotional impairments.

AM AND EMOTIONAL DISORDERS

The term autobiographical memory describes knowledge of personal facts and memories of events from one's own life (Conway, Rubin, Spinnler & Wagenaar, 2013). Generally speaking, AM can be separated into episodic and semantic components (e.g. Baddeley, 1992; Brewer, 1996; Conway, 1996; Conway & Bekerian, 1987; Larsen, 1992; Robinson & Swanson, 1990; Schacter, 1996). Episodic AM describes memory for personal past events that are specific in time and place, whereas semantic AM describes memory for personal facts (e.g. I was born in Yorkshire, my first car was a Toyota). AM functioning is considered to be closely related to several important social and psychological functions. For instance, AM has a directive function, by enabling us to use past experiences to guide present and future behavior (Bluck, Alea, Habermas & Rubin, 2005). AM is also proposed to play an important social role, as reminiscing on shared experiences can promote social bonds (Fivush, Haden, & Reese, 1996), enhance intimacy (e.g. Alea & Bluck, 2007), facilitate social interactions (Cohen, 1998), increase our capacity for empathy (e.g. Bluck, Baron, Ainsworth, Gesselman & Gold, 2013; Pohl, Bender & Lachmann, 2005) and help us to solve social problems. AM also tethers one's self in reality thus playing a fundamental role in maintaining a coherent and consistent sense of self over time (Conway & Pleydell-Pearce, 2000). In general, AM is said to be crucial in maintaining psychological well-being (Conway, 2005).

The past two decades have seen an expansion in our knowledge of how autobiographical memory impairment might play a role in psychological illnesses. In particular, research has shown that breakdowns in AM may contribute towards a diminished sense of identity (Bennouna-Greene, Berna, Conway, Rathbone, Vidailhet & Danion, 2012), disturbances of time perception (Bonnot, de Montalembert, Kermarrec, Botbol, Walter & Coulon, 2011), thought insertion (Klein, German, Cosmides & Gabriel, 2004), poor social functioning (Quinlivan et al., 2017) and difficulties in imagining the future (Williams, Ellis, Tyers, Healy, Rose & McLeod, 1996). Of relevance to bipolar disorder, autobiographical memory disturbance is also found to be closely associated with depression (see Williams, Barnhofer, Crane, Herman, Raes, Watkins et al., 2007, for a review) and the experience of psychosis (Docherty et al., 2008). Importantly, research also suggests that deficits in AM might play a role in the maintenance of emotional disorders. For instance, Serrano, Latorre, Gatz and Rodriguez (2004) found that treatment to increase the specificity of positive autobiographical memories in older adults resulted in decreased feelings of hopelessness and depression.

From a research perspective, there are many features of AM that can be operationalised and measured in clinical samples, such as, specificity, vividness, emotional valence, latency of recall, frequency of recall, importance and age at encoding. One feature of AM that is closely linked with psychopathology is over-generality, that is, difficulty generating AMs that are specific in time and place, alongside a propensity for generating AMs that are categorical (e.g. I used to walk in Victoria Park on Sundays). In the first instance, over-general AM was identified in people who had attempted suicide (Williams & Broadbent, 1986). Next, major depressive disorder (MDD) was studied and a comprehensive review by Williams and colleagues (Williams et al., 2007) concluded that over-general AM is a consistent characteristic of depression. Over-general memory has also been found to be associated with the development of posttraumatic stress disorder following trauma (e.g. Kleim & Ehlers, 2008), and people with postnatal

depression (Croll & Bryant, 2000) and schizophrenia spectrum disorder (e.g. Berna, Potheegadoo, Aouadi, Ricarte, Allé, Coutelle et al., 2015; Ricarte, Ross, Latorre & Watkins, 2017) are more likely to generate categorical than specific AMs. Recently, Berna et al. (2015) published a meta-analysis on AM deficits in schizophrenia spectrum disorder; they found convincing evidence for impairments in specificity, as well as in richness of detail and conscious recollection. Overall, the authors conclude that AM impairment should be regarded as a major cognitive deficit in schizophrenia. Although much is known about AM functioning in several emotional disorders, less attention has been paid to BD and there is not yet a comprehensive review of findings in this area. With regards to studies conducted on AM in BD, AM functioning in patients is most often compared to that of controls with no history of current or past mental illness i.e. "healthy controls". Less often, comparisons have been made with people with a primary diagnosis of depression, which is of interest in the context of contention surrounding whether or not unipolar depression and bipolar depression are distinct illnesses. As is found in the wider clinical literature, most studies exploring AM in BD use a version of the Autobiographical Memory Test (AMT; Williams & Broadbent, 1986) in which emotional cue words are used to assess AM specificity. A couple of studies that have employed the Autobiographical Memory Interview (AMI; Kopelman, Wilson & Baddeley, 1989) have also shed light on potential semantic and episodic AM distinctions in this population. One particular contribution that AM research in BD can offer is to study the phenomenon of mood dependent AM (i.e. the facilitation of memory when mood at retrieval is matched to mood at encoding) using a within-subjects design in a population who experience considerable, and sometimes rapid, fluctuations in mood. Consistent with the literature described above, most studies explore the phenomenon of over-general AM, but have attempted to extend current understandings of AM in BD by considering underlying neurological mechanisms and associations with other neurocognitive functions.

AIMS

In sum, the aims of this review were to systematically identify studies that describe the features of autobiographical memory in people with bipolar disorder, to describe the key features of these studies, and to explore the nature of the differences in autobiographical memory that present in this clinical group vs. controls. It is proposed that this review might have important clinical implications, as AM impairments are considered to play a role in onset, maintenance and recovery from of emotional disorders (e.g. Dalgleish, Spinks, Yiend & Kuyken, 2001; Hermans, de Decker, De Peuter, Raes, Eelen & Williams, 2008; Mackinger, Pachinger, Leibetseder & Fartaceck, 2000). Strong evidence for an AM deficit in BD would also point towards the need to develop cognitive therapy techniques for this clinical group, particularly cognitive remediation for AM. Promisingly, Potheegadoo, Cordier, Berna and Danion (2014) found that it is possible to reduce AM memory deficits using a specific cueing technique.

METHOD

SEARCH STRATEGY

A systematic search was performed by the author in the first week of November 2017 using the following electronic databases: PsycINFO (1806 to present), Embase (1974 to present) and Medline (1946 to present). The search strategy was as follows: (bipolar OR manic OR mania OR hypomani*) AND (autobiographical OR "personal memor*" OR "self-defining memor*" OR "episodic memor*"). Both the electronic databases and the search terms described here were chosen based on previous peer reviewed literature published in this research area. In the first instance, duplicates were removed, then titles and abstracts were screened. If it was clear from the title and/or abstract that the study either met exclusion criteria, or did not meet inclusion criteria, it was discarded. All remaining articles were then viewed in full for a final decision to be made regarding

inclusion. This review was also registered on PROSPERO ahead of data extraction (ID: CRD42018086920), which was carried out in Excel.

INCLUSION AND EXCLUSION CRITERIA

For inclusion in this review, studies had to include a sample of people with a primary diagnosis of bipolar disorder according to International Classification of Diseases (ICD; World Health Organisation, 1992) or Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 2013) criteria. Studies had to include a measure of autobiographical memory, that is, it was necessary for studies to state that they were measuring AM (i.e. personal facts and/or events from one's own life), as opposed to other types of memory, such as, episodic memory or self-defining memory. Studies also had to report on AM scores prior to any intervention that is known to impact on memory (e.g. electroconvulsive therapy).

With regards to *exclusion criteria*, studies that included participants who were not aged between 18 and 65 years were excluded, this was due to well-known differences in AM associated with age. Studies that were not published in a peer-reviewed journal were also excluded, as well as, animal studies, studies not published in English and studies reporting on previously published data. There was no exclusion criteria based on the number of participants or date of publication. In some instances, studies met multiple exclusion criteria, and are classified in the PRISMA flow diagram according to the first exclusion criteria that they met.

QUALITY ASSESSMENT

Many tools are available for assessing the quality of observational studies, but no single one has been identified as the "gold-standard" (Mallen, Peat & Croft, 2006; Shamliyan, Kane & Dickinson, 2010). In this instance, the Newcastle-Ottawa Quality Assessment Tool (Wells, Shea, O'Connell, Peterson, Welch, Losos & Tugwell, 2016; see Appendix 1) was used to assess the quality of case-control studies (n = 13), as this design was most

relevant to the aims of the current review. This tool assesses three aspects relating to quality; 1) selection of the participant groups, 2) comparability of the groups and 3) the ascertainment of the exposure of interest. Quality is rated using a 'star-system', in which a maximum of nine stars can be awarded.

All papers were rated by the current author and 10 full-text articles were also randomly selected and rated by an independent reviewer. Any discrepancies between ratings (classified as a difference of two or more stars) were resolved through discussion. To determine inter-rater reliability, intraclass correlation coefficient (ICC) estimates and their 95% confident intervals were calculated based on average measures, absolute-agreement, 2-way mixed-effects model. Overall, ICC analysis revealed an excellent degree of inter-rater reliability (ICC = .941, 95% *CI* [.7581, .985]).

SYNTHESIS OF RESULTS

At the point of data extraction, it became apparent that studies have used a limited range of methods to examine AM in BD, therefore the studies included in this review were synthesised according to the methodology used. In particular, articles have been grouped in the following way; studies using the AMT (Table 1a), studies using the AMI (Table 1b), studies examining mood-dependent memory (Table 1c) and miscellaneous studies (Table 1d).

RESULTS

SEARCH RESULTS

The search strategy for this review is highlighted in Figure 1, which demonstrates that an initial search yielded a total of 491 articles, with 315 papers screened and 124 full-text articles accessed to determine eligibility for inclusion. In each of the 17 final studies, the information that was extracted included: number of participants, illness

phase, procedural details and overall findings. Where possible, significance values (p) and effect sizes (d) have also been included. Other important AM related findings, such as, the relationships between AM and other cognitive domains and neuroimaging analyses, are not included in the tables of findings, but will be considered.

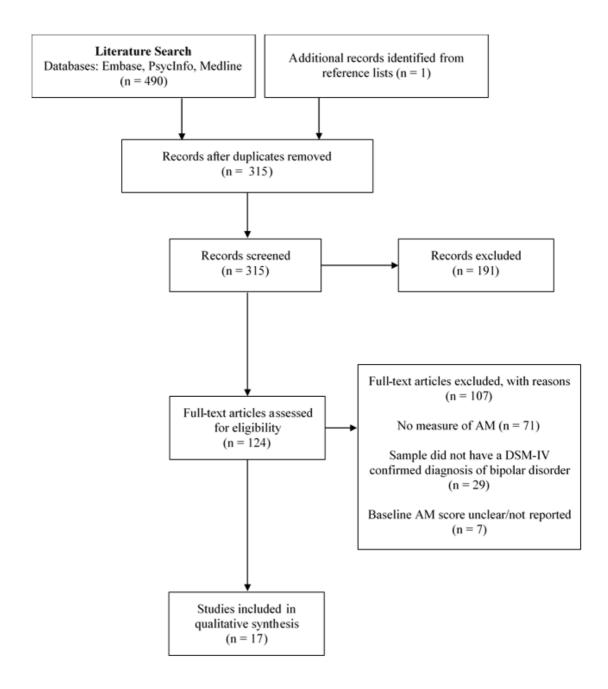


FIGURE 1; PRISMA FLOW DIAGRAM ILLUSTRATING THE SELECTION OF STUDIES

SAMPLE CHARACTERISTICS

All studies included in this review included a sample of people with bipolar disorder that was diagnosed according to DSM criteria; however, the phase of illness that participants were in at the time of testing varied. In six of the 17 studies, participants were euthymic at the time of testing (Scott, Stanton, Garland & Ferrier, 2000; Kim, Ha, Sun, Ryu, Lee, Ha et al., 2014; Mowlds, Shannon, McCusker, Meenagh, Robinson, Wilson et al., 2010; Mansell & Lam, 2004; Oertel-Knochel, Reinke, Hornung, Knöchel, Matura, Knopf et al., 2012; Gruber, Harvey & Johnson, 2009). Five studies included a sample of participants who were at various stages of illness (Quinlivan et al., 2017; Van der Gucht, Morriss, Lancaster, Kinderman & Bentall, 2009; Tzemou & Birchwood, 2007; Shimizu et al., 2009; King, MacDougall, Ferris, Herdman, Bielak, Smith et al., 2013); for instance, in the article by Shimizu et al. (2009), nine participants were depressed at the time of testing, 17 were euthymic, three were manic and two presented with mixed BD. Two of the articles exploring mood-dependent AM used a sample of people with rapidly cycling BD (Lam & Mansell, 2008; Eich, Macaulay & Lam, 1997), and both Noda et al. (2014) and Young et al. (2014) used a sample of people who were depressed at the time of testing. The participants in the study by Boulanger et al. (2014) were in remission and the remaining article by Kessler and colleagues (Kessler, Schoeyen, Andreassen, Eide, Malt, Oedegaard et al., 2014) did not specify the current mood state of their participants. In total, 497 participants with BD were compared with 398 control participants.

CONTROL GROUPS

Most frequently, researchers compared AM functioning in people with BD to age and gender matched controls with no history of psychological illness. However, four papers also included control groups of people with depression and one paper compared AM functioning in BD to that in people with anxiety disorders. Four of the papers presented in this review included no control group.

SUMMARY OF METHODOLOGIES

THE AUTOBIOGRAPHICAL MEMORY TEST

Nine of the studies included in this literature review used either the original version, or an adapted version, of the Autobiographical Memory Test (AMT; Williams & Broadbent, 1986) to examine AM in people with bipolar disorder. In the original version of the task, participants are presented with ten emotional cue words that vary in terms of their emotional valence (e.g. sad, happy) and are instructed to recall a specific AM in response to each. A specific AM is defined by the authors of this task as a personal memory that happened at a particular time and place and lasted for no longer than one day, for instance, "the Monday night I met Joe in Canary Wharf after work and went for pizza". In contrast, a more general memory might be "the times I went out for dinner in London".

Within this systematic review, the AMT was translated on two occasions - once into French (Boulanger et al., 2014) and once into Korean (Kim et al., 2014). Other adaptations included the addition of neutral words (Young et al., 2016) and rejection-related cue words (e.g. rejected, neglected, ignored, declined, unwanted; Quinlivan et al., 2017). The number of cue words used also varied amongst studies, with Mansell and Lam (2004) using just one positive and one negative cue word and Young et al. (2016) using 60 cue words (20 positive, 20 negative and 20 neutral). In six of the studies, participants verbally recalled their memories (Young et al., 2016; Scott et al., 2000; Kim et al., 2014; Mowlds et al., 2010; Tzemou & Birchwood, 2007; Mansell & Lam, 2004), in two they were asked to write the memory down (Quinlivan et al., 2017; Boulanger et al., 2014) and one study did not specify the mode of AM retrieval (Van der Gucht et al., 2009).

THE AUTOBIOGRAPHICAL MEMORY INTERVIEW

Two studies included in the review used the Autobiographical Memory Interview (AMI; Kopelman et al., 1989), which is a semi-structured interview that allows for the assessment of both episodic and semantic AM. That is, whereas the AMT assesses only episodic recall of personal events, the AMI also explores memory for personal facts (e.g. I was born in Barnsley, my first pet was a guinea pig). The original version of this task assesses recall across three distinct time periods; childhood, early adulthood and recent times.

The AMI was adapted in both papers included in this review. Oertel-Knöchel et al. (2012) used a German version of the task (Bielefelder Autobiographical Memory Inventory; Fast, Fujiwara & Markowitsch, 2004) and assessed AM across five lifetime periods (preschool, elementary school, adolescence, earlier adulthood, recent life/past 5 years). The AMI was also partially modified by Shimizu et al. (2009) who assessed episodic and semantic AM across four lifetime periods (childhood to age eleven, high school, career (i.e. life in college or first job) and recent years) and adapted the life events that participants were asked to recall according to the population. More specifically, questions relating to memories of weddings and children were excluded due to authors considering these to be less relevant to people with BD, and questions regarding recent hospital visits were removed due to them being deemed to be less relevant to control participants.

MOOD-DEPENDENT MEMORY

The cyclical nature of BD permitted some articles to assess the impact of various mood states on AM in a within participants design. This approach was adopted in two of the studies included in this review. The first of these studies employed a single-case design (Lam & Mansell, 2008), in which the specificity of AM was tested in an individual with rapidly cycling bipolar disorder on four occasions (twice when he was manic and twice when depressed). The second study used a larger sample of ten people with BD (Eich et

al., 1997) and explored 1) whether or not there is an advantage of AM recall when mood states are matched at encoding and retrieval and 2) whether more specific AMs are encoded during mania or depression. The third study to examine the impact of mood state on AM employed a retrospective design (King et al., 2013) and asked participants to recall one AM from each of the following mood states; manic, depressed and euthymic. As a comparison, healthy control participants recalled AMs from positive elevated, sad and average mood states. Ease of recall, level of re-experiencing, emotional valence and recall point of view was compared across groups and mood states.

MISCELLANEOUS STUDIES

The primary aim of the three remaining articles was not to explore AM functioning in people with BD, yet each met the criteria for inclusion in this review. For instance, Gruber et al. (2009) examined the effect of reflective vs. ruminative processing of positive memories in people with BD compared to healthy controls. Participants were instructed to recall an AM in which they felt "intense happiness" and ahead of the processing manipulation, ratings of vividness and social content were collected by the experimenter. The final two papers aimed to explore the impact of electrical brain stimulation, specifically electroconvulsive therapy and magnetic seizure therapy, on neurological functioning; whilst there are many papers that explore this, these were the only two to report baseline AM scores specifically for people with BD. Both studies used the Columbia-University Autobiographical Memory Interview Short-Form (AMI-SF; McElhiney, Moody & Sackeim, 2001), which is a structured interview that assesses memory for six autobiographical events: last major overnight trip, last New Year's Eve, last birthday, most recent employment, most recent medical illness, and details about an important family member or friend. For each event, five questions are asked to elicit AM specific details, producing a total of 30 items. Follow up testing takes place after electrical brain stimulation. Participants are re-tested on AM items that they originally

gave definite responses for and memory consistency is assessed. Responses are scored as 0 (no response or fully inconsistent), 1 (partially consistent), or 2 (fully consistent), thus providing a final AMI-SF score out of 60.

BEYOND AM SPECIFICITY

Consistent with the literature on AM in other clinical disorders, the majority of research presented in this review explored the specificity of AM in people with BD relative to controls. Other features of AM that were examined in the articles included emotional valence, recall latency, vividness, age of encoding and frequency of recall. As described above, papers using the AMI also allowed for comparisons between episodic AM functioning and memory for personal semantic facts.

Whilst the primary aim of many of the studies included in this review was to compare AM functions in people with BD to that of controls, some studies also included other important AM related findings. For instance, two of the articles included for review attempted to assess the association between AM and other cognitive domains by carrying out neuropsychological test batteries (Kim et al, 2014; Quinlivan et al., 2017). Young et al. (2016) and Oertel-Knöchel et al. (2012) used functional magnetic resonance imaging (fMRI) to determine whether functional abnormalities underlying AM recall may differentiate people with BD from people with major depressive disorder and healthy controls. King et al. (2013) examined whether deficits in recalling autobiographical information might extend to impairments in predicting future autobiographical events, and two papers measured AM function as part of research to explore the key components of Beck's (1976) model of cognitive vulnerability (Tzemou & Birchwood, 2007; Scott et al., 2000), which proposes that depression arises from an interplay between dysfunctional attitudes and over-general negative thinking about the self and past events.

TABLE 1 A; STUDIES USING THE AUTOBIOGRAPHICAL MEMORY TEST

| Study | Number of Participants | | Illness Phase | | | | Additional Measures | Findings | Quality rating | | | | | | | | | | | |
|-------------------------------|------------------------|--|--|--------------------|---|---|--------------------------|--|--|----|----|--|----|----------|---|----------------|-----------|-----------------------|--|----|
| | Bipolar Disorder | Controls | _ | Written/ Verbal | Cues | AM Parameter | _ | | | | | | | | | | | | | |
| Quinlivan et al. (2017) | 20 | 22 | Euthymic or mildly depressed | W | 15 cue words (5 positive, 5 negative and 5 rejection-related) | Specificity | Neuropsych assessment | No group difference in AM specificity ($p = 0.66$). All participants reported more specific memories in response to negative cue words than positive or rejection cue words ($p < .001$). | 9* | | | | | | | | | | | |
| Young et al. (2016) | 16 | 16 | 16 16 MDD | 1 | Depressed | Depressed V 60 cue words (20 Specificit positive, 20 neutral and 20 negative) | Specificity | fMRI | Participants with BD recalled fewer specific ($p < .001$, $d = 1.84$) and more OGAMs ($p < .001$, $d = 2.15$) than healthy controls). Participants with BD and those with MDD did not differ from each other ($p > .64$, $d = 0.02$). | 8* | | | | | | | | | | |
| | | | | | | | | | | | | Participants with BD and MDD recalled fewer positive specific memories than controls ($p < .001$). Both groups recalled fewer specific negative AMs, but the difference did not meet the corrected threshold for significance ($p > .03$). | | | | | | | | |
| Boulanger et al. (2014) | 19 | positive and 5 emotional prediction, negative) valence cognitive than controls. Functioning Participants with BD recalled more OGAMs $(p < .001, d = 1.18)$ and negative memories $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p < .001, d = 0.01)$ and more OGAMs $(p <$ | 19 | 19 | 19 | 19 | 19 | 19 | 19 | 19 | 19 | 19 | 19 | Remitted | W | positive and 5 | emotional | prediction, cognitive | Participants with BD reported fewer specific memories ($p = .01$) and more OGAMs ($p = .017$) than controls. | 8* |
| | | | Participants with BD recalled more negative OGAMs ($p < .001$, $d = 1.18$) and less specific negative memories ($p < .001$, $d = 1.00$) than controls. When the valence of the cue was positive, no group differences emerged. | | | | | | | | | | | | | | | | | |
| | | | | | | | | There was no group difference in the emotional intensity of AMs. | | | | | | | | | | | | |

| Study | Number o Participan | | Illness Phase | AM Procedural Details | | | Additional Measures | Findings | |
|-----------------------------------|------------------------|----------|---|-----------------------|--|--------------------------------|--|--|----|
| | Bipolar Disorder | Controls | _ | Written/ Verbal | Cues | AM Parameter | _ | | |
| Van der Gucht et al. (2009) | 107 | 41 | 34 (hypo)ma nic or mixed affective 30 depressed 43 euthymic | Not specifie d | 12 cue words (6 positive and 6 negative) | Specificity | Depressoge nic cognitive styles and reward responsivity | The mania group recalled fewer specific negative AMs than the control group ($p < .001$) but no differences were observed for the recall of positive AMs. | 7* |
| Scott et al (2000) | 41 | 20 | Euthymic | V | 10 cue words (5 positive and 5 negative) | Specificity and recall latency | Problem solving, dysfunction al attitudes, self-esteem, sociotropy- autonomy | Participants with BD showed less specificity in response to positive and negative cue words ($p < .03$, $d = 0.61$). There was no group difference in recall latency. | 5* |
| Kim et al. (2014) | 28 | 28 | Euthymic | V | 10 cue words (5 positive and 5 negative) | Specificity | Neuropsych assessment | Participants with BD generated more OGAMs than controls ($p = 0.05$, $d = 0.58$). Participants with BD report more negative OGAMs than controls ($p = .02$, $d = 0.64$). There was no group difference in the specificity of positive AMs ($p = .20$, $d = 0.36$). | 6* |

| Study | | Number of Participants | | | | | | AM Proce | edural Details | | Additional Measures | Findings | |
|---------------------------------|---------------------|---------------------------|-----------------------------|--------------------|---|--|------------------------------|--|----------------|--|------------------------|----------|--|
| | Bipolar Disorder | Controls | _ | Written/ Verbal | Cues | AM Parameter | _ | | | | | | |
| Mowlds et al. (2010) | 52 | 24 17 MDD 31 AD | Euthymic | V | 12 cue words (6 positive and 6 negative) | Specificity | Trauma questionnair es | Participants with BD generated more OGAMs than healthy controls ($p < .005$, $d = 1.01$) and participants with AD ($p < .005$, $d = 0.82$). Participants with BD showed the same level of OGAM as people with MDD ($p = .19$, $d = 0.12$). | 5* | | | | |
| Tzemou & Birchwood (2007) | 28 | 20 21 UP | 18 manic 10 depressed | V | 12 cue words (6 positive and 6 negative) | Specificity | Problem solving | Participants with BD showed the same level of OGAM as people with UP. People with BD were impaired in generating specific memories relative to healthy controls ($p < .001$, $d = 3.45$). | 6* | | | | |
| Mansell & Lam (2004) | 19 | 16 R-UP | Euthymic | V | One positive cue word and one negative cue word | Specificity, emotional valence, excitement, anxiety, distress, imagery, vividness, AaE and frequency | | Participants with BD generated more negative OGAMs than controls ($p < .05$). There were no group differences in the specificity of positive AMs. Participants with BD reported more frequent recollections of negative AMs during everyday life. | 6* | | | | |
| | | | | | | | | There were no other differences in AM ratings. | | | | | |

Note. Significance values (p) and effect sizes (Cohen's d) are given in parentheses. MDD = major depressive disorder, fMRI = functional magnetic resonance imaging, BD = bipolar disorder, OGAM = over-general autobiographical memory, AD = anxiety disorder, UP = unipolar depression, R-UP = remitted unipolar depression, AaE = age at encoding.

TABLE 1 B; STUDIES USING THE AUTOBIOGRAPHICAL MEMORY INTERVIEW

| Study | Number of Participants | | Illness Phase | AM Procedural D | etails | Additional Measures | Findings | Quality rating |
|-------------------------------------|------------------------|----------|---|-----------------|---|------------------------|---|----------------|
| | Bipolar Disorder | Controls | _ | Written/Verbal | AM Parameter | _ | | |
| Shimizu et al. (2009) | 31 | 38 | 9 depressed, 17 euthymic, 3 manic and 2 mixed BD | Not specified | Specificity | | Participants with BD showed no deficits in recalling semantic AMs ($p = 0.224$). Participants with BD demonstrated selective deficits in incident AM across lifetime periods ($p < 0.01$). | 6* |
| Oertel- Knochel et al. (2012) | 26 | 22 | Euthymic | V | Specificity, emotional valence, recall frequency | fMRI | There was no significant group difference in the capacity to recall semantic details ($p = 0.31$, $d = 0.38$). BD participants recalled significantly fewer specific episodic events than healthy controls ($p = 0.01$, $d = 1.00$) Relative to controls, episodic memories recalled by those with BD were more intensely emotional ($p = 0.001$, $d = 1.23$), more frequently remembered ($p = 0.03$, $d = 0.94$) and had a greater influence on their daily lives ($p = 0.001$, $d = 1.21$). | 5* |

Note. Significance values (p) and effect sizes (Cohen's d) are given in parentheses. BD = bipolar disorder, Am = autobiographical memory, fMRI = functional magnetic resonance imaging.

TABLE 1 C; STUDIES EXPLORING MOOD DEPENDENT AM

| Study | Number of Participar | | | Method | | | Findings | Quality rating |
|----------------------------|----------------------|----------|---|---|--------------------|---|---|-------------------|
| | Bipolar Disorder | Controls | - | AM Procedure | Verbal/ Written | AM Parameter | - | |
| Eich et al. (1997) | 10 | n/a | Rapidly cycling | Encoding session - Participants recalled 10 specific events that were cued by neutral noun probes. | V | Emotional valence | Participants were more likely to recall positive events when in a (hypo)manic mood relative to a depressed mood, but this did not reach significance $(p=.10)$. | |
| | | | | Retrieval session - Participants were given 5 minutes to recall as many of these events as possible. | | | There was a significant recall advantage of matched over mismatched mood ($p < .05$). | |
| Lam & Mansell (2008) | 1 (JJ) | n/a | Rapidly cycling | AM word stimuli with 4 neutral cue words. Procedure repeated twice when manic and twice when depressed | V | Specificity, age of encoding, response latency, pleasantness now and then (at time of encoding) | Mean latencies for retrieving AMs were 20.94 seconds when depressed and 3.97 when manic. When JJ was manic, 75% of his AMs were specific and 25% were general; when he was depressed 25% were specific and 75% were general. | |
| King et al. (2013) | 20 | 20 | 7 euthymic, 7 subsyndro mal, 3 moderately depressed | AM interview – participants provided a single detailed account of an event that occurred in each of the following mood states: manic/depressed/euthymic. Control mood states = positive elevated/sad/average mood state. | V | Ease of recall, re- experiencing, emotional valence and recall point of view | Participants with BD show a deficit in recalling episodic information from periods of mania ($p < .05$), but not when depressed or euthymic. Participants with BD re-experienced less vivid visual and auditory sensations for events encoded during mania ($p < .05$). People with BD were more likely to recall events from an observer perspective across mood states ($p < .01$). No group differences in emotional valence ($p > .05$) | 6* |

TABLE 1 D; MISCELLANEOUS PAPERS MEASURING ASPECTS OF AM IN PEOPLE WITH BD

| Study | Number of Participants | | Illness Phase | | | | AM related findings | Quality rating |
|-----------------------------|---------------------------|----------|------------------|---|----------------|------------------------------|--|----------------|
| | Bipolar Disorder | Controls | - | AM Procedure | Verbal/Written | AM Parameter(s) | _ | |
| Gruber et al. (2009) | 27 | 27 | Euthymic | Participants recalled one AM experience in which they felt intense happiness | V | Vividness and social content | No group differences in vividness of AM or social content ($p > .05$). | 8* |
| Kessler et al. (2014) | 51 | n/a | Not specified | Columbia University Autobiographical Memory Interview- Short Form | | Specificity | Average pretreatment score = 54.6/60 | |
| Noda et al. (2014) | 1 | n/a | Depressed | Columbia University Autobiographical Memory Interview- Short Form | | Specificity | Pretreatment score = 52/60 | |

SYNTHESIS OF FINDINGS

The main aim of this review was to identify studies that describe the features of AM in people with bipolar disorder and to explore the nature of the differences that present in this clinical group vs. controls. For the purposes of answering this review question, studies have been grouped in the following way; studies examining the specificity of AM, those investigating differences between episodic and sematic AM, and the investigation of mood dependent AM. The neuropsychological and neuroimaging data provided by these studies is also considered, as well as other AM parameters that might distinguish people with BD from controls. Several of the articles' findings span multiple areas and are therefore discussed accordingly.

OVER-GENERAL AM

Of the 11 studies examining the specificity of AM in people with bipolar disorder relative to controls, 10 found evidence for over-general AM (OGAM; Boulanger et al., 2014; Kim et al., 2014; Mansell & Lam, 2004; Mowlds et al., 2010; Oertel-Knöchel et al., 2012; Scott et al., 2000; Shimizu et al., 2009; Tzemou & Birchwood, 2007; Van der Gucht et al., 2009; Young et al., 2016). For instance, using a French version of the AMT, Boulanger et al. (2014) found that participants with BD generate significantly fewer specific AMs and significantly more categorical AMs than do age and education matched controls. Oertel-Knochel et al. (2012) and Shimizu et al. (2009) also found evidence for OGAM when examining episodic memories generated by participants on the AMI. The article by Quinlivan et al. (2017) is the only article included in this review that does not provide evidence for OGAM when comparing people with BD to healthy controls. Crucially, post hoc power estimates revealed that the power to detect a significant effect in this study was 0.11. The authors also found no group differences on various cognitive tasks and thus attribute the absence of OGAM to the use of a particularly high functioning sample of people with BD.

Collectively the articles included in the review provided evidence for OGAM in BD across

all mood states. Young et al. (2016), Tzemou and Birchwood (2007) and Shimizu et al. (2009) found evidence for OGAM in people with BD who were depressed at the time of testing, and six studies reported OGAM in samples of people who were euthymic. Van der Gucht et al. (2009) compared OGAM across people with BD who were either manic, depressed or euthymic found that only those participants currently experiencing mania recalled fewer specific negative AMs than the healthy control group. In contrast, the case report described by Lam and Mansell (2008), found that an individual with rapidly cycling BD generated more over-general AMs when he was depressed relative to when he was manic. In general, it is difficult to draw conclusions in relation to mood state due to the heterogeneity within the samples presented here, yet the finding that OGAM persists when participants with BD are euthymic is relatively robust.

It is important to note that differences in AM specificity emerged in relation to the emotional valence of the AM being recalled. Most of the studies comparing positive and negative cues found that OGAM was more pronounced when participants were recalling negative AMs relative to positive ones. For instance, Boulanger et al. (2014) found that when the valence of the cue word was negative, people with BD recalled more OGAMs and fewer specific memories than controls, but when the valence of the cue word was positive, no group differences emerged; this finding was also replicated by Kim et al. (2014) and Mansell and Lam (2004). Similarly, Van der Gucht et al. (2009) found that participants with mania recalled fewer specific negative AMs than healthy controls but found no differences in the recall of positive AMs. In contrast, Young et al. (2016) found that whilst people with BD generated fewer specific negative AMs, the difference did not meet the corrected threshold for significance, and Quinlivan et al. (2017) reported that all participants generated more specific memories in response to negative cue words than positive or rejection cue words.

In addition to examining AM in people with BD relative to healthy controls, several studies included a control group of people with a primary diagnosis of depression (i.e. major

depressive disorder or unipolar depression; Mowlds et al., 2010; Tzemou and Birchwood,

2007; Young et al., 2016). All of these studies showed that participants with BD and MDD recalled fewer specific and more categorical AMs that healthy controls but did not differ from each other. Mowlds et al. (2010) also found that participants with BD and MDD report more over-general AMs than do people with an anxiety disorder. One study included in the review did find a distinction between people with BD and those with a diagnosis of unipolar depression; Mansell & Lam (2004) found that over-generality is more pronounced in people with BD when compared with people with remitted unipolar depression. This article found no group differences in the specificity of positive memories.

In summary, people with BD experience impairments in recalling specific personal events from their past regardless of their current mood state; of note, AM is still found to be impaired in the euthymic state. The deficits in AM specificity tend to be more pronounced for negatively valenced memories, suggesting that recall is different for positive and negative AM. There is much evidence for OGAM in people with a primary diagnosis of depression and the studies reported here suggest that deficits in AM specificity in people with BD are comparable.

BEYOND AM SPECIFICITY

Many of the studies included in the review assessed multiple parameters of AM in people with BD. King et al. (2013) found that people with BD were more likely than healthy controls to recall events from an observer perspective than a first-person perspective, and Mansell and Lam (2004) found that euthymic participants report more frequent recollections of negative AMs during everyday life than people with remitted unipolar depression. Studies also reported on several features of AM that were unimpaired relative to healthy controls, such as recall latency (Scott et al., 2000), vividness (Gruber et al. 2009), emotional valence (King et al., 2013;) and the emotional intensity of AMs (Boulanger et al., 2014). When comparing people with BD to people with remitted unipolar depression, Mansell and Lam (2004) also found no group differences in vividness, excitement or anxiety felt at the time of recall, nor in age at encoding.

In sum, it can be tentatively suggested that the tendency to recall AMs from an observer perspective, and to experience negative AM intrusions in everyday life, may distinguish people with BD from healthy controls. However, many other features of AM are unimpaired in BD relative to healthy controls and people currently in remission from unipolar depression.

EPISODIC VS. SEMANTIC AM

The two studies that employed the AMI (Oertel-Knöchel et al., 2012; Shimizu et al., 2009) allowed for an exploration of whether people with bipolar disorder exhibit deficits in the recall of semantic, as well as episodic, autobiographical information. Shimizu et al. (2009) found that, relative to healthy controls, participants with BD demonstrated selective deficits in episodic AM across lifetime periods; however, participants with BD showed no deficits in recalling semantic AMs. Similarly, Oertel-Knöchel et al. (2012) found that there was no significant group difference in the capacity to recall semantic autobiographical details, yet people with BD recalled significantly fewer specific episodic events. In sum, these findings replicate many clinical studies that show that semantic AMs are preserved in instances where episodic AM is disrupted (e.g. Evans, Wilson, Wraight & Hodges, 1993; Greene, Hodges & Baddeley, 1995; Levine, Svoboda, Hay, Winocur & Moscovitch, 2002; Piolino, Desgranges, Benali & Eustache, 2002; Tulving, Schacter, McLachlan & Moscovitch, 1988).

MOOD-DEPENDENT AM

A study by Eich et al. (1997) aimed to shed light on mood-dependent memory in people who experience marked shifts in mood due to rapidly cycling BD. Participants in this study took part in an encoding session in which their current mood was assessed followed by an AM procedure in which they were instructed to recall ten specific AMs in response to neutral noun cues. Between two and seven days later, participants took part in a retrieval session, in which mood was re-assessed and participants were given five minutes to recall as many of the ten previously recounted AMs as possible. This article provided evidence for mood dependent memory in BD, as there was a significant recall advantage of matched over

mismatched moods. Results also showed that positive events outnumbered negative events when participants recalled AMs in a manic mood (ratio of 3.36 to 1) and less so when participants recalled events in a depressed mood (ratio of 1.51 to 1). The authors interpret these findings as being suggestive of mood congruence in AM, but the difference between the ratios was not significant (p < .10).

Lam and Mansell (2008) explored mood-dependent cognitive change in a 27-year-old male with rapidly cycling BD, this case study included no comparison group, but did show AM related differences according to mood. For instance, the mean latencies for retrieving AMs was 20.94 seconds when the participant was depressed and 3.97 when he was manic. In terms of specificity, on the two occasions when the participant was manic, 75% of his AMs were specific and 25% were general, whereas the pattern was reversed on both occasions when the participant was depressed: 25% of AMs were specific and 75% were general. This participant was also more likely to rate current pleasantness of memories as higher when he was experiencing mania, whereas ratings given for mood at the time of encoding showed little difference between manic and depressed episodes.

Finally, King et al. (2013) found AM differences according to mood state at the time of encoding. Participants with BD show a selective deficit in recalling episodic information from periods of mania, but not from periods when participants were depressed or euthymic. Participants with BD also re-experienced less vivid visual and auditory sensations for events encoded during mania.

In summary, current evidence suggests that people with BD might experience differences in autobiographical encoding and retrieval according to their current mood state. In terms of AM retrieval, evidence suggests that that when participants with BD experience mania, positive AMs are more readily accessible and that past events are more likely to be reflected on in a positive way. Similarly, people with BD who are experiencing depression recall fewer positive AMs, which is consistent with Beck's (1979) cognitive triad, which postulates that people who are depressed reflect negatively on their past, as well as, their

current self and the future. Whilst it is difficult to generalize findings from case studies, the evidence from Lam and Mansell (2008) is suggestive of the fact that OGAM is more pronounced during depression than in mania. With regards to encoding, the reverse might be true, as King et al. (2013) found that AM encoding is impaired during mania relative to during depression. In sum, the findings presented here suggest that there is a benefit of AM retrieval during periods of mania, but impairment in the ability to encode AMs during this phase of BD.

NEUROPSYCHOLOGICAL FINDINGS

To explore possible associations between AM specificity and other cognitive domains, three of the studies included in this review carried out neuropsychological tests alongside the AMT (Boulanger et al., 2014; Kim et al., 2014; Quinlivan et al., 2017). Kim et al. (2014) included validated measures of overall intelligence, attention, verbal memory, verbal fluency, visual memory and executive function. Correlational analyses of AMT scores with cognitive functions were performed, with demographic and clinical variables being controlled for. The authors found that AM was associated with executive functions in BD patients, whereas AM in healthy controls was related to verbal memory and fluency.

The study by Quinlivan et al. (2017) measured AM specificity alongside verbal memory, executive function and attention. Although participants with BD tended to perform poorer on neuropsychological measures, the authors found no significant group differences. For this reason, distinct relationships between AM and other cognitive functions in those with BD were not examined, but overall the results of this study indicated that verbal fluency, verbal memory and the inhibition component of executive functions all contribute independently to AM specificity.

Finally, Boulanger et al. (2014) examined the relationship between AM specificity and tests of executive function and working memory. They found that significant correlations emerged between the number of specific AMs recalled and verbal fluency, as measured by the Verbal Fluency Task (Bento, 1968), and interference, as measured by the Stroop Color-

Word Test (Stroop, 1935). In summary, these studies demonstrate a relationship between particular executive subprocesses and AM specificity in people with BD.

NEUROIMAGING FINDINGS

Two articles included in this review examined a neural basis for AM recall in people with BD. In the study by Oertel-Knöchel et al. (2012), functional magnetic resonance imaging (fMRI) was carried out whilst participants completed the AMI. Across groups, activation during AM recall was observed in the left frontal lobe, the temporal lobe bilaterally, and several limbic areas (left posterior and anterior cingulate, right posterior cingulate, amygdala bilaterally). Higher activation in the right anterior cingulate was found across groups during recall of recent AMs relative to earlier lifetime periods, and results showed no effect of AM valence on areas of activation. However, activation differences did emerge when comparing findings across groups, as there was less deactivation of the right cuneus and left lingual gyrus in people with BD relative to controls.

Young et al. (2016) also used fMRI to examine functional differences underlying AM retrieval in people with BD relative to those with major depressive disorder (MDD) and healthy controls. To do so, participants completed the AMT and a semantic example task, and differences in hemodynamic activity during the two tasks were compared between the diagnostic groups. Findings showed that participants with BD experienced increased activity in the amygdala, ventrolateral prefrontal cortex, middle temporal gyrus and the anterior insula during positive AM recall relative to healthy controls and those with MDD. The only region that was less active in BD versus MDD during positive AM recall was the dorsolateral prefrontal cortex, which is a region that has been implicated in executive function. With regards to negative AM recall, increased activity in these regions was less pronounced in people with BD than it was in those with MDD, suggesting that healthy controls and people with BD require more cognitive effort to recall negative AMs than do people with MDD.

Overall, the findings from these studies suggest that people with BD process AMs (particularly positive AMs) differently to healthy controls and people with a primary MDD diagnosis, suggesting that bipolar depression is distinct from unipolar depression. Both studies pointed towards a failure to deactivate regions of the default mode network (specifically, the cuneus and middle temporal gyrus) in people with BD. The default mode network refers to a large network of interacting brain regions that are active when a person engages in wakeful rest (i.e. daydreaming) and when a person thinks about themselves, the past or the future. This network plays a role in the capacity to relate information to the self at the point of encoding i.e. self-referential processing. Crucially, the capacity to organise information in relation to the self is thought to be central to AM functioning.

FURTHER FINDINGS

Several papers included for review examined associations between OGAM and other psychological and social functions. For instance, Scott et al. (2000) found that OGAM is significantly correlated with poorer social problem solving, but Quinlivan et al. (2017) found no significant associations between OGAM and age of onset, number of episodes or number of suicide attempts in people with BD. Boulanger et al. (2013) examined whether the deficit in recalling specific AMs extended to the capacity to imagine specific future autobiographical events. Findings showed that participants with BD generated fewer specific autobiographical future events, and more over-general autobiographical future events, than did healthy controls. The authors demonstrated that the capacity to generate specific past events is related to the capacity to generate specific future events in healthy controls, yet no significant correlation emerged in people with BD.

QUALITY ASSESSMENT

Studies generally scored two to four stars for *selection* with the majority of studies including a BD sample that was adequately defined using recognised diagnostic criteria (e.g. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition or the International Statistical Classification of Diseases and Related Health Problems, 10th revision) and using

control participants with no history of BD. Studies tended to lose stars for including samples that were unrepresentative or when representativeness was unclear. With regards to *comparability*, all studies scored at least one star; most of the studies controlled for important demographic variables, such as age and gender, but fewer controlled for variables such as IQ and years of education. Regarding *exposure*, all studies scored at least one star, as the method of ascertainment tended to be the same for participants with BD and controls, yet studies tended not to include experimenters who were blind to case/control status. See Appendix 2 for a breakdown of quality assessment ratings according to selection, comparability and exposure.

DISCUSSION

This systematic review aimed to extract studies from the literature that would help to determine features of autobiographical memory (AM) in people with bipolar disorder (BD); in particular, it aimed to answer the following question: is AM impaired in people with BD? This question is motivated by research that suggests that AM impairment is a principle feature of emotional disorders. Review articles have provided a synthesis of findings regarding AM in depression (Williams et al., 2007) and schizophrenia spectrum disorder (Berna et al., 2015; Ricarte et al., 2017), but to the best of our knowledge, this is the first systematic review of AM findings in BD.

Findings revealed that 10 of the 11 studies that compared the specificity of AM in people with BD to control participants found evidence for OGAM within this client group (Boulanger et al., 2014; Kim et al., 2014; Mansell & Lam, 2004; Mowlds et al., 2010; Oertel-Knöchel et al., 2012; Scott et al., 2000; Shimizu et al., 2009; Tzemou & Birchwood, 2007; Van der Gucht et al., 2009; Young et al., 2016). Neuroimaging studies showed a failure to deactivate regions of the default mode network in relation to this (Oertel-Knöchel et al., 2012; Young et al., 2016), and studies that carried out cognitive test batteries found an

association between particular sub-processes of executive functioning (verbal fluency and inhibition) and OGAM (Boulanger et al., 2014; Kim et al., 2014; Quinlivan et al., 2017). Several AM functions were unimpaired in people with BD, demonstrating that this group does not present with global AM impairments, and it might be tentatively suggested that AM functioning varies in BD according to mood state at the time of encoding and retrieval (Eich et al., 1997; King et al., 2013; Lam & Mansell, 2008). Given the role of AM in maintaining psychological wellbeing (Conway, 2005), findings have several important clinical implications that are discussed below. First, an interpretation of the current findings is provided, followed by the limitations of this review and the existing literature, and several suggestions for future research are made.

INTERPRETATION OF FINDINGS

Before attempting to interpret the findings from this review, it is important to note that this is a small-scale review of a relatively new area of research that requires much additional investigation. In addition, the quality review highlighted that the studies included in this review had some methodological flaws and thus the interpretation must be considered in the context of this.

The results revealed that OGAM is a characteristic of people with BD, that is, people with BD tend to recall memories that are summaries of repeated events (e.g. I used to visit Victoria Park) when instructed to recall specific memories. Where possible, effect sizes for this finding were calculated and all effects were moderate-to-large (Cohen, 1988). OGAM was also found across various mood states (i.e. depression, euthymia and mania) and in people in remission from BD symptoms, thus suggesting that OGAM might be a trait rather than a state marker of BD. This finding is significant, as the capacity to observe OGAM in the absence of clinical symptoms means that it can predict future vulnerability to psychopathology (Williams et al., 2007). Indeed, OGAM in the absence of current psychopathological symptoms has been found to predict the onset of depressive symptoms (Gibbs & Rude, 2004; Mackinger, Loschin & Leibetseder, 2000; Mackinger, Pachinger,

Leibetseder & Fartarek, 2000), dysphoria (Mackinger, Kunz-Dorfer, Schneider & Leibetseder, 2001) and emotional reactivity (Minnen, Wessel, Verhaak & Smeenk, 2005). Just one study included in this review failed to replicate OGAM in people with BD; Quinlivan et al. (2017) compared participants with BD who were euthymic or mildly depressed to healthy controls and found no group difference in AM specificity. The authors comment that this was a particularly high functioning group of people with BD and crucially, post hoc power analysis revealed that this study had 11% power to reject the null hypothesis that there was no group difference.

OGAM is characteristic of a number of emotional disorders; it is particularly well documented in unipolar depression (UD). Three studies included in this review demonstrated that people with BD experience the same level of OGAM as those with UD. However, whilst behavioural findings were indistinguishable between groups, a notable difference emerged in relation to the underlying neural activation. In particular, participants with BD failed to deactivate areas of the default mode network during the recall of AMs, relative to those with UD. This finding provides evidence against the argument that bipolar depression and unipolar depression are the same illness (Joffe, Young & MacQueen, 1999), and suggests that this could provide a clinically useful diagnostic marker. In relation to differential diagnosis, this review also showed that people with BD are impaired in recalling specific AMs relative to those with an anxiety disorder (Mowlds et al., 2010). Indeed, this is in keeping with the wider literature, which shows that people with a range of anxiety disorders are unimpaired in generating specific AMs (e.g. generalized anxiety disorder, Burke & Matthews, 1992; social phobia, Wenzel, Jackson & Holt, 2002; blood and spider phobia, Wenzel, Jackson, Brendle & Pinna, 2003; mixed anxiety disorder, Wessel, Meeren, Peeters, Arntz & Merckelbach, 2001).

MECHANISMS UNDERLYING OGAM

According to the Self-Memory System (SMS; Conway & Pleydell-Pearce, 2000), the retrieval of specific AMs is a top-down search process, in which general events are activated

first (e.g. "I used to visit Columbia Road Flower Market"), followed by event specific details ("one day I visited with my grandad and he bought me flowers"). The authors of the SMS propose that OGAM serves an adaptive function by allowing individuals to avoid the emotional impact of reliving specific past events. The act of recalling specific event details also makes it more likely that related AMs will be triggered, and it is proposed that the capacity to avoid reliving past experiences is negatively reinforced in people who experience traumatic early life experiences. In support of this theory, people experiencing adverse events in early life are particularly vulnerable to developing OGAM, and a history of trauma has been shown to impair the ability to retrieve specific memories (e.g. Hermans et al., 2008; Kuyken & Brewin, 1995; Stokes, Dritschel & Bekerian, 2004). Research also shows that there is a high prevalence of childhood trauma in people with BD (e.g. Mowlds et al., 2010).

It has been argued that if OGAM were a consequence of functional avoidance, then it would be more likely to be found in response to negative cues than positive ones. This hypothesis is consistent with some of the findings in the current review, as four studies found that negative cues elicited OGAMs, whilst positive cues did not (Boulanger et al., 2014 Kim et al., 2014; Mansell & Lam, 2004; Van der Gucht et al., 2009), yet two studies found OGAM for positive cues in the absence of an effect for negative cues (Quinlivan et al., 2017; Young et al., 2016). The wider literature also presents mixed findings with regards to the emotional valence of cue words. For instance, a review by Williams et al. (2007) found larger effect sizes for positive (d = 0.91) than negative cues (d = 0.48) in people with depression. However, valence effects might not challenge the functional avoidance hypothesis, as it is possible for negative memories to be triggered by positive cues and in addition, a positive cue does not guarantee that a positive memory will be recalled. What is more difficult to explain is the finding that OGAM presents in people who have never experienced trauma (Wessel et al., 2001). Indeed, research by Mowlds et al. (2010) showed that childhood trauma was not predictive of AM specificity in people with BD. In response to questions

raised about functional avoidance, Williams et al. (2007) proposed the CaRFaX model, which proposes that three mechanisms; Capture and Rumination, Functional avoidance and impaired eXecutive control underlie the phenomenon of OGAM. Rumination will be considered next, followed by the contribution of impaired executive control.

Rumination is the process of engaging in repetitive and passive thinking about the causes and consequences of one's mood, as opposed to attempting to generate solutions (Nolen-Hoeksema, 2000). Rumination is well documented in depression, and research has shown that people with BD engage in rumination in response to positive and negative affect (e.g. Johnson, McKenzie & McMurrich, 2008). For instance, Gruber and colleagues (Gruber, Eidelman, Johnson, Smith & Harvey, 2011) found a positive association between the frequency of rumination and the lifetime incidence of depression and mania in people with BD. Williams et al. (2007) proposed that the act of rumination contributes towards OGAM by interfering with the top-down process of retrieving a specific event memory.

With regards to impaired executive control, Conway and Pleydell-Pearce (2000) argue that the retrieval of specific AMs is an effortful task requiring limited executive functioning resources; for instance, to carry out a search process, to inhibit the retrieval of irrelevant memories and to hold the final search result in mind. In support this; there exists a curvilinear relationship between age and AM specificity, such that, the capacity to generate specific AMs emerges at the age of three or four, alongside the development of supervisor control processes (Fivush & Nelson, 2004), and decreases in older adults with impaired working memory (Winthorpe & Rabbitt, 1988). However, some studies have failed to find a relationship between executive functions and OGAM (e.g. Williams & Broadbent, 1986; Williams & Scott, 1988), leading researchers to explore the idea that the capacity to retrieve specific AMs might be dependent on executive subprocesses, as opposed to executive function in general. In particular, research has shown that OGAM is associated with failures of inhibitory control. Indeed, the capacity to retrieve a specific AM requires the inhibition of innumerable competing AMs. Consistent with this, three of the studies included in this

review (Boulanger et al., 2014; Kim et al., 2014) examined the relationship between OGAM and several cognitive domains in people with BD. These studies found that executive functions were associated with OGAM and Boulanger et al. (2014) showed that the inhibition contributes independently to AM specificity. In addition, these studies highlighted an association between OGAM and verbal fluency. Thus, the capacity to generate specific AMs relies on the capacity to carry out rapid searches whilst inhibiting competing information.

In sum, although originally created to explain OGAM in people with depression (William et al., 2007), the mechanisms proposed in the CaRFAX model seem to fit with preliminary evidence for OGAM in people with BD. However, research is yet to consider how rumination might play a role - this is an area that warrants future investigation.

Unimpaired Features of AM

The findings from this review highlight that there are features of AM that are unimpaired in people with BD; for instance, recall latency (Scott et al., 2000), vividness (Gruber et al. 2009), emotional valence (King et al., 2013) and emotional intensity (Boulanger et al., 2014). In addition, two studies showed that semantic AM is intact in BD (Oertel-Knockel et al., 2012; Shimizu et al., 2009), which provides further evidence for a distinction between episodic and semantic AM. Much of the evidence for this distinction comes from clinically motivated research. For instance, Tulving, Schacter, McLachlan and Moscovitch (1988) presented the case of KC, who was unable to recall a single autobiographical event from his life and yet could recall fragmentary autobiographical knowledge. A similar pattern of findings has also been reported in a case of transient global amnesia (Evans, Wilson, Wraight & Hodges, 1993), and on a larger scale, Greene, Hodges and Baddeley (1995) found that people in the earliest stages of Alzheimer's disease show a decline in their ability to access personal incident memory and yet not personal semantic memory. Ageing research has also proved to be fruitful in providing support for the distinction - episodic AM tends to show a temporal gradient with age whilst semantic AM does not (e.g., Levine et al., 2002;

Piolino et al., 2002). It is suggested that this pattern arises due to higher-level cognitive representations being more vulnerable to disruption than lower-level representations (Cohen, 2000).

LIMITATIONS AND FUTURE DIRECTIONS

The number of studies included in this review was relatively small, although comparable to similar reviews of AM in depression (Liu, Li, Xiao, Yang & Jiang, 2013; Van Vreeswijk & De Wilde, 2004) and schizophrenia spectrum disorder (Berna et al., 2016; Ricarte et al., 2017). In addition, methods used to assess AM parameters differed across studies, such that only a small number of studies could be directly compared. This level of heterogeneity makes it difficult for firm conclusions to be made and thus the findings presented in this review should be interpreted with some degree of caution. This review also omitted grey literature from the systematic search process, which means it is possible that studies included were subject to publication bias.

With regards to the limitations of the existing literature, most studies used relatively small samples of people with BD; the average number of BD participants in each study was 29.24. Small samples lead to limited power to detect group differences; this was particularly notable in the study that found no evidence for OGAM in people with BD (Quinlivan et al., 2017). However, results revealed moderate to large effect sizes for specificity of AMs, and the finding was robust across cueing procedures. Thus, demonstrating that BD is associated with an impaired ability to retrieve personal event memories. However, the heterogeneity of the study samples makes interpretation challenging. Indeed, it is well established that mood at the time of encoding and retrieval impacts on AM, and mood state was highly variable across the samples included in this review. Of course, this is reflective of the nature of BD, in which people experience profound, and sometimes rapid, fluctuations in mood. Much of the research presented here measured AM in people who were euthymic at the time of testing, thus the area would benefit from a more comprehensive overview of AM during periods of depression and mania. It would also be fruitful for future research to further

explore distinctions between AM according to mood state at the time of encoding. In particular, the relationship between AM and mania warrants further investigation, particularly in light of relatively recent research showing AM distinctions in undergraduate students who present with hypomanic personality features relative to undergraduate students who do not (McGill & Moulds, 2014; Robyn, Ghisletta & Van der Linden, 2012).

There is a lack of research examining the causes and consequences of OGAM in BD. Much of the research presented here is cross-sectional and thus prevents inferences regarding a causal relationship between over-generality and BD. For instance, it is not clear whether OGAM is a consequence of BD, or whether it is a cognitive deficit that increases vulnerability to developing the disorder. Longitudinal studies measuring AM and the development of emotional disorders are necessary to shed light on this. With regards to examining the psychosocial consequences of OGAM, research in depression has shown associations with poor problem solving (Evans et al., 1993; Goddard, Dritschel & Burton, 1996, 1997; Raes, Herman, Williams, Demyttenaere, Sabbe, Pieters et al., 2005), difficulties imagining future autobiographical events (Williams et al., 1996) and delayed recovery from psychopathology (Brittlebank, Scott, Willliams & Ferrier, 1993; Dalgleish, Spinks, Yiend & Kuyken, 2001; Harvey, Bryant & Dang, 1998; Peeters Wessel, Merckelbach & Boon-Vermeeren, 2002). Two studies included in this review examined the relationship between OGAM and problem solving (Boulanger et al., 2013; Scott et al., 2000); both found a significant negative relationship between these two variables. During the search process, two studies were found that considered future autobiographical event prediction (Boulanger et al., 2013; King et al., 2011); only one study met the inclusion criteria for this review (Boulanger et al., 2013), but both showed that participants with BD generate fewer specific positive and negative future events. Given the implications on psychosocial wellbeing, future research would benefit from a greater exploration of these associated deficits, as well as a consideration of the role of AM deficits in predicting recovery from BD.

CLINICAL IMPLICATIONS

Although this is a relatively small-scale review and the quality of the evidence was mixed, its findings have some clinical relevance, particularly with regards to the phenomenon of OGAM. In particular, the idea that OGAM might be related to the onset and maintenance of BD warrants further investigation, as additional evidence for such a relationship could point towards a need for cognitive remediation interventions that target OGAM. Promisingly, research shows that it is possible to enhance the specificity of AMs (e.g. Ricarte, Hernández-Viadel, Latorre & Ros, 2012; Watkins & Teasdale, 2001, 2004; Watkins, Teasdale & Williams, 2000) and mindfulness based cognitive therapy (MBCT; Segal, Teasdale, Williams & Gemar, 2002), which is effective in reducing risk of relapse in people with depression, reduces over-generality in AM (Williams, Teasdale, Segal & Soulsby, 2000). It might also be important to further explore AM in subclinical groups of people with trait vulnerabilities to developing BD, as converging evidence for distinct AM impairments in this group could have implications for investigating associations between remediation strategies that target AM and the incidence of symptoms reaching clinical threshold. Finally, it is well established that there exists an inextricable link between AM and sense of self thus any deficit in AM points towards possible impairments in identity. This warrants investigation in the context of a coherent and consistent sense of self being crucial to maintaining psychological well-being (Conway, 2005). Indeed, the relationship between self and memory in people with emotional disorders is examined in the empirical research project that is presented in the following chapter of this thesis.

CONCLUSION

In sum, this review systematically identified studies that describe features of autobiographical memory in people with bipolar disorder. Several approaches were applied in attempts to answer this question and findings point towards a deficit in the specificity of episodic AMs alongside relative preservation of other AM features. This is a relatively new area of research that requires much additional investigation. If additional evidence was to be found, then longitudinal research to tease apart the directionality of the relationship between BD and OGAM could prove to be useful. In our view, an exploration of the relationship between AM and mania also warrants attention, as this was particularly absent in the current literature. Converging evidence for OGAM deficits in BD would also clarify whether cognitive remediation research that explores the capacity for AM targeted interventions to improve symptomatology in people with BD is warranted.

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APPENDICES

Appendix 1. Newcastle-Ottawa Quality Assessment Scale

NEWCASTLE - OTTAWA QUALITY ASSESSMENT SCALE

CASE-CONTROL STUDIES

Note: A study can be awarded a maximum of one star (*) for each numbered item within the Selection and Exposure categories. A maximum of two stars can be given for Comparability.

Selection

- 1) Is the case definition adequate?
- a) yes, with independent validation *
- b) yes, e.g., record linkage or based on self reports
- c) no description
- 2) Representativeness of the cases
- a) consecutive or obviously representative series of cases *
- b) potential for selection biases or not stated
- 3) Selection of Controls
- a) community controls *
- b) hospital controls
- c) no description
- 4) Definition of Controls
- a) no history of disease (endpoint) *
- b) no description of source

Comparability

| 1) Comparability of cases and controls on the basis of the design or analysis | | | |
|---|---|--|--|
| a) study controls for | _(Select the most important factor.) * | | |
| b) study controls for any additional fac | etor * (This criteria could be modified to indicate | | |
| specific control for a second important | factor.) | | |
| | | | |
| Exposure | | | |
| 1) Ascertainment of exposure | | | |
| a) secure record (eg surgical records) * | k | | |
| b) structured interview where blind to | case/control status * | | |
| c) interview not blinded to case/contro | l status | | |
| d) written self report or medical record | lonly | | |
| e) no description | | | |
| | | | |
| 2) Same method of ascertainment for c | eases and controls | | |
| a) yes * | | | |
| b) no | | | |
| | | | |
| 3) Non-Response rate | | | |
| a) same rate for both groups * | | | |
| b) non respondents described | | | |
| c) rate different and no designation | | | |

Appendix 2. Quality assessment ratings for case-control studies

| Study | Selection | Comparability | Exposure |
|------------------------------|-----------|---------------|----------|
| Quinlivan et al. (2017) | **** | ** | *** |
| Young et al. (2016) | *** | ** | *** |
| Boulanger et al. (2014) | **** | ** | ** |
| Van der Gucht | *** | ** | ** |
| Scott et al. (2000) | ** | * | ** |
| Kim et al. (2014) | ** | ** | ** |
| Mowlds et al. (2010) | *** | * | * |
| Tzemou & Birchwood (2007) | **** | * | * |
| Mansell & Lam (2004) | ** | * | *** |
| Shimizu et al. (2009) | ** | * | *** |
| Oertel-Knochel et al. (2012) | ** | ** | * |

| Study | Selection | Comparability | Exposure |
|----------------------|-----------|---------------|----------|
| | | | |
| King et al. (2013) | *** | * | ** |
| | | | |
| Gruber et al. (2009) | **** | ** | ** |
| | | | |

EMPIRICAL RESEARCH PROJECT

WHO AM I? EXPLORING THE RELATIONSHIP BETWEEN THE SELF AND AUTOBIOGRAPHICAL MEMORY IN PEOPLE WITH PSYCHOSIS

Supervised by Dr. Vaughan Bell and Dr. Rebecca Kelly

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ABSTRACT

One long-standing theory of psychosis is that it represents a disturbance to the self. In other conditions, impairment in autobiographical memory (AM) has been cited as central to maintaining a disrupted and disordered sense of self. The present research tested the hypothesis that if there is a relationship between the self and AM in psychosis, then recall of an AM should influence the accessibility of self-statements, as has been shown in participants without psychosis. Forty-two people with psychosis took part in the present study; half gave a description of an autobiographical memory and half gave a description of a control topic with no relevance to the self. Next, participants completed the I Am Fluency Task, in which they generated as many self-defining statements as possible within a given time. Measures were also included to explore the relationship between memory and other aspects of the self, as well as between the self, AM and psychological well-being. Findings showed that people with psychosis were able to generate self-statements and were most likely to conceptualise themselves in relation to positive trait self-knowledge, yet there was no benefit of AM recall on the accessibility of self-statements. Findings lend support to the idea that the process of grounding the self in AM might be disrupted in psychosis.

INTRODUCTION

"What lies behind the symptoms is a tormented self... The clinical symptoms come and go, but this nothingness of the self is permanently there"

Kean, 2009

Psychosis is an umbrella term for a severe mental health disorder, in which delusions and hallucinations present alongside disorganised thinking, negative symptoms (e.g. diminished emotional expression and decreased motivation) and abnormal motor behaviour (American Psychiatric Association, 2013). Psychotic features manifest in a variety of medical and mental health conditions and typically emerge in late adolescence or early adulthood; the peak age of onset is reported to be late 20s for females and early to mid-20s for males (McGrath, Saha, Chant & Welham, 2008). Schizophrenia and bipolar disorder are the most predominant psychotic disorders and have typically been considered to have poor prognoses. Indeed, schizophrenia is a leading cause of disability and is associated with impairments in cognition (Tarbox & Pogue-Geile, 2008) and social functioning (Haug, Øie, Andreassen, Bratlien, Raballo, Nelson et al., 2014), as well as increased likelihood of medical illness, hospitalisations, homelessness, unemployment and premature mortality. Schizophrenia is also associated with risk-related behaviour and suicidal ideation; approximately 20% of people with schizophrenia attempt suicide and research shows that the incidence of risk increases following a psychotic episode (Hawton, Sutton, Haw, Sinclair & Deeks, 2005).

Despite the complexity of psychosis, there is a drive to move away from the conceptualisation of this as a chronic lifelong dysfunction and instead to focus on recovery; with regards to psychosis, it is now widely accepted that recovery can be achieved, or at the least meaningfully moved towards (Lysaker, Glynn, Wilkniss & Silverstein, 2010; Morrison, Law, Barrowclough, Bentall, Haddock, Jones et al., 2016). Recovery has become the expected outcome from mental health interventions and is conceptualised as considerably more than the absence of clinical symptoms (for a report on psychological approaches to understanding and promoting recovery

in psychosis, see Morrison et al., 2016). For instance, people with psychosis perceive recovery to be a process that involves re-establishing hope and rebuilding life, and the concept of self-focused recovery and of rebuilding the self are frequently described (e.g. Wood, Price, Morrison & Haddock, 2010, 2013). There is also research that supports the idea that recovery necessitates change in the experience of the self (e.g. Davidson, 2003; France & Uhlin, 2006; Lysaker and Lysaker, 2011; Resnick, Rosenheck & Lehman, 2004; Silverstein & Bellack, 2008).

Self-Disturbance in Psychotic Disorders

It is well established that self-disorders are a core symptom of psychosis. Indeed, the earliest accounts of schizophrenia described fundamental deficits in personality (Bleuler, 1911) and self-consciousness (Kraepelin, 1987; Berze, 1914). More recently, researchers such as Sass, Parnas and Nelson have argued that self-disturbance is a psychopathological trait marker of psychosis (e.g. Nelson, Yung, Bechdolf & McGorry, 2007; Parnas, Handest, Jansson & Sæbye, 2005; Parnas, 2003; Sass & Parnas, 2003; Sass, 1992) that is particularly notable in schizophrenia spectrum disorders (e.g. Haug, Lien, Raballo, Bratlien, Øie, Andreassen et al., 2012; Nelson, Thompson & Yung, 2012; Raballo & Parnas, 2012), but also present in psychotic bipolar disorder (Haug et al., 2014; Parnas, Handest, Sæbye and Jansson, 2003). However, the self is a multi-faceted construct that is notoriously difficult to define and measure, thus it is necessary to consider which aspects of the self are compromised.

Parnas (2003) identifies three levels of selfhood, the first being the basic awareness of having a sense of self and of experiences being "my" experiences. The second, more explicit, level involves the persistent experience of being one unified self over time. At the final level is the narrative self, which refers to the capacity to reflect on and describe one's own personality and characteristics. It is suggested that psychosis involves a disturbance at each level and that disturbance at the most basic, phenomenological level of the self results in various "anomalous subjective experiences" (for detailed descriptions, see Parnas & Sass, 2001; Parnas, 2003; Sass, 2001). For instance, disturbances of the basic self include stream of consciousness, in which ownership of mental content is disturbed (e.g. thought insertion and thought broadcasting);

corporeality, in which distance emerges between the self and bodily experiences; self-demarcation, in which boundaries between the self and others are disorganized; presence, that is, a sense that the "mineness" of experiences no longer exists and existential reorientation, in which individuals develop preoccupation with philosophical, supernatural, and meta physical themes in response to a breakdown of normal self-experience and subsequent attempts to incorporate anomalous experiences into existing schema (e.g. Parnas et al., 2005; Parnas & Handest, 2003). Nelson, Thompson & Yung (2012) have also demonstrated that anomalous self-experiences in those at ultra-high risk for psychosis predict time to transition to full threshold psychotic disorder. This is crucial in the context of identifying individuals in prodromal and preonset stages of psychosis and subsequently delaying or minimising the onset of symptoms.

With regards to the second and third levels of selfhood (as described by Parnas, 2003), the experience of a consistent and coherent sense of self is fragmented in schizophrenia (Boulanger, Dethier, Gendre & Blairy, 2013) and life narratives lack ownership and a sense of personal agency relative to those of healthy controls (Lysaker & Lysaker, 2002). Trait self-descriptions are also compromised in spite of the fact that they are generally more robust than phenomenological aspects of the self (e.g. Duval, Desgranges, de La Sayette, Belliard, Eustache & Piolino, 2012; Klein & Lax, 2010). For instance, they are less clearly defined and more variable over time in people with schizophrenia relative to healthy controls (Boulanger et al., 2013; Klein, Altinyazar & Metz, 2013; Nieznański, 2003). However, Klein et al. (2013) emphasised the importance of acknowledging that schizophrenia does not eliminate one's ability to provide descriptions of the self.

As highlighted above, there are aspects of recovery from psychosis that are not necessarily related to the amelioration of symptoms. Experts by experience describe self-change, rebuilding the self and developing positive self-beliefs as important components of recovery (e.g. Wood et al., 2010). Self-disturbances also positively correlate with pre-onset social dysfunction, positive and negative symptoms of schizophrenia, diagnostic severity, and suicidality (Haug et al., 2014; Parnas, Raballo, Handest, Vollmer-Larsen & Sæbye, 2011; Raballo, Sæbye & Parnas, 2009;

Skodlar & Parnas, 2010). Thus, studies exploring the mechanisms of self-disturbance, as well as means of strengthening sense of self, are warranted to improve prognosis, quality of life and recovery outcomes for people with psychosis. In the context of a wealth of research demonstrating that the self and autobiographical memory are intimately linked (e.g., Addis & Tippett, 2004; Bennouna-Greene, Conway, Rathbone, Vidailhet & Danion, 2012; Cuervo-Lombard, Jovenin, Hedelin, Rizzo-Peter, Conway & Danion, 2007; Hemsley, 1998; Raffard, D'Argembeau, Lardi, Bayard, Boulenger, Boulenger et al., 2009), research over the past decade has paid increasing attention to the role that autobiographical memory might play in the onset and maintenance of self-related disorders.

AUTOBIOGRAPHICAL MEMORY AND PSYCHOSIS

The term autobiographical memory (AM) refers to knowledge of personal facts and memories of events from one's own life (Conway, 1996). Generally speaking, AM can be separated into episodic and semantic components (e.g. Baddeley, 1992; Brewer, 1996; Conway, 1996; Conway & Bekerian, 1987; Larsen, 1992; Robinson & Swanson, 1990; Schacter, 1996). Episodic AM describes memory for personal past events that are specific in time and place, whereas semantic AM describes memory for personal facts (e.g. I was born in Yorkshire). Research provides convincing evidence that AM deficits are features of psychotic disorders. For instance, Feinstein, Goldberg, Nowlin and Weinberger (1998) found that people with schizophrenia are particularly impaired in recalling episodic events from early adulthood, which is the fundamental in the context of identity development (Rathbone, Moulin & Conway, 2008). Impairments in recalling AMs from recent times have also been found (Elvevåg, Kerbs, Malley, Seeley & Goldberg, 2003), which could imply that people with psychosis will find it difficult to update their sense of self in the context of transitional life events, such as, gaining employment, going to university or leaving hospital.

With regards to the nature of AM impairments, recent meta-analyses demonstrate a particular deficit in the ability to recall specific AMs in people with schizophrenia spectrum disorders.

Impairments in richness of detail and conscious recollection have also been documented

(Cuervo-Lombard et al., 2007; Danion, Cuervo, Piolino, Huron, Riutort, Peretti & Eustache, 2005) and there is mounting evidence that over-general AM is a feature of bipolar disorder (Boulanger et al., 2014; Kim et al., 2014; Mansell & Lam, 2004; Mowlds et al., 2010; Oertel-Knöchel et al., 2012; Scott et al., 2000; Shimizu et al., 2009; Tzemou & Birchwood, 2007; Van der Gucht et al., 2009; Young et al., 2016). Overall, it is suggested that AM impairment should be regarded as a major cognitive deficit in schizophrenia (for meta-analyses see Berna et al., 2017; Ricarte et al., 2017), yet there is limited research exploring the relationship between the self and AM in this clinical group.

THE SELF AND AUTOBIOGRAPHICAL MEMORY

From a cognitive viewpoint, the most influential model to consider the relationship between the self and memory is the Self Memory System (SMS; Conway and Pleydell-Pearce, 2000). This model suggests that there is bidirectional relationship between the self and AM, such that, memories guide knowledge and understanding of the self to tether self to reality, yet one's current self-concept determines the AM's that are encoded and retrieved at any given time. The SMS describes how memories and the self are integrated to maintain a sense of self that is coherent and consistent over time and across contexts, and this capacity is considered to be crucial in maintaining psychological well-being (Conway, 2005).

In general, research supports this idea of an inextricable link between the self and AM. For instance, Addis and Tippett (2004) showed that AMs from childhood and adulthood are associated with the strength and quality of identity in people with Alzheimer's disease. An individual's most accessible AMs cluster around times when a new self-image is formed (Rathbone et al., 2008) and, more recently, Charlesworth, Allen, Havelka and Moulin (2016) have demonstrated that it is possible to use autobiographical retrieval to increase access to self-concept statements in undergraduate participants. Participants in this study wrote a description of a personally relevant memory or a control topic (of no relevance to the self), following which they completed the I Am Fluency Task, in which they had one minute to generate as many self-defining "I am" statements as possible. Findings showed that AM retrieval increases access to

self-statements, as participants engaging in autobiographical retrieval generated significantly more statements than those in the control condition. There was also an impact of AM on the content of the conceptual self, as there was a particular increase in the proportion of psychological, trait like descriptions of the self following AM retrieval.

Given evidence from studies in other clinical populations, researchers have argued that disturbances in self-perception in psychosis may be due to the fact that the self may not be grounded in AMs in the way that it is in healthy controls. For instance, Raffard, D'Argembeau, Lardi, Bayard and Boulenger (2009; 2010) showed that people with schizophrenia find it difficult to reflect on how self-defining memories have influenced their current self. The link between AMs and self-statements is also weakened in people with schizophrenia and the AMs that do ground self-statements are less specific and less consciously recollected than those of controls (Bennouna-Greene et al., 2012).

THE CURRENT STUDY

For a long time, research in this area was encumbered by attempts to conceptualise the self as a unified construct, yet it is now widely accepted that the self is multifaceted (for reviews, see Klein, 2010, Klein & Gangi, 2010). As highlighted above, research on the self in psychosis has focused on the phenomenological aspects of self, that is, the experience of "me-ness" and of the self across time and context. Less attention has been paid to the self-statements that people use to describe their identity (Boulanger et al., 2013). Of the research that has explored self-statements, the focus has been on schizophrenia, as opposed to psychotic disorders more generally. In response, the current research used the I Am Fluency Task (Charlesworth et al., 2016) to explore the relationship between AM and self-statements in people with psychosis. Unlike much of the previous research examining self-knowledge in this clinical group, this task is open-ended and thus allows for both quantitative and qualitative exploration of self, whilst preserving the subjective and idiosyncratic nature of this construct.

This study tested the hypothesis that if there is a relationship between the self and AM in this clinical group, then recall of an AM should increase access to self-statements, as has been shown

in undergraduate participants without psychosis (Charlesworth et al., 2016). However, if self-statements are not grounded in AM in people with psychosis, as has been previously suggested (e.g. Bennouna-Greene et al., 2012), then there should be no benefit of AM recall on the accessibility of *I am* statements. To examine the relationship between the self and AM further, the participants and the experimenter rated the relatedness of AMs and *I am* statements and measures of self-concept strength and clarity were included to examine how AM retrieval might impact on various aspects of the self. Consistent with the idea that self is necessary to maintain psychological well-being, measures of anxiety and depression were also included, and several additional exploratory analyses are reported to further explore moderators and alternative measures of self-disturbance in the experimental task.

METHOD

The research was conducted in the South London and Maudsley NHS Foundation Trust and the study was given full ethical approval before testing began (London-Dulwich Research Ethics Committee; reference 17/LO/0398, see Appendix 1). All participants were provided with an information sheet (see Appendix 2) and consent was obtained before testing began (see Appendix 3).

PARTICIPANTS

42 participants aged 20-59 took part in this research (mean age = 38.95, SD = 11.70). 28 participants were male and 14 were female. All participants had experienced a psychotic episode and had received a formal diagnosis of schizophrenia spectrum or other psychotic disorder according to ICD-10 criteria (schizophrenia, N = 27, bipolar disorder with psychotic features, N = 10, depression with psychotic features, N = 20, schizoaffective disorder, N = 10, drug-induced psychosis, N = 10, psychotic disorder, N = 10. Diagnosis was given by a consultant psychiatrist during the current admission or at a previous time point and was ascertained by reviewing participants' health records. 32 participants were hospital inpatients at the time of testing and 10 participants were living in the community. Participants were excluded if they had language or

comprehension deficits and if they did not speak English fluently. Only participants who were able to provide informed consent were included in this sample.

In a between-subjects design, participants were allocated to either the autobiographical memory condition (n = 21) or the control condition (n = 21). Assignment to a condition was alternated between participants, such that the first participant took part in the AM condition, the second took part in the control condition, and so on, to avoid experimenter bias and ensure that groups were matched in size.

MATERIALS AND PROCEDURE

The procedure was based on that of Charlesworth et al. (2016) but adapted for use with a population of people with psychosis. Participants were tested in a one-off, face-to-face session with the researcher that lasted approximately 45 minutes. All instructions were read aloud by the experimenter and the participants gave all responses verbally to avoid excluding participants who were unable to read or write. The tasks are described in the order in which they were completed by participants.

AUTOBIOGRAPHICAL MEMORY MANIPULATION

Participants were assigned to an autobiographical memory (AM) condition or a control condition. In the AM condition, participants were instructed to recall a personal event memory (see Appendix 4). Specifically, they were asked to provide an account of a specific personal event that occurred at a particular time and place and lasted for no longer than one day. Participants were encouraged to recall a vivid memory that they would describe in detail for five minutes. Prompts were also used to maximise the time that participants spent reminiscing. Specifically, prompts were given in instances where participants said that they had finished recalling their memory ahead of the allocated five minutes. The prompts used were similar to those frequently used in autobiographical memory research, such as, who were you with at the time? How did you feel? Do you remember any thoughts that you had at the time? Can you recall what you could see/hear/smell/taste/feel? With prompting, 18 of the 21 participants in this condition were able to recall a specific AM, but seven participants were unable to describe their AM for five minutes. All memories were audio recorded to allow for transcription and analysis.

In the control condition, participants were instructed to provide a description of the solar system (as in Charlesworth et al., 2016, see Appendix 5), as this relies on recall from semantic memory and is unlikely to cue recall of self-relevant memories related to this topic. Specifically, participants were instructed to provide a factual description that did

not include personal details. They were encouraged to recall defining features of the solar system but were assured that this was not a test and that they should not worry about whether the details they provided were 100% accurate. As in the AM condition, prompts were used to maximise the time that participants spent providing a description. For instance, participants were prompted to describe the objects in the solar system in relation to size, shape and colour. Twenty participants were able to describe the solar system for five minutes, the remaining participant requested to stop following four and a half minutes. Ten participants made references related to the self e.g. *my favourite film is Armageddon, I used to enjoy looking at pictures of planets in a science magazine, my sister taught me about the order of the planets in relation to distance from the sun.* At these times, participants were reminded that they should not include personal details in their descriptions.

Regardless of condition, all participants completed the following tasks in the order in which they are described below.

I AM FLUENCY TASK

To explore the impact of autobiographical retrieval on the accessibility of self-statements, the *I Am Fluency Task* (Charlesworth et al., 2016, see Appendix 6) was administered. Participants were asked to produce statements to describe stable and enduring aspects of their personality in the form of statements that they felt were essential to defining who they are. To maximise understanding of the task instructions, participants were told that they might include roles, personality traits or physical traits and were given an example of what the Queen might say (e.g. "I am short, I am polite, I am a grandma"). Participants were asked to generate *I am* statements as quickly as possible and were given two minutes to do so. Two minutes were given, as opposed to one minute that was given in the original task; due to the fact executive function deficits are well documented in people with psychosis. However, the experimenter noted the

number of statements generated in one minute to allow for comparisons with the original study.

SELF-CONCEPT CLARITY SCALE

The Self-Concept Clarity Scale (SCCS; Campbell, Trapnell, Heine, Katz, Lavallee & Lehman, 1996, See Appendix 7) was administered next. This measure consists of 12 items that allow for assessment of the extent to which an individual's self-concept is stable over time, clearly defined and internally consistent (e.g. "I spend a lot of time wondering about what kind of person I really am", "If I were asked to describe my personality, my description might end up being different from one day to another day"). Participants were presented with a five-point Likert scale, ranging from strongly disagree to strongly agree, and were instructed to give the response that was most relevant for each statement.

SENSE OF SELF SCALE

The final self-measure was the Sense of Self Scale (SOSS; Flury & Ickes, 2007, see Appendix 8), which is a 12 item measure that examines four aspects of a weak sense of self; specifically, lack of understanding of one's self, sudden shifts in ones feelings, opinions and values, the tendency to confuse ones thoughts and feelings with those of others and the feeling that one's existence is tenuous. As above, items were responded to on a 5-point scale ranging from strongly disagree to strongly agree.

It was important for the three self-related measures to be administered immediately after the descriptive task, to explore the impact of AM recall on different aspects of the self, but at this point participants were offered a break of up to 30 minutes.

I AM RATINGS

Next, the experimenter revisited the *I am* statements and instructed participants to rate each one in terms of importance (i.e. how important is it to you to be a psychologist, friendly, brunette etc.) and emotional valence (how positive or negative do you feel

about being a psychologist, friendly, brunette etc.) (see Appendix 9). Responses for both of these tasks were given on a scale of 1–10, with 10 being very important/very positive and 1 being not important at all/very negative. To explore whether autobiographical retrieval increases access to related self-statements, or self-statements in general, participants were then asked to highlight the degree to which each *I am* statement was related to the description that they gave of either an autobiographical memory or the solar system (e.g. a memory of going to your first lecture might be related to the statement *I am a student*, but unrelated to the statement *I am tall*). It was predicted that ratings of relatedness between *I am*'s and the solar system would be low and that this would demonstrate the usefulness of the solar system as a control topic. As above, responses were given on a scale of 1-10, with 10 being highly related and 1 being totally unrelated.

CONTROL FLUENCY TASKS

As the task of primary interest involved generating self-statements under time pressure, several control fluency tasks were administered to examine possible group differences in general fluency speed (see Appendix 10). Category fluency was assessed by asking participants to name as many animals as they could in two minutes. Letter fluency was assessed using the FAS Controlled Oral Word Association Test (Benton, 1969). In which participants were asked to generate as many words as they could beginning with the letter 'F', then 'A' and finally 'S'; a total letter fluency score was generated by averaging the number of words generated in response to each letter. As in the *I Am Fluency Task*, participants were given two minutes for each task.

PSYCHOLOGICAL WELLBEING MEASURES

To explore the relationship between the self and psychological wellbeing, all participants completed the Beck Depression Inventory (BDI-II, Beck, Steer & Brown, 1996, see Appendix 11) and the Beck Anxiety Inventory (BAI, Beck & Steer, 1990, see Appendix 12). These questionnaires are well validated and widely used assessment tools

for depression (for a review of the psychometric properties of the BDI-II, see Storch, Roberti & Roth, 2004) and anxiety (for a review of the psychometric properties of the BAI, see Fydrich, Dowdall & Chambless, 1992). Both measures include 21 multiple-choice items to assess the presence of psychopathological symptoms.

DATA CODING

To allow for an exploration into the types of statements generated by participants, data was coded according to three categories; physical, social and psychological (as in Charlesworth et al., 2016). An *I am* statement was coded as psychological if it referred to a personality trait that was subjective in nature (e.g. *I am nice, I am a good friend, I am reserved*), physical if it referred to a physical attribute that tended to be apparent from appearance (e.g. *female, pale, brunette*) and social if it described a social category and was objectively verifiable (e.g. *student, Irish, friend*). The experimenter and one independent judge (a postgraduate student who was blind to the hypothesis) carried out coding. Post coding comparisons revealed an excellent degree of inter-rater reliability (see Results section).

STATISTICAL ANALYSES

A power analysis was conducted using G*Power software to calculate the minimum number of participants required for the present study to detect a large effect (Cohen's d) of 0.80. A medium to large effect size was expected following findings from previous research by Charlesworth et al. (2016) that showed an effect size of d = 0.74 using a similar methodology. Setting α at 0.05 for a two-sided test with power set at 80% indicated a sample size of 42 (21 per group).

All other statistical analysis was carried out using Statistical Package for the Social Sciences (SPSS) version 24. Where data was missing, SPSS excluded the participant's data for that particular test only. It should be noted that participants varied in their ability to describe specific AMs (see page 86 for additional details), yet all participant data is

included in the analysis described below to explore the feasibility of using AMs to strengthen sense of self in people with psychosis regardless of AM functioning. A series of independent t tests was used to assess group differences according to each outcome measure and a 2 x 3 (condition x statement type) mixed design ANOVA was used to explore group differences in the type of I am statement generated by participants. Pearson's correlation was used to explore the relationship between the three self-measures (I Am Fluency Task, SOSS, SCCS), as well as the relationships between these self-measures and measures of clinical symptoms of anxiety and depression (BDI, BAI). To determine inter-rater reliability for I am statement type and experimenter relatedness ratings, intraclass correlation coefficient (ICC) estimates and their 95% confident intervals were calculated based on average measures, absolute-agreement, 2-way mixed-effects model.

Preliminary checks were carried out to test normality assumptions. In instances where assumptions of normality were violated, outliers were removed, and the analysis was rerun; however, this did not affect any of the findings and therefore outliers are included in the data reported below. Levene's test was used to test for the homogeneity of variances and in instances where the null hypothesis of equal variances of the two group was rejected, the unpooled variances and corrected degrees of freedom were used in the *t* test calculation. Where appropriate, Bonferroni adjustments were also made to counteract the effect of multiple comparisons on statistical power.

RESULTS

Demographic and clinical characteristics of the two groups are presented in Table 1.

TABLE 1; DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF THE STUDY SAMPLE

| | | AM | Control |
|--------------------|----------|----------------|---------------|
| | | 7 1111 | Control |
| Sex | Female | n = 7 | <i>n</i> = 7 |
| | Male | <i>n</i> = 14 | <i>n</i> = 14 |
| Age | | 38.81 (10.58)* | 39.10 (12.99) |
| Years of education | | 13.24 (2.17) | 14.14 (1.93) |
| Verbal fluency | Letter | 14.10 (7.68) | 17.10 (5.92) |
| | Category | 24.00 (10.25) | 24.75 (9.32) |
| BDI | | 12.57 (10.64) | 14.43 (10.22) |
| BAI | | 17.10 (18.10) | 19.67 (15.10) |
| | | | |

Note. n = number of participants, * values represent mean (standard deviation).

Independent t tests revealed no group differences in age (t (38.43) = -0.8, p = 0.94, d = -0.02, CI [-7.68, 7.11]), years of education (t (40) = -1.43, p = 0.16, d = -0.44, CI [-2.18, 0.38]), general fluency (category; t (39) = -.25, p = 0.81 d = -.08, CI [-6.95, 5.45] and letter; t (37.42) = -1.41, p = 0.17, d = -0.44, CI [-7.33, 1.32]), anxiety (t (40) = -0.50, p = 0.62, d = -0.15, CI [-12.94, 7.80]) or depression (t (40) = -0.58, p = 0.57, d = -0.18, CI [-8.36, 4,65]).

I AM FLUENCY TASK

NUMBER OF STATEMENTS

A total of 561 *I am* statements were collected from people with psychosis; 271 were generated by participants in the autobiographical memory (AM) condition and 290 were generated by those in the control condition. On average, participants in the AM condition generated 12.90 (SD = 5.99) *I am* statements in two minutes, and participants in the control condition generated 13.81 (SD = 4.33) 1 . An independent *t* test revealed no group differences (t (40) = -0.56, p = 0.58, d = 0.14, CI [-4.17, 2.36]) demonstrating no effect of memory manipulation on the accessibility of self-statements. As highlighted above, there were also no group differences in general fluency speed (in both instances, p > .10)

Participants rated the importance and emotional valence of each *I am* statement on 10-point Likert scales; higher scores represented statements that were rated as more positive and more identity defining (Table 2).

TABLE 2; MEAN (SD) RATINGS ASSIGNED TO I AM STATEMENTS

| | Importance | Valence |
|---------|-------------|-------------|
| AM | 8.45 (1.23) | 8.36 (1.30) |
| Control | 7.31 (1.70) | 7.26 (1.73) |

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¹ The number of I am statements generated in one minute was also recorded to allow for comparisons with previous research using the I Am Fluency Task. Participants in the AM condition generated 8.43 (SD = 3.64) statements in one minute and those in the control condition generated 8.76 (SD = 2.93). As was the case with two-minute fluency, analysis revealed no significant group difference (t (40) = -.33, p = 0.75, d = 0.10, CI [-2.39, 1.72]). Previous research with undergraduate students revealed that those in the AM condition generated 9.38 (SD = 2.02) I am statements in one minute and that those in the control condition generated 7.92 (SD = 1.91) statements in one minute.

Independent t tests revealed significant group differences; participants in the AM condition generated self-statements that they rated as more identity defining (t (40) = 2.47, p = 0.018, d = 0.77, CI [0.21, 2.06]) and more positive (t (40) =2.34, p = 0.024, d = 0.72, CI [0.15, 2.06]) than did those in the control condition, suggesting that memory manipulation had an impact on the way in which participants reflected on their self-statements.

THEMATIC LINK BETWEEN AMS AND I AM'S

The final ratings assigned to I am statements examined the relatedness of the description given (of an AM or the solar system) and the subsequently generated self-statements, that is, each I am statement was given a rating that ranged from 1 to 10 (1 = not at all related and 10 = very much related). The experimenters also rated relatedness and average relatedness ratings are presented in Table 3.

TABLE 3; PARTICIPANT AND EXPERIMENTER RATINGS OF RELATEDNESS

| _ | Participant | Experimenter |
|---------|-------------|--------------|
| AM | 6.48 (2.69) | 3.40 (1.60) |
| Control | 5.66 (3.54) | 1.25 (0.28) |

Analysis revealed no significant group difference between the relatedness ratings given by participants (t (37) = 0.82, p = 0.42, d = 0.26, CI [-1.18, 2.80]), such that, participants perceived the solar system to be as related to identity statements as they did AMs. However, the relatedness as assessed by the experimenters was significantly higher for AMs relative to the solar system (t (40) = 6.04, p < .001, d = 1.87, CI [1.43, 2.86]). There were also significant differences between ratings generated by participants and those given by experimenters. The experimenters rated the solar system descriptions as significantly less related to self-statements than did controls (t (17) = 5.30, p < .001, d = 1.76, CI [2.64, 6.13])). The experimenters also rated AMs and self-statements as

significantly less related than did controls (t (20) = 5.35, p < .001, d = 1.39, CI [1.87, 4.26]². A second independent judge who was blind to the hypotheses also provided reliability ratings for approximately 10% of the participants (n = 6). ICC analysis revealed an excellent degree of inter-rater reliability (ICC = .804, 95% CI [-.841, .973]).

SELF-STATEMENT TYPE

To examine the types of statements that participants generated, the mean proportion of physical, social and psychological statements was calculated (Figure 1).

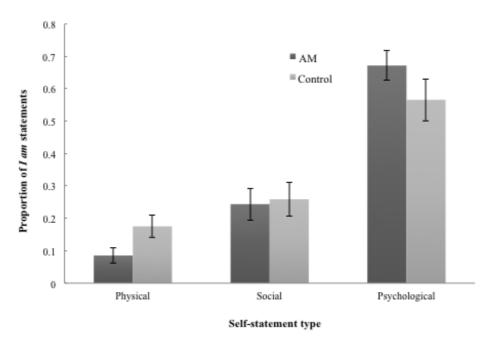


FIGURE 1; MEAN PROPORTION OF PHYSICAL, SOCIAL AND PSYCHOLOGICAL STATEMENTS GENERATED BY PARTICIPANTS IN EACH EXPERIMENTAL CONDITION. ERROR BARS REPRESENT STANDARD ERROR OF THE MEAN

Next, the type of statement generated by participants in each condition was examined using a 2 x 3 (condition x statement type) mixed design ANOVA, allowing for the incidence of an interaction between condition and statement type to be explored. The

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² These findings remain significant when using Bonferroni corrected levels of significance levels (in this case, p < .0125) to counteract multiple comparisons.

main effect of group was not significant, due to the fact that proportional data was used and thus the three statement types summed to 1 across groups. There was a main effect of statement type $(F(1.43, 57.05) = 38.90, p < .001, n^2 = 0.49)$, but the condition x statement type interaction $(F(1.43, 57.05^3) = 1.47, p = 0.24, n^2 = 0.04)$ was not significant. Bonferroni pairwise comparisons revealed that participants generated significantly more psychological statements than physical (p < .001) or social (p < .001)statements. Participants were also significantly more likely to generate social statements than physical ones (p = 0.024). A second independent judge who was blind to the hypotheses coded data; an excellent degree of reliability was found between the proportion of statements coded as physical (ICC = .995, 95% CI [.990, .997]), social (ICC = .990, 95% CI [.980, .995]) and psychological (ICC = .994, 95% CI [.988, .997]). Qualitatively, there were interesting findings in relation to the self-statements generated by people with psychosis. For instance, several participants generated statements that were conflicting in nature. Examples of contradictory statements included; creativedestructive, admired-hated, leader-servant, kind-confrontational, traveller-part of a community, extrovert-shy, patient-impatient, lover-fighter, caring-aggressive, simplecomplicated, offensive-polite, good looking-ugly, miserable-happy, aggressive-kind hearted, happy-sad. Participants also generated statements that lacked certainty e.g. a bit of a loner, easy going at times, generally happy, slightly sexist, and often generated statements that deviated from the typical I am format e.g. I watch sports, I love dogs, I believe in reincarnation, I have lived in children's homes, I know what I want from life, I get on well with people, I look like the core of the world, I can get depressed, I like Cyndy Lauper. However, due to the subjective and idiosyncratic nature of the self, the decision was made to not exclude such statements.

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³ Mauchley's test of sphericity indicated unequal variances (p < .001), so Greenhouse-Geisser corrected degrees of freedom are reported here.

OTHER SELF-MEASURES

Following the *I Am Fluency Task*, participants completed the Sense of Self Scale (SOSS) to assess self-concept strength and the Self Concept Clarity Scale (SCCS) to determine self-concept clarity. Findings are presented in Table 4.

TABLE 4; MEAN (SD) SCORES ON THE SOSS AND THE SCCS

| | SOSS | SCCS |
|---------|--------------|---------------|
| AM | 40.76 (9.94) | 37.57 (7.22) |
| Control | 37.29 (9.72) | 36.76 (10.53) |

Independent t tests revealed no group differences between scores on the SOSS (t (40) = 1.15, p = 0.26, d = 0.35, CI [-2.66, 9.61]) or the SCCS (t (40) = 0.29, p = 0.77, d = 0.09, CI [-4.82, 6.44]). Therefore, scores were collapsed across groups and correlational analysis was used to explore the relationship between the three self-measures used in this study. Analysis showed no correlation between sense of self and the number of I am statements generated (r = .26, p = 0.09), there was also no correlation between I am fluency and self-concept clarity (r = .24, p = 0.12). However, there was a moderate to large positive correlation between the SOSS and the SCCS (r = 0.66, p < .001).

THE SELF AND PSYCHOLOGICAL WELL-BEING

All participants completed the BDI and BAI to measure the severity of symptoms of anxiety and depression. Findings showed that five participants were experiencing mild levels of depression at the time of testing; depression was borderline in six participants, moderate in six participants and severe in four participants. The remaining 21 participants scored within the normal range on the BDI. With regards to the BAI, 28 participants were experiencing a low level of anxiety at the time of testing; anxiety was

moderate in seven participants and potentially concerning in seven participants. In relation to groups, findings are presented in Table 5.

TABLE 5; MEAN (SD) SCORES ON THE BDI AND THE BAI

| | BDI | BAI |
|---------|---------------|---------------|
| AM | 12.57 (10.64) | 17.10 (18.05) |
| Control | 14.43 (10.22) | 19.67 (15.06) |

As highlighted above, there were no group differences between scores on the BDI or the BAI (in both instances, p > .50). Therefore, scores were collapsed across groups and correlational analyses were used to examine the idea that disturbances in self-perception are related to impairments in psychological wellbeing. Analysis showed no correlation between *I am* fluency and depression or anxiety (in both instances, p > .17). However, there was a significant correlation between depression and self-concept clarity, and depression and sense of self, such that, lower levels of depression were associated with greater self-clarity (r = -.38, p = 0.01) and a stronger sense of self (r = -.58, p < .001). With regards to anxiety, lower levels of anxiety were associated with a stronger sense of self (r = -.40, p = .01), but there was no association between anxiety and self-concept clarity (p = 0.09).

AUTOBIOGRAPHICAL MEMORIES

All participants in the AM condition were instructed to recall a specific AM. 18 participants were able to generate a specific AM, although some participants generated a categorical memory in the first instance and required prompting to access a specific event. Three participants were unable to access a specific AM despite prompting; these participants provided a categorical AM instead. All but one participant required prompting to give a description that lasted for five minutes. Even with prompting, seven

participants were unable to talk about an AM for the entire time and nine participants required prompting within the first minute. Eight participants generated memories that were positively valenced, 11 generated AMs that were negative, and two were considered to be neutral. Most of the memories also included references to other people, just four of the memories involved the individual acting alone. Several events could be perceived to be significant and identity defining, for instance, birth of first child, death of father, mother leaving, child's baptism, being made homeless and appearing in court, whereas others were more typical events, such as, buying an ice cream, visiting a museum, getting the flu jab, going on a festival ride, attending a lecture and walking in the park.

DISCUSSION

This study provided an experimental evaluation of the relationship between the self and autobiographical memory (AM) in people with psychosis. In particular, it tested the following hypothesis; if there is a relationship between the self and AM, then recall of an AM should increase access to self-statements relative to the recall of semantic knowledge that is unrelated to the self, as has been shown in participants without psychosis (Charlesworth et al., 2016). However, findings showed no benefit of AM recall on the accessibility of self-statements. There was also no group difference between the relatedness ratings generated by participants, that is, the solar system (control topic) was perceived to be as related to self-statements as AMs. In contrast, experimenter ratings of relatedness were significantly higher for AMs relative to the control topic. Across groups, participants were most likely to describe the self in relation to trait-like descriptions and there was no impact of AM on the type of statement generated; however, those in the AM condition rated self-statements as more positive and more identity defining than did those in the control condition. With regards to other aspects of the self, there were no group differences in self-concept clarity or sense of self. Relationships were found between the self and clinical symptoms, such that,

depression was associated with reduced self-clarity and a weaker sense of self. Lower levels of anxiety were also moderately associated with a stronger sense of self, but there was no association between anxiety and self-concept clarity.

THE GROUNDING OF THE SELF IN PSYCHOSIS

The fact that AM did not increase access to the self could be interpreted in relation to the suggestion that the process of grounding the self in AM is disrupted in psychosis. This is particularly true in the context of previous research showing that the retrieval of a personally relevant memory significantly increases access to self-statements in a healthy population (Charlesworth et al., 2016). Findings from the present study are also consistent with those of Bennouna-Greene et al. (2012) who showed that the strength of the association between *I am* statements and related AMs is weaker in people with schizophrenia relative to controls. Minkowski (1927) proposed that the detachment of the self from reality is the fundamental deficit in schizophrenia. Consistent with this idea, the present research found no difference between the perceived relatedness of the self and AMs and the relatedness of the self and the solar system. In contrast, experimenter ratings of relatedness were significantly higher in the AM condition relative to the control condition. There was also a significant difference between I am and AM relatedness ratings generated by participants and those generated by the experimenter, such that, participants perceived the two to be significantly more related than did the experimenter. Indeed, previous research has shown that participants with schizophrenia are unaware of impoverished self-coherence and over-estimate the relatedness of the self and AM (Bennouna-Greene et al., 2012).

Overall, the relatedness ratings given by people with psychosis were high and this could be interpreted in relation to several psychological models of psychosis, such as, the dopamine salience hypothesis (Kapur, 2003). This hypothesis suggests that dysregulation of the dopamine system leads people to view anomalous experiences as novel, salient and personally relevant (Kapur, Mizrahi & Li, 2005). A self-focused

cognitive style has also been well-documented in people with psychosis (e.g. Freeman, Dunn, Fowler, Bebbington, Kuipers, Emsley et al., 2013). In particular, the tendency to relate negative or ambiguous material to the self is an information processing bias that is thought to maintain abnormal beliefs and persecutory delusions in people with psychosis (Higgins, 1987). Indeed, Bentall, Kinderman and Kaney (1994) proposed that "persecutory delusions may be associated with a fundamental disorder of the self-concept" (p.334). Alternatively, it is possible that high relatedness ratings were a consequence of the methodology used in the present study i.e. the nature of asking participants whether their self-statements were related to their description of either an AM or the solar system cued socially desirable responses. To explore this, it would be fruitful for future research to repeat this task with participants with no history of self-related disturbance. In addition, future research might explore relatedness by asking participants to generate qualifying statements i.e. in what way is the *I am* statement related to the AM you described?

The process of grounding the self in AM is thought to require frontal/executive functions (Benounna-Greene et al., 2012; Conway and Pleydell-Pearce, 2000) that are known to be impaired in schizophrenia, such as, working memory, mental flexibility and selective attention (e.g. Johnson-Selfridge & Zalewski, 2001). In particular, Bennouna-Greene et al. (2012) showed that self-images are typically grounded by memories that are consciously remembered i.e. accompanied by a sense of reliving, and it is widely accepted that executive dysfunction accounts for impairments in conscious recollection (e.g. Piolino, Desgranges, Manning, North, Jokic & Eustache, 2007; Piolino, Coste, Martinelli, Macé, Quinette, Guillery-Girard et al., 2010). Thus, impaired conscious awareness might explain the finding that autobiographical reverie had no influence over the retrieval of self-statements. Indeed, the absence of a basic sense of "me-ness" at the time of encoding might disrupt the capacity for typical organisation within the SMS.

PSYCHOSIS AND SELF-KNOWLEDGE

It is important to note that people with psychosis were able to generate statements to describe their sense of self and that the number generated was comparable to that generated by healthy controls (see Charlesworth et al., 2016). This finding is consistent with those of Klein et al. (2013) who argued that trait self-knowledge is relatively preserved in schizophrenia. Indeed, self-knowledge is generally found to be more robust in clinical groups than other aspects of the self (e.g. Duval et al., 2012; Klein, Chan & Loftus, 1999; Klein, Loftus & Kihlstrom, 2002; Klein, Rozendal & Cosmides, 2002; Tulving, 1993). However, the present study attempted to reduce the demands of the I Am Fluency Task, by offering specific examples of *I am* statements during the task instructions and it is likely that those examples acted as cues. In addition, the present study did not assess the accuracy or reliability of the self-statements generated, thus it is difficult to conclude whether the statements generated gave a depiction of the self that was consistent with reality. Participants often generated statements that did not conform to the typical I am format (e.g. I believe in reincarnation, I have lived in children's homes, I can get depressed). Due to the subjective and idiosyncratic nature of the self, such statements were not excluded from the analysis; however, this tendency to deviate from task instructions was more notable in the present population relative to others previously tested by the researcher. This finding may indicate that while there is no fundamental deficit in accessing self-statements in people with psychosis, there are qualitative differences in the self relative to controls.

The finding that participants are most likely to describe the self in relation to psychological traits is consistent with previous research, but unlike previous findings, there was no additional benefit of autobiographical reverie on the accessibility of trait-like descriptors of the self (Charlesworth et al., 2016), which further suggests some degree of uncoupling between the two cognitive constructs. Overall, self-statements were predominately trait-based and positive, which is a replication of findings described

by Benounna-Greene et al. (2015) and suggests that people with psychosis maintain a positive perception of the self. AM retrieval also had a positive impact on self-perception insofar as it increased participants' views of their self-statements as identity defining and positive. This finding has clinical implications regarding the potential value of incorporating narrative work (e.g. supporting people to co-author a new life story that emphasises personal strengths and values) into treatment.

To our knowledge, this is one of a few studies to use an open-ended measure of selfstatements in psychosis, thus allowing qualitative exploration of the statements that people use to describe their identity. Of note, more than a quarter of the participants in the current study (26.19%) generated statements that were contradictory in nature (e.g. creative-destructive, patient-impatient, simple-complicated, offensive-polite). This is consistent with the findings of Gruba & Johnson (1974) and similarly, de Bonis, Boek, Lida-Pulik and Féline (1995) found that people with schizophrenia report a higher proportion of opposing self-statements than do healthy controls. This somewhat contradicts Conway and Pleydell-Pearce's (2000) conceptualisation of the self as consistent and coherent over time and represents a form of cognitive dissonance that could link with aforementioned experiences that are central to psychosis (e.g. impairments in the experience of being one unified self over time). On the other hand, it is widely acknowledged that the self is changeable across time and contexts; for instance, a female in a room filled with males is significantly more likely to reference gender in self-description tasks (McGuire & Padawer-Singer, 1976). In addition, a person who defines herself as "kind" is likely to be able to recall several occasions in which she was unkind. Thus, it might be suggested that this contradiction relates to a deficit in integrating information about the self in psychosis. In relation to this, Hemsley (2005) proposes that the experience of schizophrenia arises from the failure to integrate "contextually appropriate stored material with current sensory input" (p. 43). Thus,

discrepancies within one's current experience of the self could arise from a failure to encode self-relevant events in the context of stored material about the self.

LIMITATIONS AND IMPLICATIONS

Conclusions based on the absence of a significant effect should be interpreted with caution. Indeed, the absence of significant findings in the present study could relate to the relatively small sample size or the heterogeneity of the sample in terms of diagnosis and the severity and chronicity of illness. However, analysis revealed a small effect of AM on the accessibility of self-statements in people with psychosis (d = 0.14), whereas previous research has shown a moderate to large affect in undergraduate students (d = 0.72), which goes some way in increasing our confidence in the null hypothesis. As highlighted above, the implications would be strengthened by converging evidence and the repetition of several tasks with participants with no history of self-related disturbance. Indeed, all participants in this study had received a diagnosis of a psychotic illness and thus it is not possible to draw conclusions about the nature of self-statements or relatedness ratings relative to the general population. However, anecdotal evidence from the researcher's experience of administering the I Am Fluency Task to people without psychosis suggests that the content of self-statements might be unique in this group, which would be an interesting area for future investigation.

One of the aims of this study was to test the feasibility of using the *I Am Fluency Task* with people with psychosis, thus the sample was a diagnostically mixed group. This reflects the nature of psychosis, yet could have clouded the study findings and contributed to the small effect reported above. Future research might explore this further by examining particular diagnostic groups (e.g. schizophrenia spectrum disorder) or by including a measure of psychotic symptomatology. Psychotic symptoms were not measured in this instance, as the methodology was novel and the experimenters were keen to minimise the demands of the testing session. However, testing took less time than anticipated and many participants reported that they enjoyed

taking part, thus adding a measure of psychotic symptoms is likely to be acceptable to participants in future research.

Research of this kind does not shed light on causation. Thus, it is not possible to make assumptions regarding whether AM impairments lead to the development of self-disturbances, or whether basic self-disturbance interrupts the encoding and retrieval of AM. Indeed, research on the self and memory tends to be encumbered by difficulties in disentangling the relationship between the two constructs. In addition, this study provides no implications regarding how deficits might contribute to the onset or maintenance of psychotic disorders. Longitudinal research, as well as research with prodromal and ultra-high-risk populations, would be fruitful in terms of disentangling the nature of the self-memory relationship in people with psychosis.

Despite the limitations, findings do provide additional evidence for the multifaceted nature of the self and the idea that some aspects of self are more affected than others in those who experience psychosis. It is suggested that interventions aimed at strengthening the association between the self and AM (e.g. narrative approaches) would be warranted if converging evidence for a disruption in this relationship were found. Indeed, Conway (2005) maintains that a coherent and consistent sense of self over time is crucial to maintain psychological well-being and consistent with this, the findings of the present study showed that there exists a moderate association between certain aspects of the self and clinical symptomatology. In particular, sense of self was negatively correlated with anxiety and depression. Overall, the development of a coherent life story that is tethered to reality and related to self-knowledge could promote recovery in people with psychosis (Bennouna-Greene et al., 2012; Lysaker, Bryson, & Bell, 2002; Singer, 2005).

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APPENDICES

Appendix 1. Ethical approval



Email: hra.approval@nhs.net

Dr Lara Charlesworth Trainee Clinical Psychologist

South London and Maudsley NHS Foundation Trust Addiction Sciences Building Institute of Psychiatry, Psychology & Neuroscience 4 Windsor Walk, London SE5 8AF

18 April 2017 - reissued 24 April 2017 to include consent form

Dear Dr Charlesworth,

Letter of HRA Approval

Study title: Does autobiographical memory increase access to the

self in people with psychosis?

IRAS project ID: 215653 REC reference: 17/LO/0398

Sponsor King's College London

I am pleased to confirm that <u>HRA Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read** Appendix B **carefully**, in particular the following sections:

 Participating NHS organisations in England – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities

- Confirmation of capacity and capability this confirms whether or not each
 type of participating NHS organisation in England is expected to give formal
 confirmation of capacity and capability. Where formal confirmation is not
 expected, the section also provides details on the time limit given to
 participating organisations to opt out of the study, or request additional time,
 before their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A List of documents reviewed during HRA assessment
- B Summary of HRA assessment

After HRA Approval

The document "After Ethical Review – guidance for sponsors and investigators", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- · Registration of research
- · Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics
 Committee, as detailed in the After Ethical Review document. Non substantial amendments should be submitted for review by the HRA using the
 form provided on the HRA website, and emailed to hra.amendments@nhs.net.

 The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **215653**. Please quote this on all correspondence.

Yours sincerely

Michael Pate

Assessor

Email: hra.approval@nhs.net

Copy to: Mr Keith Brennan – King's College London – Sponsor contact

Ms Jennifer Liebscher - South London and Maudsley NHS

Foundation Trust – Lead NHS R&D contact.

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

| Document | Version | Date |
|--|---------|------------------|
| Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [CAG approval] | 1 | 21 February 2017 |
| Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [Sponsorship approval] | 1 | 21 February 2017 |
| Copies of advertisement materials for research participants [Recruitment poster] | 4 | 27 March 2017 |
| Copies of advertisement materials for research participants [Recruitment poster] | 2 | 21 February 2017 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [KCL insurance] | | 10 February 2017 |
| IRAS Application Form [IRAS_Form_13022017] | | 13 February 2017 |
| Non-validated questionnaire [I Am Fluency Task] | 2 | 21 February 2017 |
| Participant information sheet (PIS) [PIS] | 4 | 24 March 2017 |
| Participant consent form [Consent form] | 3 | 04 February 2017 |
| Referee's report or other scientific critique report [Reviewers report] | 1 | 04 November 2016 |
| Research protocol or project proposal [Protocol] | 4 | 24 March 2017 |
| Summary CV for Chief Investigator (CI) [CV] | 1 | 06 February 2017 |
| Summary CV for student [Chief Investigator - CV] | 1 | 09 November 2016 |
| Summary CV for supervisor (student research) [Supervisor CV] | 1 | 09 November 2016 |
| Summary CV for supervisor (student research) [Supervisor CV] | | 10 February 2017 |
| Validated questionnaire [BDI-II] | 1 | 06 February 2017 |
| Validated questionnaire [BAI] | 1 | 06 February 2017 |
| Validated questionnaire [Self Concept Clarity Scale] | | 10 February 2017 |
| Validated questionnaire [Sense of Self Scale] | | 10 February 2017 |

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in

England, please refer to the, participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Mr Keith Brennan

Tel: 0207 848 7960

Email: keith.brennan@kcl.ac.uk

HRA assessment criteria

| Section | HRA Assessment Criteria | Compliant with Standards | Comments |
|---------|---|--------------------------|---|
| 1.1 | IRAS application completed correctly | Yes | No comments |
| 2.1 | Participant information/consent documents and consent process | Yes | No comments |
| 3.1 | Protocol assessment | Yes | No comments |
| 4.1 | Allocation of responsibilities and rights are agreed and documented | Yes | This is a single site study where that site is a co-sponsor. Therefore, no agreement would be expected. |
| 4.2 | Insurance/indemnity arrangements assessed | Yes | Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this |
| Section | HRA Assessment Criteria | Compliant with Standards | Comments |

| | | | research study |
|-----|---|-------------------|---|
| 4.3 | Financial arrangements assessed | Yes | This study is conducted for partfulfilment of the Doctorate in Clinical Psychology thesis – it will receive £1000 funding from the Institute of Psychiatry, Psychology and Neuroscience for this purpose. As the site is working under joint arrangements, it is expected that the funding arrangements have been agreed between the parties. |
| | | | |
| 5.1 | Compliance with the Data Protection Act and data security issues assessed | Yes | No comments |
| 5.2 | CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed | Not Applicable | No comments |
| 5.3 | Compliance with any applicable laws or regulations | Yes | No comments |
| 6.1 | NHS Research Ethics Committee favourable opinion received for applicable studies | Yes | No comments |
| 6.2 | CTIMPS – Clinical Trials Authorisation (CTA) letter received | Not Applicable | No comments |
| 6.3 | Devices – MHRA notice of no objection received | Not Applicable | No comments |
| 6.4 | Other regulatory approvals and authorisations received | Not Applicable | No comments |

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

One participating site, conducting all activities as per the protocol; therefore, one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

This is a single site study co-sponsored by the site. The R&D office will confirm to the CI when the study can start.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A local Principal Investigator should be in place at site, and has been identified as the doctorate student.

No additional training is expected of the student, in order to conduct this study.

GCP training is <u>not</u> a generic training expectation, in line with the <u>HRA statement on training expectations</u>.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

All researchers hold a contract with the single participating site, thus no letters of access or Honorary Research Contracts are expected.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

☐ The applicant has indicated that they <u>do not intend</u> to apply for inclusion on the NIHR CRN Portfolio.





Date

PIS Version 4 24.03.17 IRAS Project ID: 215653

Exploring the impact of autobiographical memory on the self in psychosis

Participant Information Sheet

Invitation and brief summary

Thank you for taking the time to read this information sheet. You are being invited to take part in a research project that explores the relationship between our memories from the past and the way that we define ourselves in the present. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and if you have any questions please feel free to ask. After you have read and discussed this information sheet with the researcher you will have at least 24 hours to decide if you would like to take part.

Why is this research important?

There is a lot of evidence to suggest that sense of self is impaired in people with psychosis, this is important because having a strong sense of self has been shown to be important in maintaining psychological health and well-being. It is hoped that findings from this research will highlight a potential means by which self might be strengthened in people with psychosis.

To ensure that the aims of this project meet the needs of service user, expert service users have been consulted regarding the design of the study. The Psychological Interventions Clinic for outpatients with Psychosis (PICuP, at the Maudsley Hospital) also has two service users who act as peer support workers, providing advice and guidance to researchers carrying out projects with people with psychosis. They will be consulted on how findings from this study might be applicable to improving patient care.

What would taking part involve?

If you are interested in taking part you will meet with a researcher to complete the study. The meeting will take place either at an NHS site or at King's College London at a time and place most convenient for you. It might also be possible to carry out testing in your own home if travelling to a research site is difficult for you. It is important that you are aware that taking part in this study will have no impact on the standard care that you receive.

When taking part you will be asked to do a series of short tasks, lasting no more than a few minutes each. Firstly, you will be given a participant number and then asked to talk about a topic chosen by the researcher. It is important that you understand that we definitely do not expect you to talk about anything that you would not be comfortable sharing.

Next, you will be asked to complete questionnaires that ask about your sense of self and identity. The final task will be for you to complete two short questionnaires that measure symptoms of anxiety and depression. The experimenter will talk you through each stage of the study and be with you to answer any questions you may have. The session should last no more than one hour in total, or up to 90 minutes if you would like a break. However, it is important for you to remember that you can stop taking part at any time without having to give a reason.

Why have I been invited to take part?

Participants are being recruited from services that provide care for people who have experienced psychosis; we will be recruiting around 48 people to take part in this study. You are being invited to take part because a member of your care team has informed us that you are happy to be contacted by someone in our research team. Alternatively, you may have been contacted as your name is on a research register that you have agreed to be part of, or because you saw this study advertised in a poster and contacted us for more information. At this point, we have no further information about you.

Do I have to take part?

You do not have to take part in this research; it is completely up to you whether you decide to take part or not. If you decide to take part you will be asked to sign a consent form to say that you are happy to do so. If you decide to take part you can change your mind at any point and leave the study without having to give a reason for doing so. A decision to not take part, or to withdraw from taking part at any time, will not affect any aspect of your current or future care.

Will I be reimbursed for taking part?

We are offering £15 to compensate people who volunteer their time to participate. You can choose to receive this as cash or as a voucher if you prefer. It should also be possible for any travel expenses to be reimbursed, please discuss this with the researcher.

What are the potential benefits of taking part?

We cannot guarantee any specific treatment benefits from taking part in this study. However, it is hoped that findings will be valuable in suggesting ways in which we might improve the mental health and wellbeing of people with psychosis in the future.

What are the potential disadvantages of taking part?

It is not anticipated that there is any potential risk to taking part in this research; however, recalling memories from our past can be an emotional experience and so it is important that you consider this before agreeing to take part. If you do find the experience upsetting we can talk to your care team on your behalf to have someone discuss it with you if this would be helpful.

Will anyone be able to find out what answers I give?

Firstly, we will not tell your doctor or clinical team what answers you give. They are entirely confidential. The only exception to this is if you tell us something that suggests there is an immediate risk to your safety or someone else's safety, then we have to pass the information on to your clinical team.

All data is stored anonymously with no personal details. This is how we do it:

A small part of the session will be voice recorded on a recording device that is password protected. One of the researchers will type up the information in the recording, but they will not include any information that could identify you, such as names, addresses or personal details. The recording will then be deleted. Instead of your name or personal details, the typed-up recording and the answers you give on the questionnaires will be given a unique participant number so no one can work out who gave these answers.

We store the information sheets or any contact details separately from the participant numbers so after the recording is deleted the information you have provided will be anonymous.

All of the data from this study will be stored in an office on King's College London premises; the office is accessible only by swipe card and is protected by 24-hour security.

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 favourable opinion by the London-Dulwich Research Ethics Committee.

Further information

If you do decide to take part it is important that you are aware of a few things. First of all, this study has received full ethical approval from the NHS Research Ethics Committee (ref number 17/LO/0398). Secondly, you have the right to withdraw from this research at any time and without giving a reason. If you choose to withdraw you can request that any data that has been collected be discarded.

We anticipate that the results of the study will be published in an international academic journal, presented at conferences and shared with other academic peers. Quotations from the study might be included in write-ups of the results if appropriate; however, no names or personal details will ever be included. We will also send you a summary of the results of this study once we have them.

This project is being carried out as part of the researcher's Doctorate in Clinical Psychology at the Institute of Psychiatry, Psychology and Neuroscience, King's College London. The project is also funded by King's College London. The project is supervised by Dr Vaughan Bell (vaughan.bell@kcl.ac.uk) and Dr Rebecca Kelly (rebecca.kelly@slam.nhs.uk) who work within the South London and Mausdley NHS Foundation Trust to provide treatment and support for people with psychosis. The supervisors have reviewed the scientific quality of this study on multiple occasions and they have contributed substantially to the design and methodology of the study. Furthermore, members of the academic/research team on the Doctorate in Clinical Psychology have independently reviewed and approved the research.

Thank you very much for taking the time to read this information sheet. After you have taken part in this study there will be an opportunity for you to ask more questions and for the researcher to give you more information if you would like. This information sheet is yours to keep and if you have any questions after taking part please feel free to contact me using the email address below.

Lara Charlesworth

Trainee Clinical Psychologist

Email: lara.charlesworth@kcl.ac.uk

Telephone: 07391 187771

Please note.

If you have a concern about any aspect of this study, you can ask to speak to the researchers who will do their best to answer your questions (email: lara.charlesworth@kcl.ac.uk).

If you would prefer to speak to someone who is not part of the research team then you can contact the South London and Maudsley Patient Advice and Liaison Service (PALS) on freephone 0800 731 2864 or by email at pals@slam.nhs.uk.

If you remain unhappy and wish to complain formally, you can do this by contacting Dr Gill Dale, Director of Research Quality; Head, Joint R&D Office of South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, Psychology & Neuroscience (POO5, Institute of Psychiatry, Psychology & Neuroscience, King's College London, De Crespigny Park, London SE5 8AF).





| a | TA T | 1 |
|----------|------|-------|
| Centre | NIII | nher: |

Study Number:

Participant Identification Number:

Exploring the impact of autobiographical memory on the self in psychosis

Researcher: Lara Charlesworth

CONSENT FORM

- 1. You are invited to take part in a research study that will involve answering some questions and completing some brief questionnaires. The aim of this study is to explore a way in which sense of self might be strengthened in people with psychosis.
- 2. You will have been given a participant information sheet (version 4), which describes the purposes of the study and what your participation will involve. This information sheet is for you to keep and refer to. Please read it before deciding whether or not to participate and giving your consent.
- 3. Please ask the researcher any questions you may have about this project before you decide whether you would like to participate.
- 4. If you decide, now or at any stage, that you do not wish to participate in this research, this is entirely your right and your treatment will not be affected at all.

| | | | | | Please ini | tial boxes |
|--|------------|-------------------------------------|--------------------|-----------------|------------|------------|
| I confirm that I have r for the above study. | ead the in | formation sheet | dated 24.03.17 | (version 4) | | |
| for the above study. | | | | | | |
| I have had the opportu have had these answer | | | mation, ask ques | tions and | | |
| I understand that my p withdraw at any time v legal rights being affect request that all of my of | without gi | ving any reasor derstand that if | n, without my me | dical care or | | |
| I am over 18 years of | age at the | time of signing | | | | |
| I am happy for my res anonymised, and for q ups of the research res | uotations | from my answe | | | | |
| I am happy for my dat London. | a to be he | ld by the resear | rch team at King's | s College | | |
| I understand that the a could identify me be r so I cannot be identified | emoved a | nd all the data v | will be stored ano | | | |
| | | | | | | |
| I agree to take part in | the above | study. | | | | |
| | | | | | | |
| Name (participant) | | Date | | Signature | | |
| Name (researcher) | _ | Date | | Signature | _ | |
| If you are currently an signature | inpatient | in hospital, we | also require som | eone to witness | s your | |
| Name (witness) | — Date | | Signati | ıre | | |

Appendix 4. Autobiographical memory instructions

<u>Autobiographical memory instructions</u>

I want you to tell me about a memory of a specific event that has happened in your life. The memory should be 1) of an event that occurred at a particular time and place 2) it should have lasted no longer than one day 3) it should be a memory from your life that you remember very clearly because I'm going to ask you to tell me about it in as much detail as you can, so keep in mind that this should be a memory that you feel comfortable in sharing.

I'll give you a minute to think of a memory and then you will have five minutes to tell me about it, in as much detail as possible, as if you were telling a story.

< Record 5 minutes >

Recall time:

Prompts

If the memory is too general provide the following cues;

- 1. Where were you at the time?
- 2. What were you doing?
- 3. Who was there?
- 4. How did you feel?
- 5. What were you thinking?
- 6. What could you see, hear, smell, taste, feel?

Appendix 5. Control topic instructions

Control instructions

I want you to tell me as much as you can about the solar system. The description you give should be a factual one and should not include any personal details. For instance, think of defining features or any facts that you know about the solar system, such as, the solar system consists of the sun and planets like Mars. Don't worry about whether or not the things that you tell me are 100% accurate, this is not a test, I just want you to just tell me as much as you can.

I'll give you a couple of minutes to think about what you know and then you will have five minutes to tell me about it, in as much detail as possible. You should imagine that I am a person who has never heard of the solar system before and tell me all that you can about it.

| < | Record | l 5 | minutes | > |
|---|--------|-----|---------|---|
|---|--------|-----|---------|---|

Recall time:

Prompts

If the description is too general provide the following cues;

- 1. What sorts of things are there in the solar system (other than planets)?
- 2. How big is the solar system and how big are the things in it?
- 3. How would you describe what the solar system looks like?
- 4. How would you describe colours, shapes etc.?
- 5. Do you know anything about temperatures/the weather in the solar system?
- 6. Can people travel around it?

I Am Fluency Task

Read the following instructions to participants;

I would like you to think of words that describe you and tell me as many of these words as you can. Each thing you tell me about yourself should start with the words 'I am' and be short statements of just one or two words. Please try to make them words that describe your identity, rather than just how you feel today. So the words might describe your roles, personality traits or physical traits. For example, if the Queen was doing this task she might say I am the Queen, I am short and I am kind.

Try to do this as quickly as you can, you will have two minutes to tell me as many of these words as possible.

< Time 2 minutes >

Appendix 7. Self-Concept Clarity Scale

Self-Concept Clarity Scale

| 1. | My beliefs about | myself often co | nflict with one ar | nother.* | |
|----|---|----------------------|-------------------------------|--------------------|----------------|
| | 1 | 2 | 3 | 4 | 5 |
| | Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| 2. | On one day I migh have a different o | • | nion of myself an | d on another d | ay I might |
| | 1 | 2 | 3 | 4 | 5 |
| | Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| 3. | I spend a lot of tir | ne wondering a | bout what kind c | of person I really | y am.* |
| | 1 | 2 | 3 | 4 | 5 |
| | Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| 4. | Sometimes I feel t | that I am not rea | ally the person th | nat I appear to I | oe.* |
| | 1 | 2 | 3 | 4 | 5 |
| | Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| 5. | When I think about what I was really | | erson I have beer | n in the past, I'n | n not sure |
| | 1 | 2 | 3 | 4 | 5 |
| | Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |

| 1 | 2 | 3 | 4 | 5 |
|------------------------|--------------------------------------|---------------------------------|-----------------|-----------------|
| Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| 7. Sometimes I th | ink I know other | people better tha | an I know mys | elf. * |
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| 8. My beliefs abou | ut myself seem t | o change very fre | quently.* | |
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| | to describe my p one day to anoth | personality, my de ner day.* | escription migh | nt end up being |
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| 10. Even if I wanted | d to, I don't thinl | ι I could tell some | eone what I'm | really like.* |
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| 11. In general, I have | ve a clear sense | of who I am and v | what I am. | |
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | Disagree somewhat | Neither agree nor disagree | Agree | Strongly Agree |
| | | - | | |

6. I rarely experience conflict between the different aspects of my personality.

12. It is often hard for me to make up my mind about things because I don't really know what I want.*

1 2 3 4 5

Strongly Disagree Neither agree Agree Strongly Agree disagree somewhat nor disagree

Scale ranges from 1 (strongly disagree) to 5 (strongly agree).

^{*} Indicates reverse-keyed item.

Appendix 8. Sense of Self Scale

Sense of Self Scale (Flury & Ickes, 2007)

Below are a number of statements concerning your personal attitudes and characteristics. Please listen to each statement and consider the extent to which you agree or disagree with it.

- 1 strongly disagree
- 2 disagree somewhat
- 3- neither agree nor disagree
- 4 agree somewhat
- 5 strongly agree

| 1. | I wish I were more consistent in my feelings |
|-----|---|
| 2. | It's hard for me to figure out my own personality, interests, and opinions. |
| 3. | I often think how fragile my existence is |
| 4. | I have a pretty good sense of what my long-term goals are in life |
| 5. | I sometimes wonder if people can actually see me |
| 6. | Other people's thoughts and feelings seem to carry greater weight than my own. |
| | |
| 7. | I have a clear and definite sense of who I am and what I'm all about. |
| 8. | It bothers me that my personality doesn't seem to be well defined. |
| 9. | I'm not sure that I can understand or put much trust in my thoughts and feelings. |
| | |
| 10. | Who am I? is a question that I ask myself a lot |
| 11. | I need other people to help me understand what I think or how I feel |

12. I tend to be very sure of myself and stick to my own preferences even when the

group I am with expresses different preferences. _____

Appendix 9. I am ratings task

Read the following instructions to participants:

A little while ago, I asked you to tell me as many words as you could think of that describe you. Now I would like you to give some ratings to those words.

First of all, I would like to know how important each I am statement is to you. On a scale of 1 to 10, with 10 being very important and 1 being not important at all, how important is <read statement >?

<Record responses in column 1>

Next, I would like to know whether these words describe things that you like about yourself, or things that you don't like about yourself. On a scale of 1 to 10, with 10 being like very much and 1 being don't like at all, how much do you like <read statement>?

<Record responses in column 2>

Finally, I would like to know whether any of the I am statements are linked to the AM that you recalled. So if one of my I am's was I am a friend and the memory was of a friends birthday party those two would be linked. There is no right or wrong answer here, I just want your opinion on whether they are linked.

Record participant responses in the "I am" column below.

| | l am | 1 | 2 | 3 |
|----|------|---|---|---|
| | | | | |
| 1 | | | | |
| 2 | | | | |
| 3 | | | | |
| 4 | | | | |
| 5 | | | | |
| 6 | | | | |
| 7 | | | | |
| 8 | | | | |
| 9 | | | | |
| 10 | | | | |
| 11 | | | | |
| 12 | | | | |
| 13 | | | | |
| 14 | | | | |
| 15 | | | | |
| 16 | | | | |
| 17 | | | | |
| 18 | | | | |
| 19 | | | | |
| 20 | | | | |
| 21 | | | | |
| 22 | | | | |

Appendix 10. Verbal fluency tasks

Verbal fluency

Category

For this task all you have to do is think about different kinds of animals and say as many different kinds as you can. Please do this as quickly as possible as you have only two minutes.

| < time 2 | ! minutes > |
|----------|-------------|
| 1. | |
| 2. | |
| 3. | |
| 4. | |
| 5. | |
| 6. | |
| 7. | |
| 8. | |
| 9. | |
| 10. | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |

Letter

This is a similar task except this time you have two minutes to say as many words as possible starting with the letter F. Avoid names, like Fred, non-English words, and saying the same word but with different endings. For example, if you were given the letter J you can say jump, but you cannot then say jumped, jumping or jumps. Does that make sense?

| < time 2 | ! minutes > |
|----------|-------------|
| 1. | |
| 2. | |
| 3. | |
| 4. | |
| 5. | |
| 6. | |
| 7. | |
| 8. | |
| 9. | |
| 10. | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |

Now you must do exactly the same for the letter 'A', remember to avoid names, non-English words, and derivatives of the same word.

| 1 |
|----|
| 2 |
| 3 |
| 4 |
| 5 |
| 6 |
| 7 |
| 8 |
| 9 |
| 10 |
| 11 |
| 12 |

13. _____

14. _____

15. _____

16. _____

17. _____

20. _____

< time 2 minutes >

Just one more letter to do the same thing for, the last letter is 'S' $\,$

< time 2 minutes >

| 1 |
|----|
| 2 |
| 3 |
| 4 |
| 5 |
| 6. |
| 7 |
| 8 |
| 9 |
| s |
| 10 |
| 11 |
| 12 |
| 13 |
| 14 |
| 15 |
| 16 |
| 17 |
| 18 |
| 19 |

Beck's Depression Inventory

This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire.

- 1. 0 I do not feel sad. 1 I feel sad 2 I am sad all the time and I can't snap out of it. 3 I am so sad and unhappy that I can't stand it. 2. 0 I am not particularly discouraged about the future. 1 I feel discouraged about the future. 2 I feel I have nothing to look forward to. 3 I feel the future is hopeless and that things cannot improve. 3. 0 I do not feel like a failure. I feel I have failed more than the average person. 1 2 As I look back on my life, all I can see is a lot of failures. 3 I feel I am a complete failure as a person. 4. 0 I get as much satisfaction out of things as I used to. 1 I don't enjoy things the way I used to. 2 I don't get real satisfaction out of anything anymore. 3 I am dissatisfied or bored with everything. 5. 0 I don't feel particularly guilty 1 I feel guilty a good part of the time. 2 I feel quite guilty most of the time. 3 I feel guilty all of the time. 6. 0 I don't feel I am being punished. 1 I feel I may be punished. 2 I expect to be punished. 3 I feel I am being punished. 7. 0 I don't feel disappointed in myself. I am disappointed in myself. 1 I am disgusted with myself. 2 3 I hate myself. 8 0 I don't feel I am any worse than anybody else. I am critical of myself for my weaknesses or mistakes. 1 2 I blame myself all the time for my faults. 3 I blame myself for everything bad that happens. 9. 0 I don't have any thoughts of killing myself.
 - 1 I have thoughts of killing myself, but I would not carry them out.
 - 2 I would like to kill myself.
 - 3 I would kill myself if I had the chance.

10.

- 0 I don't cry any more than usual.
- I cry more now than I used to.
- 2 I cry all the time now.
- 3 I used to be able to cry, but now I can't cry even though I want to.

| 11. | |
|-----|---|
| 0 | I am no more irritated by things than I ever was. |
| 1 | I am slightly more irritated now than usual. |
| 2 | I am quite annoyed or irritated a good deal of the time. |
| 3 | I feel irritated all the time. |
| 12. | I feel inflated an the time. |
| 0 | I have not lost interest in other neonle |
| | I have not lost interest in other people. |
| 1 | I am less interested in other people than I used to be. |
| 2 | I have lost most of my interest in other people. |
| 3 | I have lost all of my interest in other people. |
| 13. | |
| 0 | I make decisions about as well as I ever could. |
| 1 | I put off making decisions more than I used to. |
| 2 | I have greater difficulty in making decisions more than I used to. |
| 3 | I can't make decisions at all anymore. |
| 14. | ŕ |
| 0 | I don't feel that I look any worse than I used to. |
| 1 | I am worried that I am looking old or unattractive. |
| 2 | I feel there are permanent changes in my appearance that make me look |
| 2 | unattractive |
| 3 | I believe that I look ugly. |
| 15. | I believe mai I look ugiy. |
| | I t1 t 11 1 f |
| 0 | I can work about as well as before. |
| 1 | It takes an extra effort to get started at doing something. |
| 2 | I have to push myself very hard to do anything. |
| 3 | I can't do any work at all. |
| 16. | |
| 0 | I can sleep as well as usual. |
| 1 | I don't sleep as well as I used to. |
| 2 | I wake up 1-2 hours earlier than usual and find it hard to get back to sleep. |
| 3 | I wake up several hours earlier than I used to and cannot get back to sleep. |
| | 1 |
| 17. | |
| 0 | I don't get more tired than usual. |
| 1 | I get tired more easily than I used to. |
| 2 | I get tired from doing almost anything. |
| 3 | |
| _ | I am too tired to do anything. |
| 18. | |
| 0 | My appetite is no worse than usual. |
| 1 | My appetite is not as good as it used to be. |
| 2 | My appetite is much worse now. |
| 3 | I have no appetite at all anymore. |
| 19. | |
| 0 | I haven't lost much weight, if any, lately. |
| 1 | I have lost more than five pounds. |
| 2 | I have lost more than ten pounds. |
| 3 | I have lost more than fifteen nounds |

20. 0 I am no more worried about my health than usual. 1 I am worried about physical problems like aches, pains, upset stomach, or constipation. 2 I am very worried about physical problems and it's hard to think of much else. 3 I am so worried about my physical problems that I cannot think of anything else. 21. I have not noticed any recent change in my interest in sex. I am less interested in sex than I used to be. 1 2 I have almost no interest in sex. I have lost interest in sex completely.

INTERPRETING THE BECK DEPRESSION INVENTORY

Now that you have completed the questionnaire, add up the score for each of the twenty-one questions by counting the number to the right of each question you marked. The highest possible total for the whole test would be sixty-three. This would mean you circled number three on all twenty-one questions. Since the lowest possible score for each question is zero, the lowest possible score for the test would be zero. This would mean you circles zero on each question. You can evaluate your depression according to the Table below.

| Total Score | Levels of Depression | | |
|-------------|---|--|--|
| 1-10 | These ups and downs are considered normal | | |
| 11-16 | Mild mood disturbance | | |
| 17-20 | Borderline clinical depression | | |
| 21-30 | Moderate depression | | |
| 31-40 | Severe depression | | |
| over 40 | Extreme depression | | |

Beck Anxiety Inventory (BAI)

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.

| | Not At All | Mildly but it didn't bother me much | Moderately - it wasn't pleasant at times | Severely – it bothered me a lot |
|----------------------------|------------|--|---|---------------------------------------|
| Numbness or tingling | | | | |
| Feeling hot | | | | |
| Wobbliness in legs | | | | |
| Unable to relax | | | | |
| Fear of worst happening | | | | |
| Dizzy or lightheaded | | | | |
| Heart pounding/racing | | | | |
| Unsteady | | | | |
| Terrified or afraid | | | | |
| Nervous | | | | |
| Feeling of choking | | | | |
| Hands trembling | | | | |
| Shaky / unsteady | | | | |
| Fear of losing control | | | | |
| Difficulty in breathing | | | | |
| Fear of dying | | | | |
| Scared | | | | |
| Indigestion | | | | |
| Faint / lightheaded | | | | |
| Face flushed | | | | |
| Hot/cold sweats | | | | |

Volume II

CLINICAL CASE STUDIES

&

SERVICE RELATED PROJECT

Dr. Lara A. Charlesworth

Thesis submitted in partial fulfilment of the degree of

Doctor of Clinical Psychology

Department of Psychology

Institute of Psychiatry, Psychology & Neuroscience

King's College London

2018

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CASE STUDY I

COGNITIVE BEHAVIOUR THERAPY FOR LOW MOOD IN A 24-YEAR-OLD FEMALE WITH ADHD

Supervised by: Dr. Katja Schulze

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ABSTRACT

This case study presents the assessment, formulation and treatment of low mood in a 24-year-old female with Attention Deficit Hyperactivity Disorder (ADHD). This client was initially assessed by IAPT and referred by them to an Integrated Psychological Therapies Team (IPTT) due to the complexity and chronicity of her difficulties. An individualised cognitive-behavioural approach, adapted specifically for people with ADHD (Young & Bramham, 2012), was used throughout treatment. The therapy was successful in improving mood and motivation, and reducing hopelessness, but difficulties in her capacity to establish a daily routine persisted. Reflections focus on the notion of ending therapy before the client had reached her primary goal.

INTRODUCTION

ATTENTION DEFICIT HYPERACTIVITY DISORDER

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder that is characterised by three primary difficulties - inattention, hyperactivity and impulsivity. Symptoms of ADHD develop in childhood, but the disorder is heterogeneous in that presentation can vary greatly from one person to the next. Difficulties typically emerge in organisation and time management, problem solving, forming and maintaining interpersonal relationships and memory. There is also evidence for a shift in symptomatology with age, as adults with ADHD tend to experience remission of hyperactivity and impulsiveness alongside the persistence of inattentiveness (Biederman, Mick & Faraone, 2000; Hart, Lahey, Loeber, Applegate & Frick, 1995; Marsh and Williams, 2004; Wilens, Biederman, Fafaone, Martelon, Westerberg & Spencer, 2009).

It is well established that the severity of ADHD declines with age (e.g. Larsson, Lichtenstein & Larsson, 2006), yet a proportion of adults continue to experience difficulties. For instance, Faraone, Biederman and Mick (2006) found that 15% of adults who were diagnosed with ADHD in childhood continued to meet threshold for diagnosis and 65% experienced difficulties at a subclinical level. In response to evidence for the persistence of difficulties into adulthood, NICE (National Institute for Health and Clinical Excellence, 2009) introduced international guidelines on treatment across the lifespan. They stipulate that Trusts providing mental health services should also have expertise in the diagnosis and management of ADHD. NICE also recommends medication as a first line treatment for ADHD in adulthood, with the addition of psychological therapy to improve residual difficulties.

LOW MOOD AND ADHD

Research shows that anxiety and mood disorders emerge frequently in children (Biederman, Newcorn & Sprich, 1991) and adults (Marks, Newcorn & Halperin, 2001) with ADHD. There is also evidence that whilst the severity of ADHD-related symptoms decreases with age, the severity of comorbid disorders increases (Bramham, Murphy, Xenitidis, Asherson, Hopkin & Young, 2012). Given that depression is also associated with cognitive impairment, such as deficits in episodic memory and executive functioning (Austin, Mitchell & Goodwin, 2001), it is likely that the neuropsychological deficits experienced by those with ADHD will be exacerbated by a co-morbid mood disorder. In the context of the present case study, it is also important to note that the severity of depression has been shown to increase the longer the disorder is left undiagnosed and untreated (Halperin, Trampush, Miller, Marks & Newcorn, 2008). In sum, it is likely that adults with ADHD who present to psychological services will be presenting with difficulties that are complex and chronic. According to Young and Bramham (2012), therapists often feel apprehensive and underequipped to provide psychological therapy for people with ADHD. The Young Bramham Programme was designed in response, as a guide for practitioners treating both the core features of ADHD, as well as co-morbid difficulties.

A COGNITIVE BEHAVIOURAL MODEL OF ADHD

From a cognitive perspective, mood disorders in ADHD emerge in response to negative appraisals that are learned following repeated experience of early life failures (Young & Bramham, 2012). More specifically, ADHD is characterised by deficits that make it likely that a young person growing up with the disorder will experience failure to achieve academically, to build social networks and to find an occupation that suits their needs. A history of failure can make a person susceptible to experiencing learned helplessness and low self-esteem and might result in them engaging in unhelpful behaviours in response. For instance, an individual with ADHD might withdraw from social situations and avoid events that might result in perceived failure. The combination of negative behaviour and negative

thoughts about oneself and the future induce a negative mood state that could further impact on neuropsychological capabilities. Thus, the young person with ADHD gets stuck in a negative cycle of expecting and experiencing failure.

CASE DESCRIPTION

REASON FOR REFERRAL

Sophie had been seeking individual psychological therapy for two years when we met for our first session and at this point she described herself as being "desperate for help". She was seen for assessment in primary care services, but her difficulties were considered to be complex and thus she was referred to IPTT (secondary care). She had diagnoses of Unipolar depression, ADHD and oppositional defiant disorder (ODD), which is described by the DSM 5 (American Psychiatric Association, 2013) as "a pattern of angry/irritable mood, argumentative/defiant behaviour, or vindictiveness lasting at least 6 months" (p. 462). Sophie was referred for psychological assessment and treatment to improve her mood, selfesteem and interpersonal difficulties.

PRESENTING DIFFICULTIES

The initial assessment was carried out by my supervisor in a single session. During the assessment, Sophie described her main difficulties as procrastinating and not sticking with plans, lack of motivation, low mood, low self-esteem and relationship problems.

Sophie described a reverse sleep/wake cycle in which she stayed awake until approximately 5am and slept until the early afternoon. She reported that when she was able to get out of bed she would feel unmotivated and lacking in energy and although she often made plans (e.g. to look for work, go to the gym or do coursework) she often failed to see them through. As a result of failing to complete tasks, Sophie would feel like a failure, criticise herself and dwell on the aspects of her life that she felt were not going well. She described getting lost in

daydreams to distract herself from difficult thoughts. This improved her mood temporarily, but worsened it in the long term, as it interrupted her capacity to achieve things. Indeed, Sophie was spending a lot of time at home, alone and unoccupied, which was likely to maintain low mood.

Sophie reported a number of interpersonal difficulties. She declined social invitations in relation to anxiety. In particular, she felt anxious about the prospect of making small talk and felt that she had little to offer in terms of interesting conversation due to her "lack of progress in life". Sophie often misunderstood or misinterpreted things that others said and thus felt attacked or criticised. She felt that others did not respect her or value her opinion, which resulted in her "feeling bad" about herself. Sophie also described frequent arguments with her mother, who was her main contact. She felt that her parents showed preference for her siblings and had low expectations for her. Sophie also found it difficult to maintain focus during conversations.

RELEVANT BACKGROUND

Sophie was diagnosed with ADHD at the age of 22 (two years prior to our first meeting). She reported a long history of educational difficulties, she had been described by family and school staff as "an underachiever". With the help of a particularly supportive teacher, she obtained low grade GCSEs in maths and English. Sophie was not employed at the time of treatment but was attending college sporadically. She did not suffer from any other serious medical conditions. There was no history of deliberate self-harm and no risk to self or others was identified.

PREVIOUS TREATMENT

Sophie was prescribed Methylphenidate at the time of her ADHD diagnosis, but experienced several negative side effects. She was prescribed Dexamphetamine as a substitute but felt that this did not significantly improve her symptoms. Sophie had also previously attended

group therapy for young people with ADHD, but disengaged, as she was keen to receive individual therapy.

FORMULATION AND MODEL

Based on the NICE guidelines and the above information from the assessment, CBT formulation and treatment were adopted to improve her ongoing difficulties. Figure 1 depicts an idiosyncratic CBT case formulation of Sophie's presenting difficulties (adapted from Young & Bramham, 2012); this was developed in our initial sessions and elaborated on during our work together.

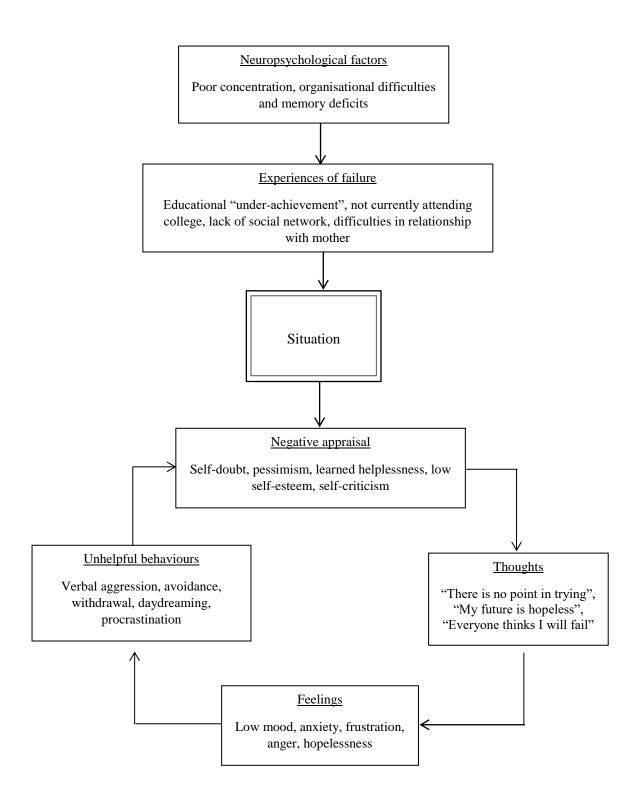


FIGURE 1; A COGNITIVE-BEHAVIOURAL FORMULATION, ADAPTED FROM YOUNG AND BRAMHAM (2012), TO DESCRIBE THE DEVELOPMENT AND MAINTENANCE OF SOPHIE'S PRESENTING DIFFICULTIES

Sophie has experienced neuropsychological deficits for as long as she could remember. In particular, difficulties in maintaining concentration, being able to organise activities of daily living and forgetfulness led her to experience a number of early and ongoing failures. She was described as an "underachiever", had struggled to find a job that suited her needs, felt socially rejected and would frequently experience difficulties in her relationship with her parents. This led to a tendency for Sophie to negatively appraise a situation, she doubted herself and her capabilities, was pessimistic about her ability to achieve things, had learned helplessness (i.e. she had learned to stop trying to achieve things to avoid the negative experience of failing) and had low self-esteem. Her tendency towards negative appraisal resulted in several negative behaviours – she was verbally aggressive towards her parents, withdrew from socialising, avoided getting out of bed and spent a lot of time daydreaming. In relation to negative thoughts, these were most often self-critical in nature and she was prone to mindreading (i.e. projecting the negative thoughts that she had about herself onto others). The combination of negative thoughts and behaviours resulted in low mood, anxiety, frustration and hopelessness, which further perpetuated her tendency for negative appraisal. Sophie described having been stuck in this negative cycle for approximately two years. Sophie engaged well with developing a joint formulation, she contributed ideas and showed good understanding of the relationship between thoughts, feelings and behaviours; however, seeing her difficulties written down initially brought about feelings of hopelessness. This was addressed by discussing the idea that the joint understanding was a starting point from

GOALS

which we could tackle her difficulties.

Goals were difficult to establish, as Sophie was preoccupied with the idea of becoming a "balanced person" but was initially unable to elaborate on what she meant by this. It is possible that Sophie's cognitive difficulties hindered her capacity to set realistic goals that were also specific, therefore SMART goals were established over the course of our work together. Using guided discovery, the following goals were elicited:

- 1) To establish a routine that was healthy, fulfilling and enjoyable
- 2) To learn strategies to improve her ADHD related difficulties

These goals were broken down further overtime using problem solving techniques, as well as a weekly planner, which allowed us to develop a concrete example of what a "healthy, fulfilling and enjoyable" routine would involve. The weekly planner was reflected on and revised throughout treatment and overtime Sophie learned the value of setting goals that were realistic and achievable, which subsequently had a positive impact on her mood and motivation.

Assessment Measures

The Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM; Evans, Connell, Barkham, Margison, McGrath, Mellor-Clark et al., 2002) and CORE-10 were used to assess changes in Sophie's difficulties during therapy. The CORE-OM is a 34-item self-report measure of psychological distress that was used to determine pre and post therapy changes. The CORE-10 is a 10-item version of the CORE-OM that was administered every 2-3 weeks in order to monitor areas of improvement, as well as areas of ongoing difficulty.

INTERVENTION

16 sessions of CBT were completed with Sophie. Treatment took place over a four-month period and each individual session lasted approximately one hour.

Initial sessions were spent developing rapport, considering goals and gathering information for formulation (see Figure 1). Below is a summary of the work that followed these initial stages. Treatment in this case was not linear and so is not necessarily described in the order that it was carried out. The co-morbidity of Sophie's presenting problems was difficult to work with at times and supervision was crucial in providing a space to reflect on how our work together was progressing (or not, at times). Consultation with the adult ADHD team

was also sought to shed light on the relationship between Sophie's ADHD related difficulties and her mental health difficulties.

Socialisation and Psychoeducation

It was particularly important to integrate psychoeducation about ADHD into the work carried out with Sophie, in our first session she told me that she was "completely obsessed" with her diagnosis and yet "overwhelmed" by the information that she had gathered from researching it. Thus, it felt important to educate Sophie on her difficulties in a way that prevented her from feeling overwhelmed. First of all, we considered how her approach to learning about her diagnosis was actually hindering her capacity to gain a better understanding and this provided rationale for breaking learning into chunks. Together we worked through the Young and Bramham (2012) manual, within which each chapter addresses a different difficulty that is often experienced by people with ADHD.

Psychoeducation was crucial in reducing self-blame and feelings of frustration, Sophie found it particularly helpful to learn that her capacity to achieve things would fluctuate daily in the context of ADHD. Externalising "the ADHD" was also instrumental in reducing self-blame. Sophie engaged well with the CBT model and quickly gained insight into the thoughts, feelings and behaviours that maintained her low mood. Helping Sophie to understand her difficulties was a key part of intervention.

REVERSING THE SLEEP-WAKE CYCLE

Sophie was finding it difficult to attend out sessions on time, often arriving half an hour late, as she was unable to get out of bed on time. She found this very distressing as it impacted on her ability to "make the most of therapy". Thus, an initial aim was to improve her sleep/wake cycle, which Sophie agreed was closely related to her capacity to establish a routine that was healthy, fulfilling and enjoyable. The first step involved learning sleep hygiene techniques and those that were particularly helpful to Sophie were having a regular bedtime, avoiding eating a large meal close to bedtime and associating bed with sleep (i.e.

not using her phone in bed). These were introduced over several sessions to avoid overwhelming Sophie. An important second step in improving her sleep pattern was to improve her assertiveness through role-play, as Sophie had a long-distance partner who lived in a different time zone and would spend most of the night speaking to him. She felt unable to tell him that she needed to sleep without being offensive. By session six, Sophie reported that her sleep pattern had improved dramatically, she was sleeping by midnight and would wake at 9am, this later shifted to 8am as she began to develop a more demanding daily routine.

DEVELOPING A ROUTINE

Strategies for developing a routine were adapted from recommendations by Young and Bramham (2012). Given that Sophie was easily overwhelmed, a key step in developing a routine was for her to learn how to break tasks down into manageable steps. Time management was broken down into six steps; 1) set goals 2) make lists, 3) prioritise activities, 4) estimate time to complete tasks and 6) incorporate rewards. Problem solving was broken down into five steps; 1) define the problem, 2) generate solutions, 3) evaluate solutions, 4) implement chosen solution and 5) evaluate success. It was also important to incorporate personally meaningful rewards into Sophie's daily routine; this involved "me time" such as painting her nails or plaiting her hair. Sophie also found positive self-talk to be particularly helpful, such as "don't be too hard on yourself, it's great that you've tried".

MINDFULNESS

One important step in improving Sophie's low mood, anxiety and frustration was to replace "daydreaming" with mindfulness. To generate motivation for Sophie to engage in this we formulated daydreaming as an unhelpful coping strategy by exploring the costs and benefits of the behaviour - the benefit being that it improved her mood in the short term and the cost being that it maintained depression in the long term by preventing her from achieving things (e.g. completing college work, going to the gym, meeting friends). Initially, we used

mindfulness exercises during our sessions (e.g. paying attention to the present moment using the five senses) and after Sophie experienced a benefit she was motivated to use this strategy outside of our sessions. She described how mindfulness reduced the time that she spent daydreaming and improved her feelings of connectedness with the things that were happening around her.

THOUGHT CHALLENGING

Thought challenging was important in motivating Sophie to get out of bed, as she would wake up and think "there is no point in getting up, I never achieve anything". Together we gathered evidence for and against this thought and positively reframed it using a simplified version of a formal thought record (for an example of a thought challenging record, see Appendix 1). Sophie found it helpful to replace the original thought with the following statement - "Today is going to be a good day in which I try to achieve things, this might not be easy, but I will be much more likely to succeed if I get up and give it a go". Sophie also created a poster that included this statement, which she added to her noticeboard as a reminder. It was also important to challenge Sophie's negative appraisals of the behaviour of others, particularly her parents. Sophie had a tendency to jump to negative conclusions in the company of others. This allowed her to gather "evidence" to support the belief that her parents had no expectations for her or her future. By learning to scrutinise the "evidence" before accepting it and think through alternatives, Sophie learned to challenge these thoughts. This was initially done together in session using examples that Sophie brought from the previous week and once Sophie had gained some confidence in thought challenging it was set as a homework task. By the end of therapy, Sophie was engaging in thought challenging independently and without the use of formal thought challenging hand-outs. This led to improved mood and a more positive relationship with her parents. By learning to think through alternatives, Sophie was also able to re-evaluate interactions with friends and subsequently re-established contact with her closest friend towards the end of therapy.

IMPROVING SELF ESTEEM

To improve Sophie's self-esteem, we developed a list of 20 positive statements that she or others would use to describe her (as recommended by Fennell, 1997). These included caring, beautiful, creative, loyal and fun. Sophie felt that someone who possessed these qualities could be described as "a really nice person, with a lot to offer" and this was a poignant moment in therapy. To bring these positive statements to the forefront of her everyday experience, Sophie began to keep a diary of events in which she demonstrated these qualities and she was continuing to do so when therapy ended.

ENDING AND RELAPSE PREVENTION

The final sessions were used to draw a blueprint with Sophie. We reflected on all that she had learned and the techniques that she had found particularly helpful. Within the blueprint we also thought about what the next steps towards having a routine that was healthy, fulfilling and enjoyable would be. Sophie created an exhaustive list of all of the activities that she could try out and thought about how she might incorporate her favourites into a weekly schedule. The final sessions were also used to normalise difficult emotions around ending therapy and to normalise and plan for setbacks.

OUTCOMES

QUANTITATIVE OUTCOMES

Figure 2 presents the average CORE scores reported by Sophie during the course of therapy, a lower score represents less distress.

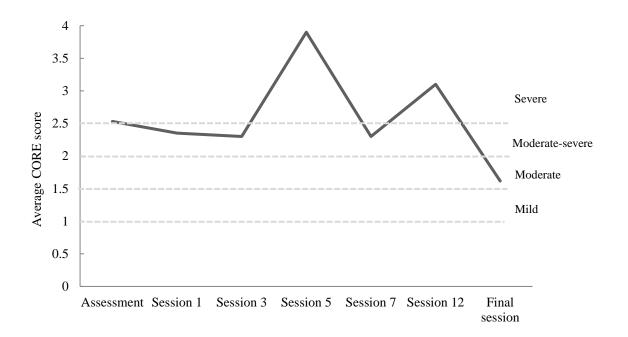


FIGURE 2; AVERAGE CORE SCORE ACROSS SESSIONS

Overall, there was a decrease in Sophie's CORE-OM score at the end of therapy compared to that at assessment, showing that her general level of distress had decreased from severe to moderate. However, the negative relationship between number of sessions and level of distress was not linear. There was a notable increase in the distress level reported by Sophie in Session 5, which she attributed to difficulties in the wider system, particularly her relationships with her mother and long-distance partner. She reported that elevated distress in Session 12 reflected increased anxiety about the prospect of therapy ending.

Figures 3 and 4 show items from the CORE-OM which were most relevant in the context of Sophie's goals and presenting difficulties. Each item on the CORE is scored on a scale of 0-4, where 4 = most or all of the time and 0 = not at all. Figure 4 shows items relating to negative affect.

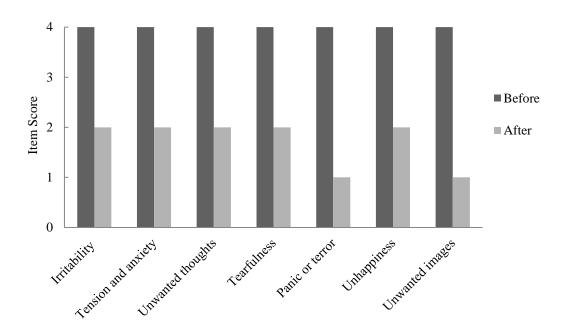


FIGURE 3; CORE-OM ITEMS RELATING TO SOPHIE'S NEGATIVE AFFECT BEFORE AND AFTER THERAPY

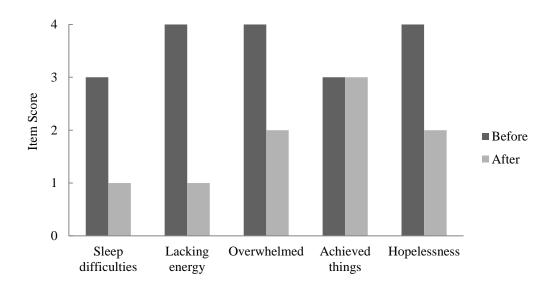


FIGURE 4; CORE-OM ITEMS RELATING TO SOPHIE'S DIFFICULTIES IN ESTABLISHING A ROUTINE

Overall, scores show improvements in Sophie's affect, as well as improvements in difficulties that impaired her capacity to develop a daily routine. However, there was no change in her self-reported feelings of achievement. This could demonstrate that Sophie had not succeeded in achieving her goal of establishing a routine that was fulfilling, or that she was continuing to discount her gains, struggling to acknowledge partial successes or was engaging in ongoing self-criticisn.

QUALITATIVE OUTCOMES

Qualitatively, there was a shift in Sophie's presentation during therapy. In relation to her goal of improving her ADHD related difficulties, she developed an awareness of her thoughts drifting and an ability to bring herself back to the present moment. This had a notable impact on her capacity to focus in our sessions. Her ability to listen and turn-take in conversations also improved and she became less anxious about the importance of "making the most of therapy" once she began to see improvements in her difficulties. She reported that time management strategies had been especially useful, and she was continuing to create a daily schedule for herself. She also found the integration of rewards helpful in maintaining her focus and learning to breakdown goals into manageable steps reduced feelings of being overwhelmed.

The act of formulating together using the CBT model of ADHD in adults was valuable in helping Sophie to understand her ongoing difficulties. It was also evident that Sophie had developed skills in noticing her negative automatic thoughts and reframing them. This was evident in our final session when she told me that she had been able to positively reframe the end of therapy.

ONWARD REFERRAL

Given that Sophie was experiencing ongoing difficulties at the time therapy ended, and that the time-limited nature of our work did not provide scope to address interpersonal difficulties, we discussed the option of a re-referral for group therapy within a specialist

ADHD team. Sophie was keen for a referral to be made and was motivated to engage with this. There was a six-month waiting list for group work and Sophie was initially disappointed and anxious about this; however, she was able to reframe this as an opportunity to work on her personal difficulties before moving onto interpersonal difficulties. This was an example of Sophie being able to positively reframe, delay gratification and breakdown goals into manageable steps.

DISCUSSION

Sophie is a 24-year-old female who was experiencing low mood in the context of a relatively recent diagnosis of ADHD. She described her main difficulties as procrastinating and not sticking with plans, lack of motivation, low mood, low self-esteem and relationship problems and was referred for help in improving these difficulties.

It was challenging to use sessions effectively in the initial stages of our work, as Sophie spoke a lot, yet her speech was often empty of meaningful content. She was also easily distracted, tended to go off on a tangent and was difficult to interrupt. She would interrupt me often, as she was unable to delay responding if she felt that she had something valuable to say. It took around eight sessions to get to a point where we were both able to use our sessions efficiently. This was facilitated by reflecting on previous sessions and linking the importance of staying on track to Sophie's goals. We also worked collaboratively to find ways of staying on track, such as, getting permission to interrupt and refocus Sophie and encouraging Sophie to time-keep. Conversations about sharing responsibility for improving Sophie's difficulties were also invaluable and increased her motivation to remain active and focused during sessions.

Sophie was preoccupied by the need to "make the most of therapy". This was helpful in some respects, as she was incredibly dedicated to our work together. For instance, she recorded all of our sessions and listened to them at least once a week. However, this preoccupation also caused anxiety, which hampered therapeutic progress. Thus, part of

therapy involved managing her expectations and it was also important to reflect on the fact that at times I was drawn into her need to rush through things. It was important to use supervision to reflect on this and on the idea that it is better to do a small number of things well than to try to do too much at once and risk leaving Sophie with another experience of failure. It was invaluable to communicate this to Sophie by referring back to the joint formulation that we developed.

There was subjective and objective evidence that therapy had been effective in improving Sophie's difficulties, yet she still met the threshold for moderate psychological distress in the final session. Overall, we were limited by the number of sessions that I was able to offer as a trainee in a six-month placement, particularly in the context of Sophie's neurodevelopmental difficulties. In order to maximise therapeutic impact, I attempted to empower Sophie to continue to use the strategies and techniques that she learned in therapy once our sessions ended. This was done using repetition and practise to allow her to gain confidence in using techniques, creating visual aids and reminders (e.g. posters), and encouraging Sophie to share what she learned with her wider system, particularly family and friends. On reflection, involving her wider system in our sessions might have been fruitful in maximising the benefits of this.

There was a notable shift in Sophie's presentation during therapy and the development of skills in thought challenging seemed to be pivotal in this. By learning to consider alternatives and weigh up evidence, Sophie saw improvements in all aspects of her life. Indeed, this fits with the formulation presented in Figure 1 and the idea that negative cycle is likely to begin with negative appraisals. Thus, this piece of work provided good support for the use of the Young Bramham Programme (Young & Bramham, 2012). However, if I was to work with Sophie again, I would introduce the concept of thought challenging before attempting to teach strategies to improve her ADHD-related difficulties, as negative appraisals impeded on her ability to master these techniques.

REFLECTIONS

I found therapy with Sophie challenging at times. As a new trainee I wanted to please her and to do a good job, but ultimately doing a good job required disappointing Sophie, as I learned that it was crucial that her expectations for therapy were realistic. On reflection, it would have been helpful for me to address this explicitly with her at an earlier stage in our work, as her progress in therapy improved after we made this explicit.

I found supervision very helpful in working with Sophie; although I felt comfortable reading the treatment recommended by Young and Bramham (2012), the application of this was rarely straightforward and my supervisor helped me to tailor the intervention to this particular client. She also helped me to reflect on the process of therapy, which is something that I did not pay enough attention to, given my preoccupation with delivering treatment. I found this to be invaluable in ensuring that my client experienced gains in therapy and something that I always consider in future work.

The prospect of ending therapy before Sophie had fully achieved her goal was disappointing, especially given all of the hardwork that we had invested. However, in the end we were both able to reflect on therapy as a positive experience. When I first met Sophie she felt hopeless and was almost entirely lacking in motivation – by the end of our work together she was more hopeful and was looking forward to what her future might hold. On reflection, the act of working towards a goal felt as crucial to this client as the act of achieving it. I feel that I was able to provide her with a positive experience of aiming for something, not quite achieving it, but that being OK.

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APPENDIX

Appendix 1. Thought challenging example

| Situation | Automatic Thought(s) | Emotion(s) | Adaptive response |
|--|--|---|---|
| What was happening? | What thought (s) and/or image(s) went through your mind? How much did you believe each one at the time? | What emotion(s) (sad/anxious/angry/etc.) did you feel? How intense (0-100%) was the emotion? | Is there an alternative explanation? |
| Alone in my room, reading about problem solving strategies | "I'm never going to progress" (90%) | Tearful (95%) Hopeless (100%) Moody (80%) Depressed (90%) | "If I keep practising therapy strategies, then I will keep progressing. This won't be easy, but I am going in the right direction!" |

CASE STUDY II

COGNITIVE BEHAVIOUR THERAPY FOR OBSESSIVE COMPULSIVE DISORDER IN A 15-YEAR-OLD GIRL

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ABSTRACT

This case study presents the formulation and treatment of obsessive compulsive disorder (OCD) in a 15-year-old female who was referred to the specialist adolescent service by her GP. An individualised cognitive behavioural approach was used throughout treatment with this client, who held the belief that she was responsible for the health and safety of her family and developed a series of debilitating compulsions in response to this. Therapy was successful in reducing symptoms of OCD and the young person felt that she had fully achieved her goals when our sessions ended. Reflections focus on the validity of using psychometric measures to evaluate outcomes and the idea that an OCD identity might persist after the amelioration of symptomatology.

INTRODUCTION

OBSESSIVE COMPULSIVE DISORDER

OCD is characterised by recurrent, intrusive thoughts and/or images (obsessions), and physical or mental acts that are repeated by an individual in order to reduce distress and prevent harm to self and/or others (compulsions) (American Psychiatric Association, 2013). OCD is a heterogeneous disorder in that the content of obsessions and nature of compulsions varies from one individual to the next; however, research and clinical evidence suggests that there exist four key categories (McKay et al., 2004):

- Obsessions relating to responsibility for causing harm, alongside compulsions intended to prevent this.
- 2) Contamination obsessions, with compulsions to wash and/or clean.
- 3) Symmetry obsessions, with compulsions to order, arrange and/or count until the individual experiences a feeling of something being "just right".
- 4) Unwanted obsessions relating to sex, violence or religion, alongside compulsions that are not visible i.e. mental rituals.

Hoarding was also previously considered to be a subcategory of OCD but has more recently been re-classified as a distinct disorder (American Psychiatric Association, 2013).

Research suggests that around 80% of the general population experience intrusive thoughts (Rachman, & de Silva, 1978; Salkovskis, & Harrison, 1984) and that more than half of the population engage in ritualised behaviour (Muris, Merchelback, & Clavan, 1997). In order for a diagnosis of OCD to be given, obsessions and/or compulsions must cause distress to the individual and must be present on most days during two successive weeks (World Health

Organisation, 1992). The National Institute for Health and Care Excellence (NICE, 2005) estimates that between 1-3% of the population reach the threshold for OCD diagnosis.

THEORIES OF OCD

The incidence of OCD has been associated with several neurobiological features, including genetic, anatomical and chemical abnormalities (Abramowitz, Taylor & McKay, 2009).

Theories relating to the disruption of the brain's serotonin system gained popularity following evidence of the effectiveness of selective serotonin reuptake inhibitors (SSRIs) in alleviating symptoms of this disorder (Lopez-Ibor Jr, 2003). With regards to psychological theories, psychoanalysts argued that OCD emerged following the presence of weak ego boundaries and considered it to be crucial that rituals were performed in order to prevent the onset of psychosis (Salkovskis, 1999). In contrast, behaviour therapists explored the usefulness of exposing people with OCD to feared stimuli and then preventing them from performing ritualistic responses. In support of the latter approach, Rachman, de Silva and Röper (1976) showed that anxiety spontaneously decreases if people are prevented from carrying out compulsions. Early work by behaviourists forms the foundation of the current evidence-based psychological treatments for OCD. Indeed, high relapse rates following the cessation of SSRIs, as well as the negative side effects of medication, have resulted in psychological therapy becoming the principle treatment.

COGNITIVE BEHAVIOURAL MODEL OF OCD

The cognitive behavioural model of OCD proposes that it is an individual's interpretation and subsequent response to their intrusive thoughts that leads to OCD symptomatology (Salkovskis, 1999). For instance, intrusive thoughts about harming others are not uncommon in the general population, but an individual with OCD interprets the thought as an indication

that they will act on it, this is referred to as thought-action fusion (Rachmann, 1993).

Another core feature of OCD is inflated responsibility (Salkovskis et al., 1995), that is, an individual believes themselves to possess the power to prevent a personally devastating outcome (Veale, 2007) and acts out compulsions in response. These features of the disorder are consistent with Beck's cognitive model of emotional disorders (Beck, 1976), which proposes that emotional distress arises in response to the meaning attributed to experiences, as opposed to experiences themselves. The behavioural aspect of this model involves the formation of an association between anxiety and intrusions that were previously unthreatening. An individual develops compulsions as a means of neutralising the anxiety associated with intrusions and subsequently prevents opportunities for spontaneous habituation and extinction.

There is a strong evidence base for the use of CBT in the treatment of OCD in adults (for a meta-analysis, see Olatunji, Davis, Powers & Smits, 2013) and children (for meta-analyses, see Abramowitz, Whiteside & Deacon, 2006 and Watson & Rees, 2008). The case description presented here illustrates a client-centred CBT approach to OCD, based on the model proposed by Salkovskis, Forrester and Richards (1998).

CASE DESCRIPTION

REASON FOR REFERRAL

Lucy was referred to the adolescent service by her GP, who suspected that she had developed OCD over a period of several months. The GP described excessive hand washing that emerged in response to Lucy's belief that she would make her mother ill if she did not engage in this ritual. The GP requested a detailed assessment of Lucy's difficulties, as well

as support in adjusting to her change of circumstances and reduction in excessive hand washing.

PRECIPITATING FACTORS

Lucy's difficulties emerged following several challenging and significant life events. Lucy's mother was recovering from breast surgery that was carried out one year previously, thankfully this was not cancerous and did not require chemotherapy, but since this time Lucy became very worried about making her mother ill. The family also moved into social housing due to financial difficulties. At the time, Lucy was living with her mother and brother in accommodation that was described by them as unpleasant, unsafe and inadequate. For instance, the family described being harassed by an unknown person who would climb up the fire escape and tap on their window late at night. Lucy reported that her difficulties emerged following moving into this accommodation.

PRESENTING DIFFICULTIES

An initial assessment was carried out by one of the junior doctors in the specialist adolescent team. Following this assessment, Lucy was considered to be appropriate for intervention within the team and was referred to me for treatment. The information gathered at initial assessment and in the assessment that I carried out myself is presented below.

Lucy initially developed concerns about making her mother unwell following her mother's illness, from this Lucy developed worries that if she didn't wash her hands she would make others unwell. In particular, Lucy felt that shoes were very dirty and was 65% certain that someone would get ill if she touched her shoes and did not wash her hands multiple times afterwards. Lucy also became preoccupied with checking that the doors and windows in her home were locked, which she mostly did at nighttime. She reported that she checked three

times per-night to keep her family safe. Lucy denied any intrusive images and recognised that the thoughts about things being unclean/unsafe as her own, she also described attempts to resist washing her hands/checking but was mostly unsuccessful.

Lucy described her mood as "OK" at the time of assessment and described herself as having always been an anxious person. For instance, she would avoid answering questions in class and described feeling shy with new people. She reported no risk with regards to self or others. Lucy was keen to engage in psychological therapy and reluctant to take medication to reduce symptomatology.

SOCIAL NETWORK

Lucy reported having a core group of eight girlfriends who she enjoyed spending time with. Her relationship with her mother was warm and supportive and the two spoke openly and honestly in front of one another. Lucy's mother was receiving psychological therapy for anxiety at the time of Lucy's treatment. Lucy also described a positive relationship with her 13-year-old brother, who was diagnosed with autism spectrum disorder in childhood.

PRESENTATION

FORMULATION

NICE (2005) recommends that young people with OCD and moderate to severe functional impairment are offered CBT, with exposure and response prevention as a key element. Lucy met the diagnostic criteria for OCD, as described below. Based on this and the information gathered at assessment CBT formulation and intervention were adopted. NICE also recommends that treatment is adapted to suit the developmental age of the young person and that a family member/carer is involved wherever possible.

Figure 1 depicts an idiosyncratic CBT case formulation of Lucy's presenting difficulties (adapted from Salkovskis, et al., 1998); this was developed in our initial sessions and elaborated on during our work together.

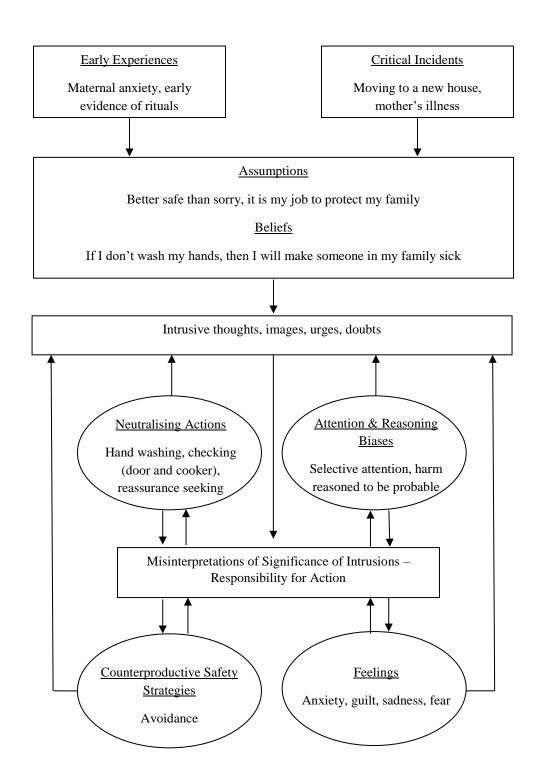


FIGURE 1; A COGNITIVE-BEHAVIOURAL FORMULATION TO DESCRIBE THE DEVELOPMENT AND MAINTENANCE OF LUCY'S DIFFICULTIES

GOALS

Lucy developed three primary goals for our work together. Her progression towards her goals was monitored weekly:

- To stop washing her hands after touching items that have come into contact with the floor, particularly shoes.
 - 2) To stop checking that the cooker is turned off.
 - 3) To stop checking that the door is locked.

ASSESSMENT MEASURES

The Children's Obsessive Compulsive Inventory (ChOCI-R, Shafran, Frampton, Heyman, Reynolds, Teachman & Rachman, 2003) was used to assess OCD symptomatology. The ChOCI-R is a two-part questionnaire designed to assess the presence of obsessions and compulsions and was administered pre and post therapy. The Revised Children's Anxiety and Depression Scale (RCADS; Chorpita, Yim, Moffitt, Umemoto & Francis, 2000) is a 47 item self-report measure that was completed to assess symptoms of the following psychological disorders: separation anxiety disorder, social phobia, generalised anxiety disorder, panic disorder, obsessive compulsive disorder and major depressive disorder. Items are rated on a 4-point Likert scale (0 = never, 1 = sometimes, 2 = often and 3 = always). Finally, the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) was administered, which is a self-report measure designed to assess 25 behavioural attributes (e.g. I try to be nice to other people. I care about their feelings; I am helpful if someone is hurt, upset or feeling ill). For each item, respondents are required to indicate whether the attribute is "not true", "somewhat true", or "certainly true". All questionnaires have parent

and self-report versions and were completed by Lucy and her mother. To evaluate outcomes, questionnaires were administered at assessment and in the final session.

INTERVENTION

14 sessions of CBT were completed with Lucy. Treatment took place over a four-month period and our sessions lasted approximately one hour. Lucy's mother joined us for most of our sessions, most of the time she joined for the second half of the session, but this varied according to the aims and our agenda. NICE guidelines recommend that a family member/carer is involved wherever possible when working with young people with OCD. In this instance, it was crucial to engage Lucy's mother in treatment for several reasons. First, treatment for OCD involves exposure to feared stimuli and it was important that Lucy's mother understood the rationale for placing Lucy in situations that she found distressing. Second, Lucy required encouragement and support in engaging with exposure and response prevention (ERP) outside of sessions. Finally, Lucy's mother was playing a maintaining role by allowing Lucy to take on much of the responsibility for the family's safety. Thus, increasing her awareness of this, as well as having discussions around redistributing responsibility, was key.

The initial sessions were used to set goals and develop rapport, this was considered to be a crucial stage in developing a therapeutic relationship, particularly as another member of the Specialist Adolescent Team carried out Lucy's initial assessment. Treatment comprised of two main elements; discussion and ERP. Lucy found her compulsion to wash her hands the most distressing and was keen to prioritise this in therapy. Therefore, our work often involved working directly on contamination fears using cognitive restructuring and in situ exposure. Lucy was encouraged to generalise the techniques that she learned to checking behaviours and homework tasks provided additional opportunities for ERP.

NORMALISATION, FORMULATION AND PSYCHOEDUCATION

Helping Lucy to understand that anxiety is "normal" was a key part of the intervention. The early stages of therapy involved psychoeducation relating to the role of anxiety in preparing us for the 'fight or flight' response and the physiological impact of adrenaline. Together we thought about why anxiety is helpful in some situations, but unhelpful in others. I took the lead in formulating Lucy's hand washing behavior and in subsequent sessions she was able to take the lead in formulating her compulsion to check that the door was locked, and that the cooker was turned off. Psychoeducation on the role of maintenance factors, particularly avoidance and neutralising behaviours, was instrumental in providing motivation to participate in behavioural experiments. Lucy engaged well with this and was able to understand how compulsions prevented opportunities for her to test out her unhelpful beliefs.

Providing psychoeducation to Lucy's mother was also key in helping her to understand the rationale for ERP thus allowing her to support Lucy outside of our sessions. This was also used as a means of empowering Lucy and of ensuring her understanding, as she would take the lead on educating her mother in the second half of many of our sessions.

INFLATED RESPONSIBILITY

It was evident that Lucy felt an unrealistic amount of responsibility for protecting her family. In our sessions, Lucy's mother described herself as tired and forgetful, Lucy also told me of times when her mother had forgotten to turn off the cooker or lock the door. In the context of this, it was perhaps unsurprising that Lucy felt inflated responsibility. We used responsibility pies to explore this. Responsibility pies revealed that Lucy felt that she would be 40% responsible if her mother was to get an upset stomach, whilst her mother felt that Lucy would not be responsible at all. Lucy also felt that she would be 20% responsible

if someone broke into their home, whereas her mother felt that Lucy would be just 2% responsible. Allowing Lucy and her mother to compare their ratings was crucial in providing Lucy with an alternative perspective and she said that she found this exercise particularly helpful.

Discussions regarding responsibility were also helpful and three discussions in particular led to a reduction in the frequency of Lucy's compulsive behaviours. First of all, we thought about the role of the fire alarm in being responsible for alerting the family to a fire, secondly, we discussed Lucy's mother taking responsibility for locking the door and finally, we considered the idea that we aren't always able to keep the people who we love safe no matter what we do.

WHAT'S THE EVIDENCE?

At the start of therapy, Lucy was 65% certain that she would make herself, her mother or her brother ill if she touched her shoes without washing her hands afterwards. In our third session we thought about evidence for and against this belief. Lucy found it difficult to produce evidence that supported her belief, she said that she felt it "could happen" and so she engaged in compulsions "just in case". Evidence against was much easier to ascertain and was gathered from both the past and the present. This included statements, such as, "I never used to wash my hands after changing my shoes and no one in my family got ill" and "I have friends who play sports that involve lots of contact with the ground and they don't get ill". After discussing the evidence, Lucy said that the strength of her belief fell from 65% to 30%.

TESTING OUT BELIEFS

After considering evidence for and against her belief, Lucy discovered that she was unsure about whether someone would get ill if she did not wash her hands. She engaged well with the idea that an important next step in therapy would be to test this out. Together we created a hierarchy of feared situations. We ate with our hands after touching the floor and eventually licked our hands after rubbing the bottom of our shoes.

Lucy was consistently most anxious before carrying out a behavioural experiment and her anxiety would fall by at least half immediately after she engaged in the behavioural task. Research shows that the presence of a therapist decreases discomfort during exposure tasks (e.g. Röper & Rachman, 1976) and so Lucy was also encouraged to engage in self-directed exposure at home. By the end of therapy Lucy reported that she was able to rub the bottom of her shoe and lick her hand without feeling any anxiety.

SELF-DIRECTED EXPOSURE

Lucy tended to "forget" to do homework, sometimes she would remember to carry out behavioural experiments the day before our sessions, but most of the time she would forget to complete diaries and to put up reminders. We considered ways to overcome this and Lucy felt that her mother could play a role; however, she was also forgetful and so attempts to get Lucy to monitor her compulsions were largely unsuccessful. Motivational interviewing was key to increasing motivation to engage with behavioral experiments outside of therapy. Lucy also reported that improvements in her symptoms were much more significant when she did things at home and this motivated her further.

HABIT REVERSAL

In the latter stages of therapy, Lucy said that her belief relating to hand washing was "almost non-existent" and she described a number of times when she had left the house without washing her hands at all. However, the hand washing behavior continued whenever she was at home. Lucy described how hand washing had become a habit, she said that she felt no anxiety after touching her shoes but washed her hands multiple times "without thinking". We thought of lots of ways to reverse this habit, including putting the soap out of reach, learning to wash her hands like her mother and replacing hand washing with other behaviours (e.g. moisturising her hands, talking to her mother, mindful colouring etc.). These techniques worked to varying degrees; in the end Lucy found it most helpful to put a poster above the sink in the bathroom to remind her that she didn't need to carry out the hand washing ritual.

ENDING AND RELAPSE PREVENTION

In the final session we reviewed what had been achieved, session-by-session, and developed a therapy blueprint. This detailed techniques that Lucy had found particularly helpful, how to identify early warning signs, likely triggers and what to do if she experiences similar difficulties in the future.

OUTCOMES

As depicted in Figure 2, Lucy's self-reported symptoms and levels of impairment reduced over the course of therapy, as measured by the ChOCI-R. Previous research has shown that a total impairment score of 17 has adequate sensitivity and specificity to establish a

diagnosis of OCD (Shafran et al., 2003), indicating that Lucy was no longer meeting threshold for diagnosis at the end of our sessions.

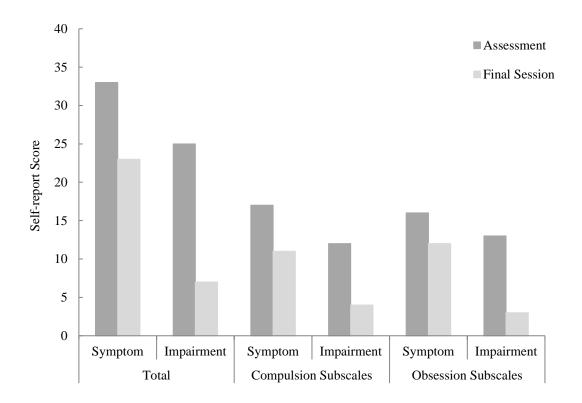


FIGURE 2; LUCY'S SELF-REPORTED SCORES ON THE CHOCI-R

Note. Impairment scores relate to the level of severity/distress caused by OCD symptoms, whereas symptom scores relate to the level of complexity and pervasiveness of symptoms. Total score range = 0 - 40, compulsion and obsession score range = 0 - 20.

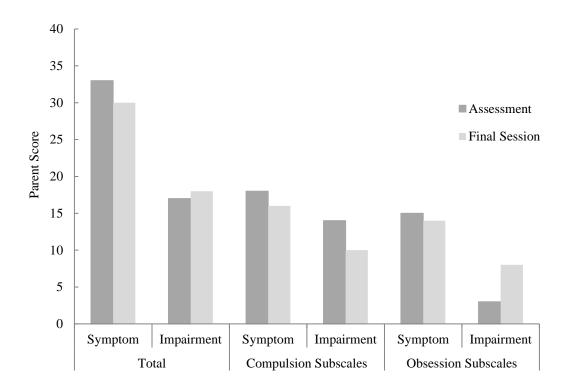


FIGURE 3; PARENT SCORES ON THE CHOCI-R

Note. Impairment scores relate to the level of severity/distress caused by OCD symptoms, whereas symptom scores relate to the level of complexity and pervasiveness of symptoms. Total score range = 0 - 40, compulsion and obsession score range = 0 - 20.

Figure 3 depicts the final session scores given by Lucy's mother. These demonstrate that she perceived higher levels of symptoms/impairment following treatment than did Lucy. This is particularly true for the level of obsession impairment, which Lucy's mother reported an increase in the severity of. This was surprising in the context of the improvements that Lucy's mother reported having seen in Lucy in the qualitative feedback that she gave and in the ratings that she gave on the OCD subscale of the RCADS (see Figure 5). This will be reflected on towards the end of this case report.

Figure 4 shows scores on the RCADS. Lucy's score on the OCD subscale had decreased notably in our final session relative to her self-reported score before therapy.

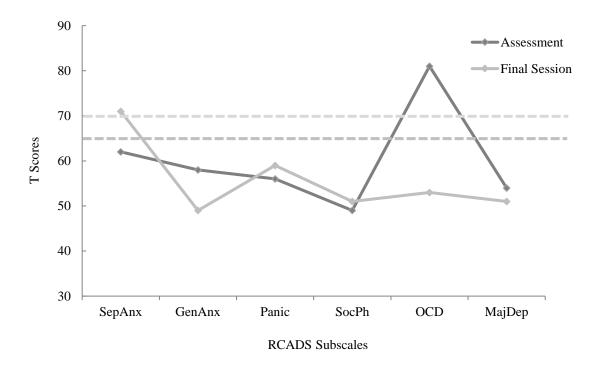


FIGURE 4; LUCY'S SELF-REPORTED SCORES ON THE RCADS

Note. SepAnx = separation anxiety, GenAnx = generalized anxiety, Panic = panic disorder, SocialPh = social phobia, OCD = obsessive compulsive disorder, MajDep = major depression. Dashed lines represent cut-off scores for clinical threshold for OCD diagnosis according to RCADS scoring criteria. A score of 65 represents borderline clinical threshold, 70 represents clinical threshold.

Before therapy, Lucy scored well above threshold on the OCD subscale only. At the end of therapy, Lucy was below clinical threshold on all subscales, except for separation anxiety, for which she was marginally above threshold. This score is consistent with qualitative feedback from Lucy's mother, who felt that although therapy addressed Lucy's OCD, she still experienced anxiety in relation to being separated from her mother. Lucy's score on the major depression subscale did not change in the course of therapy; this is consistent with her

presentation in our sessions, as her mood did not appear to fluctuate in relation to her level of anxiety.

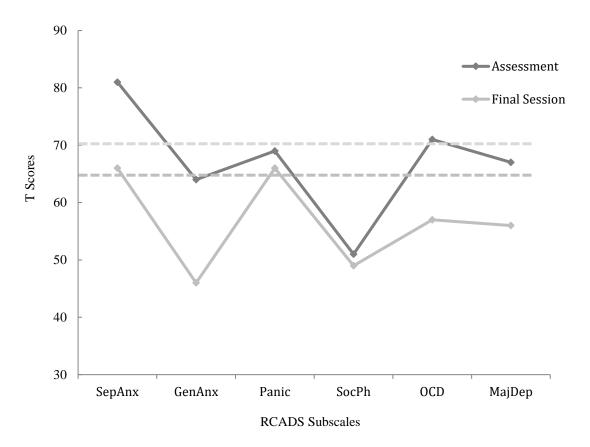


FIGURE 5; PARENT SCORES ON THE RCADS

Note. SepAnx = separation anxiety, GenAnx = generalized anxiety, Panic = panic disorder, SocialPh = social phobia, OCD = obsessive compulsive disorder, MajDep = major depression. Dashed lines represent cut-off scores for clinical threshold for OCD diagnosis according to RCADS scoring criteria. A score of 65 represents borderline clinical threshold, 70 represents clinical threshold.

There are some discrepancies between the scores reported by Lucy and those reported by her mother, but overall, Lucy's mother reported improvements across all subscales in the final therapy session relative to those given at assessment.

The final measure completed by Lucy and her mother was the SDQ. Importantly, Lucy reported an improvement on all subscales of the SDQ following therapy and her mother reported an improvement on all subscales except for peer relationships.

TABLE 1; SELF- AND PARENT-REPORT SCORES GENERATED ON THE SDQ

| | Self-report | | Parent | |
|------------------------|-------------|---------------|------------|---------------|
| | Assessment | Final session | Assessment | Final session |
| Total | 11 | 7 | 20 | 11 |
| Impact | 0 | 0 | 2 | 0 |
| Emotional | 6 | 3 | 6 | 3 |
| Conduct | 1 | 0 | 1 | 0 |
| Hyperactivity | 4 | 4 | 3 | 2 |
| Peer relationships | 0 | 0 | 2 | 3 |
| Prosocial behaviour | 6 | 9 | 8 | 9 |

Note. A lower score indicates improvement on all subscales except for the prosocial behavior subscale, for which a higher score indicates improvement.

A four-fold classification system has been developed for scoring the SDQ, this is based on a large UK community-based sample of scores and the classifications are as follows; 'close to average', 'slightly raised', 'high' and 'very high'. Of note, Lucy's mother reported her total

difficulties score to be in the very high range at assessment and close to average in our final session. Both Lucy and her mother reported her emotional difficulties score as high at assessment and close to average in our final session.

DISCUSSION

The CBT that was carried out with Lucy was successful from both an objective and subjective perspective. Objectively, her self-reported scores on standardised measures of OCD decreased to below clinical threshold and the level of difficulty she experienced fell to within the average range. Subjectively, both Lucy and her mother reported improvements in symptomatology. Lucy reported that she had found therapy to be helpful and her mother also confirmed that Lucy was no longer carrying out compulsive behaviours when our sessions ended. Lucy's mother described her as "much happier and more relaxed" and while Lucy tended to downplay her triumphs, she told me that she was proud of what she had achieved.

The improvements that Lucy experienced are consistent with the research evidence, which shows that CBT is effective in the treatment of OCD in young people (e.g. Abramowitz, Whiteside & Deacon, 2006 and Watson & Rees, 2008). CBT for OCD aims to shift inaccurate and unhelpful beliefs about the impact of engaging in, or not engaging in, a particular behaviour (in this case, failing to handwash and/or failing to check). Both cognitive and behavioural techniques were key to shifting Lucy's beliefs. In particular, cognitive work was more pertinent in shifting beliefs about checking, whereas ERP was key to shifting beliefs about contamination. This difference in emphasis emerged in response to the nature of Lucy's beliefs, as well as the likelihood of her feared consequences occurring. With regards to limitations, what Lucy and I achieved together in therapy did not impact on the social challenges that she continued to face. This case highlighted to me the importance

of systemic factors in a way that I have not been exposed to before. I will always be more aware of such influences in my future work, as well as the limitations of being a clinical psychologist working in the context of complex social difficulties.

REFLECTIONS

I very much enjoyed working with Lucy, she was polite and engaged but also dubious at times (particularly when prompted to eat things off the floor), but I enjoyed the challenge of getting Lucy onboard with ERP and it was rewarding to see her bravery in trying out the peculiar tasks that were suggested to her. The work was also frustrating at times, as Lucy did not engage well with doing tasks outside of our sessions. I felt that this slowed progress considerably. On reflection, it might have been helpful to spend time alone with Lucy's mother, to check out her understanding of the importance of encouraging Lucy to engage with therapy outside of sessions. Towards the end of therapy, Lucy started to challenge herself between sessions and subsequently reported much greater improvements. Lucy reached her checking goals around the midpoint of therapy but did not reach her goal to stop hand washing until our final session. At this point, I wished that we had had more sessions, or the opportunity for a follow up session, as I felt dubious about Lucy's motivation to problem solve any recurrence or setbacks. Lucy's improvements felt somewhat fragile and I don't think that the new 'OCD free' Lucy had become a tangible part of her identity when we ended. This seems to be reflected in the final session ChOCI, as when asked to name her compulsions she listed hand washing, checking the door and checking the cooker, despite reporting that she was no longer engaging in these behaviours.

Involving Lucy's mother in sessions was invaluable, particularly in educating her about OCD and ERP, and in allowing Lucy to delegate some of the responsibility that she had taken on in the context of her mother's illness. It was also helpful to get feedback from her

regarding her opinion on Lucy's progress. In the context of this it was disappointing to see the scores that she gave for Lucy on the ChOCI in our final session (see Figure 3). I chose to take this to supervision to reflect on what might have been going on. On reflection, I wonder whether involving Lucy's mother in our sessions exposed her to the extent of her daughter's difficulties and subsequently explains why she reported that Lucy's level of impairment had increased in our final session. Lucy's mother was also receiving individual therapy for anxiety during the time of my sessions with Lucy and it is possible that a heightened score reflected her heightened anxiety about Lucy's sessions coming to an end. Indeed, Lucy's mother described being exhausted by all the social and parental demands placed on her and I think that by holding Lucy's anxiety I provided some respite for her. It was not possible to follow up this discrepancy in scores due to the time constraints of being a trainee on a sixmonth placement, which has been a recurring source of frustration. Time limitations also prevented the opportunity to follow up with Lucy, which would have been valuable in the context of her recovery feeling fragile. Instead I was left wondering whether all of the hard work that Lucy and I had done was going to be short lived. However, in the context of funding limitations and restrictions on services, this was a valuable learning experience. The dilemma of when to end sessions is not something that I anticipated prior to training but demonstrates well the complexities of being a clinical psychologist in an increasingly stretched NHS.

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CASE STUDY III

COGNITIVE BEHAVIOUR THERAPY FOR SOCIAL PHOBIA IN AN ADULT WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

This case study presents the formulation and treatment of social phobia in a 36-year-old male with Asperger's syndrome. This gentleman was referred for cognitive behaviour therapy that was adapted for Autism Spectrum Disorder (ASD). An individualized and adapted approach was used throughout treatment with this client, whose negative experience of growing up with ASD had led to an intense fear of being perceived to be "stupid" by others. Therapy was successful in reducing symptoms of social phobia and this client was discharged following 11 of a possible 20 sessions. Reflections will focus on the use of transparency as a therapeutic tool and on the decision to end sessions early following a successful outcome.

INTRODUCTION

AUTISM SPECTRUM DISORDER

Autism Spectrum Disorder (ASD) describes a cluster of neurodevelopmental conditions that have three key features in common 1) social communication difficulties 2) social interaction difficulties and 3) impairment in social imagination/flexible thinking (American Psychiatric Association, 1994). ASD occurs in approximately 0.6% of the population, is considered to be present at birth (e.g. Kuban, O'Shea, Allred, Tager-Flusberg, Goldstein & Leviton, 2009; Matson, Wilkins, Sevin, Knight, Boisjoli & Sharp, 2009; Watson, Baranek & DiLavore, 2003) and is most frequently diagnosed in childhood (Fombonne, 2005). However, the difficulties experienced by some young people can be subtle and thus remain unnoticed until early adulthood, when the demands placed on a person increase considerably (Cath, Ran, Smit, Van Balkom & Comijs, 2007). At this time, it is not uncommon for people with undiagnosed ASD to present to services with co-morbid mental health difficulties; unfortunately, ASD might continue to be overlooked in such circumstances, due to professionals working in adult services being less attuned to the ASD phenotype (Jones, 2000). Awareness of ASD has increased considerably in recent years, leading to a surge in the number of adults who receive diagnosis following a long history of difficulties that have been misunderstood (Howlin & Moss, 2012). Unsurprisingly, this can have a considerable impact on mental health functioning.

SOCIAL PHOBIA AND ASD

Social phobia is characterised by an intense fear of humiliation or negative evaluation in social situations (Veale, 2003). The prospect of social encounters leads to intense anxiety for individuals with social phobia and such encounters are thus avoided or endured only with the aid of safety behaviours. The presence of anxiety can have debilitating consequences on

an individual's life; distress regarding social situations may serve as a barrier to education, employment and establishing meaningful social relationships (Tantam, 2000). The lifetime prevalence of social phobia in the general population is estimated to be 8% (American Psychiatric Association, 1994; Costello, Egger & Angold, 2005; Grant, Hasin, Blanco, Stinson, Chou, Goldstein et al., 2005).

Research suggests that individuals with ASD may exhibit significantly higher levels of anxiety than the general population (Bellini, 2006; Gillott, Furniss & Walter, 2001; Green, Gilchrist, Burton & Cox, 2000; Kim, Szatmari, Bryson, Streiner & Wilson, 2000). Indeed, when first describing autism, Kanner (1943) suggested that the core symptoms of autism are anxiety-driven. A relatively recent systematic review revealed that 39.6% of young people with ASD have at least one comorbid DSM-IV anxiety disorder (van Steensel, Bögels & Perrin, 2011) and the National Autistic Society estimates that 40% of people with an ASD also have at least one anxiety disorder at any time, compared with only 15% of the general population. With regards to social phobia, this was the third most commonly co-occurring anxiety disorder. The prevalence of social phobia in young people with ASD was found to be 16.6%, which is approximately twice that of the rate reported in young people who do not have a neurodevelopmental disorder. Increased prevalence rates amongst those with ASD are perhaps unsurprising in the context of the social communication and social interaction difficulties that are experienced (Fombonne, 2005; LoVullo & Matson, 2009).

Despite increased prevalence rates, research shows no discrepancies between the level of distress experienced by adults with social phobia and that experienced by adults with social phobia and comorbid ASD (Cath, Ran, Smit, Van Balkom & Comijs, 2007). Thus, ASD might increase vulnerability to social phobia, but once threshold for social anxiety has been reached, difficulties experienced by those with and without comorbid ASD do not seem to

vary. In addition, adults with social anxiety present with deficits in social skills that are comparable to those demonstrated by adults with ASD (Cath et al., 2007). The similarities in presentation suggest that treatments that have been developed for adults with social anxiety should also be efficacious in the treatment social anxiety in the context of ASD.

CBT FOR SOCIAL PHOBIA IN THE CONTEXT OF ASD

There is a strong evidence base for the use of CBT in the treatment of social anxiety (for a meta-analysis, see Hofmann & Smits, 2008). With regards to autism, positive outcomes from CBT for anxiety have been found to be ubiquitous in adults with and without comorbid ASD (Lang, Regester, Lauderdale, Ashbaugh & Haring, 2010).

With this in mind, a cognitive behavioural model of social phobia (Wells & Clark, 1997) was adopted in the treatment of the client described throughout this report. Given that most people experience negative social interactions, the cognitive behavioural model proposes that it is the interpretation of the interaction that is crucial in cases of social phobia. The model maintains that in social phobia, a social situation activates an individual's assumptions about their inability to convey a favorable impression of themselves to others. Given these assumptions, people with social phobia perceive danger in social situations, leading to anticipatory worry (e.g. "I will stumble over my words") and/or negative automatic thoughts (e.g. "this person thinks I am stupid"). A key feature of this model is the 'processing of self as a social object', which the authors describe as a response to the perception of danger. Self-processing describes a shift in attention towards processing the self in relation to detailed self-observation and monitoring; information gathered in this process is used by the social phobic to make inferences about how they appear to others and how others are evaluating them. Safety behaviours emerge as a means of preventing social catastrophe, but function to maintain anxiety over time by contributing to heightened self-

focus, prevention of disconfirmation, drawing attention to the self, feared symptoms (e.g. trembling, sweating) and contamination of the social situation (e.g. by making the individual with social phobia appear unfriendly). Often social situations are avoided altogether, thus preventing disconfirmation of beliefs. Post event processing also contributes to the maintenance of social phobia overtime, as the individual with social phobia scrutinises social encounters and draws negative conclusions regarding their performance.

CASE DESCRIPTION

REFERRAL AND PRESENTING DIFFICULTIES

Adam was referred to a specialist adult autism service by his GP after he self-referred to Improving Access Psychology Therapies (IAPT) and was considered by them to require more specialist input than they were able to offer. Adam self-referred to IAPT following a long history of low mood and general anxiety but felt that both had improved greatly during the time he waited for the present treatment to begin. Adam waited three years from seeking treatment with IAPT to our initial session. Adam attributed improvements in his symptomatology to Citalopram, which had been prescribed by his GP. At our initial session, he described his presenting difficulty as social phobia.

PREDISPOSING FACTORS

From information gathered in our sessions, it appeared that Adam's ASD and anxiety were interrelated and served to maintain his difficulties. As is common for adults with an ASD, Adam experienced several negative early life experiences as a consequence of being undiagnosed and misunderstood. Adam experienced a lack of empathy from teachers and bullying from peers and these distressing experiences led him to develop an intense fear of

being perceived to be "stupid" by other people. It is this fear that emerged as underlying Adam's social anxiety.

Several features of ASD predisposed Adam to difficulties, such as, his preference for familiarity. Adam found unfamiliarity to be anxiety provoking and this contributed to his trepidation about meeting new people and going to new places. Adam's tendency to all or nothing/black and white thinking also played a role, as any social interaction that was not "perfect" was perceived by him to be disastrous and proof of the fact that he would "never socialise like a normal person". Of course, difficulties in social communication and social interaction are core features of ASD. In the context of this, Adam found it difficult to 'read between the lines' in conversations, often leading to miscommunication and misunderstanding. It was these interactions that Adam felt portrayed him as "stupid". Adam also lacked curiosity in the interests of others, which he reported to make meeting new people and making small talk challenging.

PERPETUATING FACTORS

Avoidance played a key role in maintaining and perpetuating the social anxiety that Adam experienced. He described avoiding social situations and people that were not familiar to him, as he felt that by avoiding such situations he would also avoid being judged negatively. However, avoidance prevented Adam from being able to test out the negative predictions that he was making (e.g. "I won't be able to think of things to say", "it will be awkward", "people will not enjoy talking to me").

We also identified that Adam was engaging in safety behaviours when socialising.

Particularly drinking alcohol, trying not to attract attention, talking less, rehearsing sentences in his mind, and staying on the edge of groups. Following psychoeducation, Adam

was able to recognise how these behaviours reduced the anxiety that he felt in the short term but maintained it in the long term.

STRENGTHS AND PROTECTIVE FACTORS

Adam had many strengths. It was possible to have a flexible reciprocal conversation with Adam. He did not consistently use eye contact to regulate social interaction but was able to use facial expressions to reflect his thoughts. Adam was polite and responsive in social situations. He lived with a friend who he described as being very supportive; he also had a social network and felt that friends approached him for "logical solutions to their emotional problems". Adam was in long-term employment; he supported young people with mental health difficulties in a mainstream secondary school. He was also a talented artist, a creative writer and had a keen interest in renaissance fencing. Adam was motivated, determined and a pleasure to work with.

PRESENTATION

FORMULATION AND MODEL

The National Institute for Health and Clinical Excellence (NICE, 2012) makes several recommendations for the treatment of co-existing mental health difficulties in adults with ASD. Guidelines that were relevant in the context of the features of ASD that Adam presented with were; 'avoidance of excessive use of metaphor and hypothetical situations', 'placing greater emphasis on changing behaviour, rather than cognitions', and 'maintaining the person's attention by incorporating their special interests into therapy' (NICE, 2012). NICE also recommends that clinicians delivering therapy to people with ASD should understand the core symptoms of autism, as well as advice from a specialist autism team;

crucially, this case was supervised by a clinical psychologist in a specialist adult autism service.

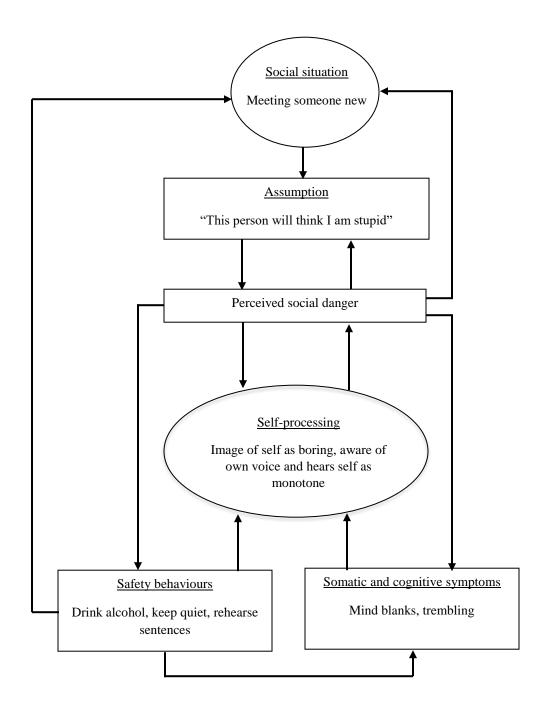


FIGURE 1; A COGNITIVE-BEHAVIOURAL FORMULATION TO DESCRIBE THE FEATURES OF ADAM'S SOCIAL PHOBIA IN A TYPICAL SITUATION

GOALS

Adam developed three goals for our work together:

- 1) To stop catastrophising
- 2) To socialise more, particularly with new people
- 3) To organise social events

ASSESSMENT MEASURES

All questionnaires described below were self-report measures that were completed by Adam in session one and session ten. These are standard measures that were used by the team to evaluate outcomes.

The first measure that was completed by Adam was the CORE Outcome Measure (CORE-OM; Evans, Connell, Barkham, Margison, McGrath, Mellor-Clark et al., 2002), which is a measure of global psychological distress. This measure consists of 34 items that are responded to on a 5-point Likert scale, ranging from 'not at all' to 'most or all of the time'. The client responds to the questions in relation to how they have been feeling over the past week and scores are averaged to produce a rating of distress that ranges from 'healthy' to 'severe'.

Next, the Work and Social Adjustment Scale (WSAS; Mundt, Marks, Shear & Greist, 2002) was completed to assess the impact of Adam's difficulties on day-to-day functioning, particularly in the domains of work, home and social life. The five items in this measure are responded to on a scale of 0 to 8, with 0 indicating no impairment at all and 8 indicating very severe impairment. With regards to determining overall degree of impairment, a total

score between 1 and 10 indicates mild functional impairment, 11-20 indicates moderately severe functional impairment and scores above 21 indicate severe functional impairment.

The Toronto Alexithymia Scale (TAS-20; Bagby, Parker & Taylor, 1985) was included as a measure of alexithymia, that is, difficulty in identifying and describing one's own emotions. This 20-item measure includes three subscales that map onto the difficulties experienced in alexithymia; 1) difficulty in describing emotions, 2) difficulty in identifying emotions and 3) externally-oriented thinking, which assesses the tendency of individuals to focus their attention externally. Each item in the TAS-20 is responded to on a 5-point Likert scale, in which 1 = strongly disagree and 5 = strongly agree. Summing the responses to each item derives a total alexithymia score. The following cut off scores can also be applied; $\leq 51 = \text{non-alexithymia}$, 52 - 60 = possible alexithymia, $\geq 61 = \text{alexithymia}$.

Finally, the 12-item version of the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0; Üstün, Chatterji, Kostanjsek, Rehm, Kennedy, Epping-Jordan et al., 2010) was completed. The WHODAS 2.0 is a measure of disability across six domains i.e. cognition (understanding & communicating), mobility (moving & getting around), self-care (hygiene, dressing, eating & staying alone), getting along (interacting with other people), life activities (domestic responsibilities, leisure, work & school) and participation (joining in community activities). Items are scored on a five-point scale, ranging from 0-4 (0 = none and 4 = severe, extreme or cannot do) and the sum of the scores of the items across all domains constitutes a statistic that is sufficient to describe the degree of functional limitations (0= least severe and 100= most severe).

INTERVENTION

Funding in this team was provided on a session-by-session basis and each client who is accepted for treatment is offered and funded for 20 sessions of individual therapy. However, just 11 sessions of CBT were completed with Adam. Treatment took place over a three-month period, in which sessions were held weekly. After session eight we had a four-week break for Adam to apply what he had learned. Adam also disengaged for a fortnight after session 10, which he said he did to avoid our sessions ending. This avoidance of ending will be considered in the reflections section of this case report.

BUILDING ON EXISTING KNOWLEDGE OF CBT

Adam arrived at therapy with a clear idea of his difficulties, which he had mapped out in detail, and his therapeutic goals. The initial sessions were used to introduce Adam to CBT. Due to his role in supporting young people with mental health difficulties, Adam had some knowledge of CBT and was able to build on this in our sessions with relative ease. We developed basic 'hot-cross bun' formulations using Adam's own examples, as they were more relevant and meaningful to him. Adam noticed that his tendency to catastrophise impacted greatly on his mood and subsequent behavior. At this point, the concept of unhelpful thinking styles was introduced, and Adam found it helpful to consider those that he engaged in at times when he noticed his mood worsening or anxiety increasing. Next, the concept of thought challenging was introduced. We used thought challenging techniques together in sessions and Adam was keen to apply these techniques outside of our sessions too. Adam found it to be particularly helpful to notice times that he was catastrophising and to consider evidence for and against each distressing thought. Thought challenging is a technique that we often returned to in sessions and Adam's success in applying these techniques improved throughout the course of treatment.

MINDFULNESS AND THOUGHT DEFUSION

As an adjunct to thought challenging, the concept of thought defusion was introduced to Adam. Adam described patterns of becoming 'obsessed' with particular thoughts. He quickly got caught up in a negative cycle of increasingly catastrophic thoughts and it was evident that Adam would find it helpful to learn to take a step back from thoughts at these times. We practiced thought defusion techniques, such as, 'leaves on a stream' and mindfulness exercises, such as, mindful breathing and body scan. Adam found these techniques to be helpful and downloaded the 'MindShift' app to facilitate his practice at home. He reported using the app on his commute to and from work and found that this provided focus and a sense of calm ahead of busy days.

Social Anxiety: Formulation and Psychoeducation

Adam found that his mood improved after he learned these initial techniques that he could generalise to unhelpful thinking across contexts. Next, we shifted the focus of our attention to social anxiety. We worked collaboratively and developed a joint formulation of Adam's social anxiety (see Figure 1) and extended this 'here-and-now' formulation to consider early experiences that could underpin his fear of being perceived to be stupid. It was a poignant moment in therapy when Adam realised that his current fear of being perceived to be stupid linked to early experiences of being bullied and misunderstood; Adam described this as a "light-bulb" moment. Psychoeducation on the role of avoidance and safety behaviours in maintaining social anxiety was provided and Adam found it particularly helpful to consider what maintained his anxiety. Adam was motivated to engage in exposure and behavior experiments to test out his anxious predictions, which he often phrased as "doing the opposite of what the anxiety is telling me to do".

BEHAVIOURAL EXPERIMENTS

It is likely that Adam's strong motivation to engage with behavioral experiments outside of sessions related to several factors, including, his improved mood, evidence from initial sessions that therapy can be effective, his determined personality and his confidence in me (which was encouraging, but also daunting at times). It was helpful that Adam already had hobbies and a small social network, as this meant that there were regular opportunities for him to be exposed to social gatherings.

Behavioural experiments began by Adam engaging in the things he had previously avoided, we then worked on him engaging in these activities whilst dropping safety behaviours. For example, Adam was anxious about initiating conversations. To address this, we set up an experiment that involved him initiating conversations with people he wasn't familiar with at a friend's birthday party. Adam enthusiastically fed back on how well this had gone; however, when exploring this further it emerged that Adam had consumed alcohol as a first step when arriving at the party. Adam reveled that in the past his drinking behavior had become problematic, as he relied on it in order to socialise. By returning to our formulation we were able to agree that a logical next step in addressing Adam's social anxiety would be to socialise in the absence of alcohol.

Following each behavioural experiment we reflected in detail on what Adam had learned. He described the following learning points as being key; "I often make a good impression when I socialise" and "even if I don't make a good impression when I socialise, I can cope".

UPDATING INACCURATE SELF-PROCESSING

Adam strongly believed that he tripped over his words and experienced long, awkward silences in social interactions. He also felt that his voice was monotone and that he was

perceived by others to be boring. To modify this, Adam was exposed to his true observable self. An assistant psychologist joined us in one of our sessions to chat to Adam for 10 minutes. She provided feedback and the interaction was also recorded and reviewed by Adam and myself in a subsequent session. This component of treatment was particularly powerful; Adam was pleased to learn that the long pauses that he experienced were not noticeable to others and that his voice was not monotonous, as he had anticipated. Following reviewing the recording, Adam felt that he appeared "much more normal" in social situations than he imagined.

SOCIAL SKILLS TRAINING

Difficulty in sharing the interests of others was one way in which ASD manifested itself in Adam. He felt that this resulted in particular difficulties when meeting new people, for instance when making small talk or getting to know people who might not share the same interests. We used role-play to allow Adam to practice ways in which he can ask about the interests of others. Normalising the idea that everyone has different interests was also helpful in reducing Adam's anxiety when meeting someone he had little in common with.

THERAPEUTIC BREAK

By session eight Adam described his mood as 9 out of 10, with 10 being the best that it had ever been. By session nine, he had volunteered to speak publicly for a charity in front of up to 100 people. We considered what would be helpful for Adam to work on given the considerable progress that he had made by this point. Adam still held the belief that he was an "imposter" within his group of friends. That is, he felt that he was invited to parties as a "friend of a friend", as opposed to being invited because others enjoy his company specifically. Adam felt that, in order to test out this belief, he would have to organise his own social event to invite people to. With this and Adam's progress in mind we decided to

have a four-week break from sessions in order for Adam to put into practice all that he had learned. Adam agreed to engage in behavioural experiments during this time so that we could subsequently problem solve any obstacles.

When Adam returned to therapy he felt that he had fully achieved the goals that we set out in session one. During the break he had continued to engage in behavioural experiments, whilst dropping all safety behaviours, and had set up a role-playing group for himself and his friends, which he had received rave reviews on. Given Adam's tendency to think in black and white, I was mindful of the possibility that this was being played out in his enthusiasm for having achieved his goals in just 10 sessions. We explored this in session (despite my anxiety about the possibility of this conversation 'bursting his bubble'). Adam very eloquently described how his experiences in therapy differed from previous experiences of socialising "perfectly" or "disastrously". He explained how therapy had allowed him to carefully and methodically build a strong foundation on which to base his new, more accurate beliefs about himself and his ability to socialise. With this in mind, we decided to meet for one final session to develop a therapy blueprint, which Adam started to work on as homework.

ENDING

Adam did not attend for three weeks following session 10 and when he did arrive for his final session, he was 30 minutes late. Adam confirmed that this was due to avoidance, he described "burying his head in the sand" to avoid therapy ending. In the final 30 minutes that we had, we reviewed what had been achieved and reflected on the therapy blueprint that he had worked on between sessions. This blueprint detailed techniques that Adam had found particularly helpful, how to identify early warning signs, likely triggers and what to do in case these happen. Adam was concerned that if things got difficult in the future he would

discount all the progress he had made in therapy, so we decided that it would be helpful for him to write a letter to this potential future self. Included in this letter would be Adam's current thoughts and feelings on his therapeutic journey and the progress that he had made. He decided he would seal this letter and open it only if he experienced doubt in himself in the future.

Adam had demonstrated a good grasp of therapeutic techniques throughout our sessions and so we were able to review the blueprint in the 30 minutes that we had remaining. Adam was tearful when saying goodbye, but I felt happy and proud of what he had achieved. Adam had particular strengths in generalising what he had learned in therapy for himself and others (he reported using CBT techniques to help a friend with a relationship dilemma), and I was confident in his capacity to do this in order to stay well in the future.

Given that Adam and I felt that it was appropriate to end at session 11, and yet he was offered 20 sessions, there was potential for me to offer follow up appointments. This is not something that training had previously provided an opportunity for and so I was keen to offer, and Adam was keen to accept. However, the team held a strict 'did not attend' (DNA) policy, which stipulates that clients are discharged following two DNAs. When Adam DNA'd twice prior to our final session, I took this to supervision and my supervisor gave me the autonomy to decide whether to offer a follow up appointment. Adam did not have a follow up appointment and reflections on making this decision are included in the Reflections section of this report.

OUTCOMES

By the end of sessions, Adam reported that he had fully achieved his goal to socialise more. With regards to catastrophising, Adam noticed his tendency to jump to negative conclusions in response to certain situations but was able to respond using thought challenging or thought defusion and thus prevent catastrophic misinterpretation. Adam's score across all outcome measures corroborated the positive outcomes that he described.

With regards to Adam's CORE-OM score, this was 1.56 in session one, reflecting moderate levels of distress. In session 10, Adam's CORE-OM score had fallen to 0.47, which is within the non-clinical range and demonstrates a clinically significant improvement in his level of global distress following treatment.

The WSAS was included to determine the impact of Adam's mental health difficulties on his ability to function in daily life. His pre-treatment score was 14, indicating moderately severe functional impairment. Following treatment, Adam's score reduced to 7, which demonstrates only mild impairment and an increase in his ability to function in terms of work, home management, social leisure, private leisure and personal or family relationships.

Adam's TAS-20 score was 47 before therapy and 42 afterwards, this illustrates that Adam was below threshold for diagnosis of alexithymia prior to treatment ($\leq 51 =$ non-alexithymia). Adam's scores reflect slight improvement in his ability to understand, process and describe emotions following therapy.

The final outcome measure completed by Adam was the WHODAS 2.0, which was included to determine the degree of functional impairment. Overall scores on this measure are given as a percentage whereby 0 = least severe impairment and 100 = most severe impairment. Adam's pre-treatment score was 43.75% and his post-treatment score was 10.42%.

REFLECTIONS

I appreciated the autonomy that my supervisor gave me on this case. I am encouraged by the trust that she placed in my ability to formulate and deliver this treatment relatively autonomously. That is not to say that I wasn't supported by my supervisor, but that she understood my strengths and needs, and provided an opportunity for me to grow in confidence as I progressed through training. The decision about when to end sessions with Adam is a particular example. I was keen to experience having a follow up session with a client, particularly a client who had experienced considerable improvements in such a short period of time; however, this was in conflict with the service's policy regarding DNA's. Given my role as a trainee in the service, my supervisor offered flexibility with regards to this policy and so the decision became one about whose needs were being met by the follow up session – Adam's or mine. Adam was keen to have a follow up appointment, but as we explored this further it became clear that the function of this was that it allowed him to avoid ending. With this in mind, I decided not to offer follow up and Adam agreed that this was the most helpful decision for him, despite the anxiety that he felt about it.

As I grow in confidence, I have learned the value of using transparency as a therapeutic aid. When I got stuck in sessions, I shared this with Adam and we problem solved together. I also shared my apprehension in deciding when to end our sessions. I feel that this promoted a strong, collaborative relationship, which encouraged Adam to share ownership of his treatment.

This case provided several opportunities for me to reflect on the rationale behind the therapeutic decisions that I make, particularly when this rationale is grounded in my own needs and experiences. Learning to use reflection in this way has been invaluable in developing my therapeutic skills.

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CASE STUDY IV

COGNITIVE BEHAVIOUR THERAPY FOR LOW MOOD IN THE CONTEXT OF CHRONIC PAIN AND COMPLEX PHYSICAL HEALTH COMORBIDITIES

Supervised by: Dr. Helen Lister

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ABSTRACT

This case study presents a cognitive behavioral therapy intervention for depression in a 68-year-old male who had experienced poor and worsening physical health for 17 years prior to referral. An individualised cognitive behavioural approach was used throughout treatment with this client; this was integrated with cognitive defusion and mindfulness techniques to manage symptoms of depression, anxiety and chronic pain. Therapy was successful in ameliorating symptoms, such that he no longer met clinical threshold for depression at the end of treatment. In general, the client felt that he had greatly improved his quality of life when sessions ended. Reflections focus on the complexity of working with comorbid physical and mental health difficulties, and on the benefits of employing an integrative and client-centred approach to treatment.

INTRODUCTION

DEPRESSION IN OLDER ADULTS

Epidemiological research suggests that the prevalence of major depressive disorder (MDD) is lowest in older adults compared to all other age groups (Hasin, Goodwin, Stinson & Grant, 2005). Most large-scale studies show that the prevalence of MDD in a community sample of older adults ranges from 1-5% (e.g. Hasin et al., 2005), although many consider this to be a low estimate. MDD in older adults is said to be under-diagnosed and under-recognised (e.g. Rodder, Walker & Carter, 2011), possibly due to cohort beliefs about seeking help for mental health difficulties (Pachana, 2008) and/or the belief that the emergence of depression in later life is inevitable (Burroughs, Lovell, Morley, Baldwin, Burns & Chew-Graham, 2006). In general, accurate diagnosis and effective treatment is crucial given that depression in those over 65 tends to be more severe and riskier, with suicide rates being higher among older adults than younger adults (Fiske, Wetherell & Gatz, 2009).

The same criteria are used for diagnosing depression in both working age and older adults and is dependent on guidelines set out by the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-5; American Psychiatric Association, 2013). In order for a diagnosis to be given it is necessary for either depressed mood and/or anhedonia (loss of interest) to be present. The symptoms must also cause distress and persist for at least two successive weeks. Other symptoms include loss of energy, disturbed appetite and sleep, feelings of worthlessness, difficulty concentrating, psychomotor agitation and suicidal ideation. Presentation has been found to vary in relation to age, with older adults being more likely to present with somatic disturbances, such as, disturbed sleep and anhedonia, and less

likely to report feelings of sadness (e.g. Christensen, Jorm, Mackinnon, Korten, Jacomb, Henderson & Rodgers, 1999; Prince, Beekman, Deeg, Fuhrer, Kivela, Lawton et al., 1999).

Among older adults who receive an MDD diagnosis, more than half are reported to be experiencing the first episode (Brodaty, Luscombe, Parker, Wilhelm, Hickie, Austin et al., 2001; Bruce, 2002). With regards to what leads an adult to become depressed in later life, this is considered to be a result of complex interactions between age-associated neurobiological changes and stressful life events (e.g. Brodaty et al., 2001; Hickie, Naismith, Ward, Turner, Scott, Mitchell et al., 2005). The onset of depression in older age is also associated with disability, increased mortality, and poorer outcomes from physical illness (Rodder, Walker & Carter, 2011).

PHYSICAL HEALTH AND MENTAL HEALTH: COMPLEXITY AND COMORBIDITY

Poor physical health is a risk factor for developing depression in later life (e.g. Aziz & Steffens, 2013; Beekman, Deeg, van Tilburg, Smit, Hooijer & van Tilburg, 1995*a*; Berkman, Kasl, Freeman Jr, Leo, Ostfeld et al., 1986; Geerlings, Beekman, Deeg & Van Tilburg, 2000; Gurland, 1983; Murrell, Himmelfarb & Wright, 1983; Schulberg, Saul, McClelland, Ganguli, Christy & Frank, 1985). Indeed, long-term health difficulties can diminish functional abilities, limit independence and reduce quality of life. Rates of depression are also higher in medical inpatients (10-12%) and medical outpatients (5-10%; Blazer, 2003; Djernes, 2006). The relationship between physical health and depression is also complicated further in instances where chronic pain is present.

There exists strong evidence for a relationship between depression and chronic pain; people with depression experience more pain and people who suffer from chronic pain are significantly more likely to be diagnosed with depression than the general population

(Karapetyan & Manvelyan, 2017). Chronic pain can also exacerbate difficulties, as sleep disturbances, lack of physical activity, loss of appetite and low energy levels function to worsen depressive symptomatology. The interrelatedness of depression and pain make diagnosis difficult and depression in chronic pain frequently remains undiagnosed and thus untreated. Encouragingly, there exists good evidence that depression in the context of chronic pain can be treated when it is accurately diagnosed (for a systematic review and meta-analysis of randomised control trials of CBT for chronic pain, see Morley, Eccleston & Williams, 1999).

TREATMENT OF PHYSICAL AND MENTAL HEALTH COMORBIDITIES IN OLDER ADULTS

The National Institute for Health and Clinical Excellence (NICE) does not offer particular guidelines for the treatment of comorbid difficulties in older adults. With regards to the treatment of depression, NICE (2009) recommends antidepressant medication combined with CBT or interpersonal therapy. Research shows that CBT alone produces significant reductions in depressive symptoms in older adults and is also more efficacious than pharmacotherapy at three and six-month follow-up (Laidlaw, Davidson, Toner, Jackson, Clark, Law et al., 2008). In particular, CBT is shown to be efficacious in improving mood, reducing pain and restoring function in individuals with chronic pain (Morley et al., 1999). In this instance, CBT was also supplemented with thought defusion techniques in response to growing evidence that ACT techniques are effective in the treatment of chronic pain (e.g. Buhrman, Skoglund, Hussell, Bergstron, Gordh, Hursti et al., 2013; Dahl, Wilson & Nilsson, 2004; Thorsell, Finnes, Dahl, Lundgren, Gybrant, Gordh et al., 2011; Wetherell, Afari, Rutledge, Sorrell, Stoddard, Petkus et al., 2011; Wicksell, Ahlqvist, Bring, Melin & Olsson, 2008; Wicksell, Kemani, Jensen, Kosek, Kadetoff, Sorjonen et al., 2012).

CASE DESCRIPTION

REASON FOR REFERRAL

David was referred by a Psychiatric Liaison Nurse (PLN) who assessed him on admission to hospital following bleeding from a perianal wound, which was a result of previous surgery. The PLN described how David had complex physical health problems, all of which were detrimentally affecting his day-to-day life in terms of functional ability and quality. In particular, he was reported to have experienced deterioration in his mood with tearfulness, reduced concentration and lack of motivation. The referral stated that, in spite of the physical health challenges he faced, David was keen to engage in psychological therapy to return to some semblance of normality in terms of activities of daily living and to improve his quality of life. This was David's first presentation to mental health services and no current or previous risk to self or others was identified at the time of referral.

PRECIPITATING FACTORS

The onset of David's low mood was precipitated by a long history of severe and complex physical health difficulties. He had experienced two acute myocardial infarctions, requiring coronary artery bypass graft operations, and had been diagnosed with bowel cancer, resulting in the removal of the majority of his bowel and a permanent colostomy bag. David was given a poor prognosis following the cancer diagnosis and thus sold the businesses that he owned and gave the money to charities. As a consequence, David's days became characterised by financial difficulties, a lack of meaningful activities and recurring health problems. David also described having been in pain for 10 years prior to therapy. He described pain as the first thing that he was aware of each morning.

Presenting Difficulties

The initial assessment was carried out over two one-hour sessions. A slightly longer assessment period was deemed to be necessary in the context of David's complex physical health history. In these sessions, it was established that David's mental health had deteriorated particularly in the past year; he described feeling as if he had been in a "black hole" during this time. He was hopeless, severely lacking in interest, motivation and energy, experiencing difficulty concentrating, and had lost all sense of having control over his life. David explained that the deterioration in his mood had coincided with his deteriorating physical health and chronic pain, which made it difficult for him to engage in everyday activities, such as walking, sleeping and cooking. David spent up to 24 hours a day sitting in a chair in his lounge. Medical equipment filled his bedroom and prevented him from sleeping in his bed, and he left the house only to buy food or attend hospital appointments. Following withdrawal from activities, David described having lost his confidence in carrying out previously surmountable tasks e.g. filling in forms and walking his dog. In our initial session, David also reported experiencing anxiety "all the time" in relation to worries about his physical health.

SOCIAL NETWORK

David had a reduced social network, with just one close friend who visited daily to walk his dog. Aside from this, the only social contact that David had was with nurses who visited twice daily and a carer who visited daily to support David to clean his home. David attributed being socially isolated to his illness, which had resulted in him having to move home and prevented him from being able to keep in contact with friends. David was divorced and had one daughter who he was not in contact with; he described having reduced his contact with her due to feeling that he was a "burden"

INTERVENTION

Twelve sessions of CBT were completed with David over a period of four months. Several breaks were necessary towards the end of our work together due to annual leave and David being admitted to hospital for surgery. Sessions lasted approximately one hour and were completed either in David's home or in the community depending on our agenda.

OVERVIEW

SESSIONS 1-2: RAPPORT BUILDING, FORMULATION, GOAL SETTING AND PAIN $\,$

MANAGEMENT TECHNIQUES

To help with socialisation to the model, a basic formulation cycle was collaboratively developed; drawing links between David's physical health, chronic pain and mood and is displayed in Figure 1.

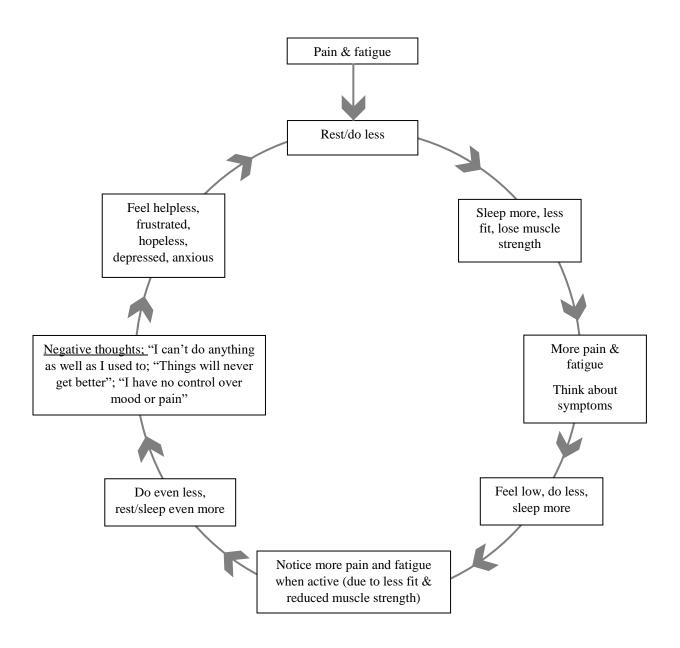


FIGURE 1; FORMULATION CYCLE LINKING PAIN AND FATIGUE

David found this formulation accessible and described it as "fitting perfectly" with the difficulties he experienced. A more detailed conceptualisation was also developed to inform the intervention but was not shared with David (see Appendix 1).

Once David grasped the links between his difficulties he felt more able to generate goals.

The overarching goal for our work together was to improve David's quality of life by rebuilding his confidence and re-establishing his independence. In terms of SMART goals, David initially identified walking his dog independently and later visiting London landmarks independently.

During the earliest stages of our work together, when David was being socialised into working psychologically and rapport was being built, thought defusion techniques were introduced to help David to manage pain. The technique that David found particularly helpful was safe place relaxation. Teaching David this technique proved to be crucial in increasing his motivation to engage in therapeutic work, as once he had experienced the benefits of a technique he was motivated to learn more.

We explored many techniques to help David to manage pain and anxiety, including mindfulness, external focus of attention and self-soothing (e.g. have a cup of coffee, pet his dog). David found distraction techniques, such as watching a film, listening to music or knitting, particularly helpful.

SESSION 3: RISK

In session 3, David disclosed thoughts of suicide after having received bad news relating to his benefits, which left him feeling frustrated and hopeless. A risk assessment was completed to ascertain the level of risk and his intent, after which we were able to construct a crisis plan to ensure his safety. David engaged well with this and his risk was assessed to

be low prior to ending the session. Following this incident, risk was monitored throughout treatment, but suicidal ideation did not re-present.

David described himself as being severely restricted by his physical health conditions, which made it difficult for him to engage in activities. Muscle wastage and poor fitness also exacerbated this. In the context of David's goal of walking his dog, the fourth session was used to do this together. Predictions and emotions were collected before, during and after using a record sheet for noting behavioural experiments (see Appendix 2). David experienced considerable improvement in his mood following this experiment, which provided motivation to continue working on this goal. He also experienced an increase in pain, but was able to use pain management techniques, developed in our earlier sessions, to manage this. In session five, the experiment was repeated, but it was agreed that David would walk ahead, as talking had been identified as a safety behavior. Following session five, David was able to walk his dog independently to a local park for the first time in three years.

SESSIONS 7-10: THOUGHT CHALLENGING/THINKING ERRORS

Behavioural gains were built on by attempting to solidify David's understanding of the cognitive component of the model. Thinking errors were identified, namely the tendency for David to make catastrophic predictions for the future (for examples, see Appendix 3). His risk example from session 3 was referred to as an example of this. Thought challenging techniques were discussed and David was encouraged to keep thought records, but tended to avoid this despite problem solving, thought challenging and exposure to filling in forms in sessions. Although David avoided pen and paper tasks, he did show evidence of having

reframed the negative thoughts that he had about his future and his physical health towards the end of therapy.

SESSION 11-12: ENDING THERAPY AND RELAPSE PREVENTION

A therapy blueprint was developed over the final two sessions (see Appendix 4) with the focus on how David could maintain the gains that he had experienced in therapy. Attention was also paid to thinking about how he could build on and utilise the techniques he had learned once sessions ended. In the final session, David reflected on what he felt had been achieved through therapy and a 'positive' formulation was created collaboratively to illustrate how David's positive mood had developed and was being maintained (see Appendix 5).

OUTCOMES

The Clinical Outcomes in Routine Evaluation 10 (CORE-10) is a 10-item self-report measure that measures global distress. It is the preferred measure used by the Older Adults Psychology and Psychotherapy Service. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is a 14-item scale that is designed to measure anxiety and depression in people with physical health problems; seven items assess symptoms of anxiety and seven items assess symptoms of depression. Both measures were administered before, during and after intervention to allow for progress to be monitored and outcomes to be determined

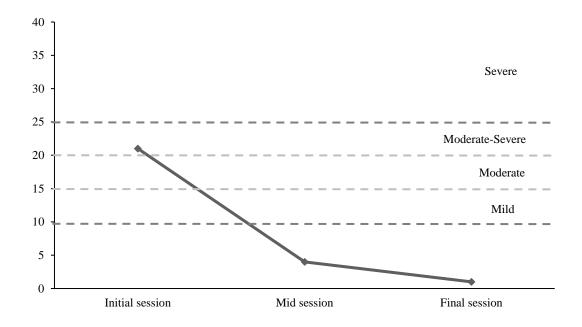


FIGURE 2; DAVID'S SELF-REPORTED CORE-10 SCORES

As highlighted in Figure 2, David's initial CORE-10 score was 21, which is above the clinical cut-off and reflected moderate-severe levels of distress. This score fell to six midtherapy and one by the end of therapy, both of which are within the non-clinical 'healthy' range and demonstrate a clinically significant improvement in his level of global distress.

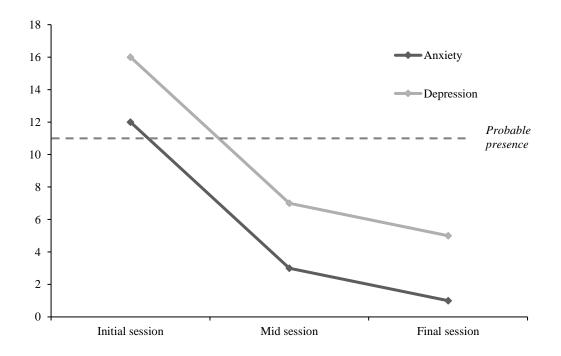


FIGURE 3; DAVID'S SELF-REPORTED SCORES ON THE HADS

As depicted in Figure 3, David's symptoms of anxiety and depression reduced over the course of therapy, as measured by the HADS. A cut-off point of 11 (out of 21) in either subscale is considered to represent the "probable presence" of anxiety and/or depression (Snaith, 2003), demonstrating that David presented with clinically significant symptoms of both at session one. Symptoms of anxiety and depression had decreased to below clinical threshold by session six, with David continuing to make additional gains in the second half of therapy. When sessions ended, David was below clinical cut off for a diagnosis of anxiety and depression.

ADDITIONAL OUTCOMES: GOALS AND QUALITATIVE FEEDBACK

With regards to SMART goals, David had achieved his goal to walk his dog independently by session five. At this point, goals were revisited, and he set a new goal to visit London landmarks independently. David did not achieve this goal by the end of sessions and this will be reflected on in the discussion.

David reported that therapy had been "tremendously helpful". He felt he had achieved his overarching goal of rebuilding confidence and independence and said he had been able to re-discover his identity amidst the chaos and uncertainty of living with chronic and complex physical health difficulties. In the final weeks of therapy, David had started to sort through paperwork that he had previously avoided, he had contacted the council and organised for DIY to be carried out in his home, he helped one friend with a tax-related problem and another with managing their finances, he had found someone to refurbish his garden, challenged himself to walk home from a GP appointment and had returned to sleeping in his bed at night. Overall, David reported considerable improvement in his quality of life.

DISCUSSION

David engaged well with the therapeutic process, despite initial reservations regarding its potential to be effective. He was able to meet his goal of walking his dog independently following just five sessions, and by session six he no longer met clinical threshold for depression or anxiety. David continued to build on these gains during the second half of therapy, despite expressing sadness and anxiety about sessions ending.

It is important to note that David experienced positive physical health outcomes during therapy. Between session six and twelve he had an operation to close a wound that had caused him severe pain for three years. Following this operation, he experienced significantly less pain, which functioned to further improve his mood, reduce anxiety and remove some limitations with regards to going out of the house. He was still restricted by

his poor physical health and many hours of nursing per week but was more able to look forward with enjoyment to activities.

David found thought challenging difficult throughout our sessions, despite revisiting this and using his own real-world examples, and he did not identify this as a useful strategy when creating the therapy blueprint. This case provides support for the usefulness of CBT in treating depression in older adults, but highlights that focusing on behavioural techniques may be most valuable when working with older adults who can find psychological and abstract thinking difficult.

As mentioned above, David achieved his initial SMART goal quickly and it was therefore necessary to revisit goals in session six. Visiting London landmarks independently became David's new goal; however, he had not achieved this when sessions ended. On reflection, more time might have been spent on ensuring that David's second goal was 'SMART' (particularly, realistic) and meaningful. The treatment may have benefitted from a wider formulation that considered historical and longitudinal factors. This would have allowed goals to be set in the context of David's values.

REFLECTIONS

In the context of David making considerable gains by session six it was frustrating when we became 'stuck' on thought challenging in sessions seven to ten. We couldn't challenge David's catastrophic thoughts during sessions in a way that impacted on his ratings of mood and/or anxiety and David did not complete thought challenging homework between sessions. On reflection, it would have been helpful to check in on David's understanding and correct him more often. This is something that I avoided due to David's low self-esteem

and my anxiety about embarrassing him by highlighting errors. This avoidance will be important for me to look out for in future work; however, since our sessions ended I have been able to reflect on the fact that David was engaging in less catastrophising and was considerably more hopeful about his future when sessions ended.

My limited knowledge of David's physical health difficulties made it challenging to disentangle dysfunctional thoughts from realistic appraisals. This is particularly true when engaging David in behavioural activation to meet his goal of visiting London landmarks independently. For example, David cited angina as a reason for not going out on a day when it was hot; however, it is possible that avoidance and dysfunctional thinking were also contributing. It would have been helpful to dedicate time to exploring why David wasn't working towards this goal. It is possible that this goal wasn't meaningful enough to motivate David. In the context of him achieving many things during therapy, such as reconnecting with friends and carrying out home improvement, it is possible that I persevered with the goal because of having projected my own beliefs about what "quality of life" means onto David.

As with other older adults that I have worked with, I wondered whether some of the therapeutic gains were a result of having regular company; however, David was able to make gains with others and was less socially isolated when sessions ended. By reflecting on my concerns about gains not being maintained I made the decision to dedicate more time to ending than I have previously. This allowed us to consolidate and explore everything that David could do to keep himself well in future.

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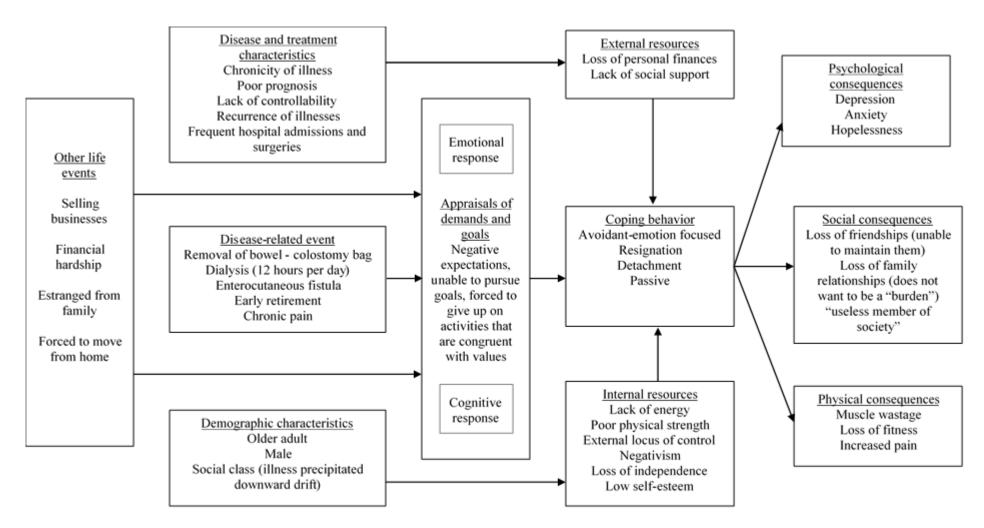
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APPENDICES

Appendix 1. Conceptualisation of David's presenting difficulties based on Maes, Leventhal and DeRidder (2002)



Appendix 2. Record sheet for noting behavioural experiments

Institute of Psychiatry

at The Mandsky

RECORD SHEET FOR NOTING BEHAVIOURAL EXPERIMENTS



| | Situation | Prediction What do you think will happen? How much do you believe it will, 0-100? How would you know if it had? | Experiment What can you do to test the prediction? (remember to focus on what actually happens rather than your feelings & let go of Safety Behaviours) | Outcome Where was your attention focused? What actually happened? Was the prediction correct? | What I learned Is there a more balanced view? How likely is it that your predictions will happen in the future? (0-100%) |
|-------|-----------|--|---|---|--|
| 74. g | | FEAR OF PAIN STARTING (100) (5) BART EXFERIENCE HAS PRODUCED BOIN CAUSING ME TO SLOW DOWN AND BECOME FRUSTRATED GENERALY TRY AND DISTRACT MYSELF IN A BID TO REDUCE THE FEELING OF PAIN AND PLUSTRATION. | | PAIN NOT AS SEVERE AS EXPECTED. THE EXPECTED FEAR DID NOT OCCUP. NOTHER DID THE | SLOWED DOWN WHILST OUT, BUT CAUSED BY A SHORTAGE OF BREATH AND NOT FROM ANY PAIN. ALTIVITIES SEEN WHILST OUT BECAME A TOTAL DISPLACTION AS TO HOW I WAS FEELING BEFORE |

Appendix 3. Examples of predications made by David, alongside the situation and actual outcome.

| Situation | Prediction | Actual outcome |
|------------------------------|------------------------------|-----------------------------|
| D.1 | (ITT) 211 C | DVD 1 |
| Delay in receiving Personal | "They will refuse to pay the | PIP payments were received |
| Independence Payment | PIP benefits that I am | within 10 days. |
| | entitled to, I will have to | |
| | take them to court, I won't | |
| | be able to afford to eat in | |
| | the meantime" | |
| David's wound isn't healing | "The wound is as bad as it | The changes in the wound |
| as well as it was previously | was three years ago, every | were minor and surgery one |
| | operation that I have had to | month later resulted in the |
| | fix it has been pointless" | open wound being fully |
| | | closed. |
| Delayed discharge from | I will be here for weeks, | David was discharged two |
| hospital | there is no way I will be | days after making the |
| | discharged before the | predictions and once home |
| | weekend, the operation has | reported being delighted |
| | been pointless. | that he no longer woke up |
| | | in pain. |
| | | |

Appendix 4. Blueprint

What were the difficulties to start with?

- Couldn't be bothered
- Totally lost interest
- Struggled to get up in the morning
- Lost control
- Felt hopeless
- Had a constant feeling that something bad was going to happen

What did you find out about what may keep these difficulties going?

- Negative spiral (see handout)
- Lack of pleasure, achievement and closeness with others

What techniques or ideas did you learn in therapy that you find helpful?

- Safe place relaxation going to Cornwall
- Distraction read a book, watch a good film, listen to my favourite music, go outdoors, walking, knitting, talking to others
- Taking my mind away from what is making me feel negative
- Pain and mood are related, when my mood is better I feel less pain, when I am in more pain my mood gets worse <u>BUT</u> I can do things to get out of this negative spiral (see positive spiral)
- Having things to look forward to helps on days when it isn't possible to go out

What things improve your mood?

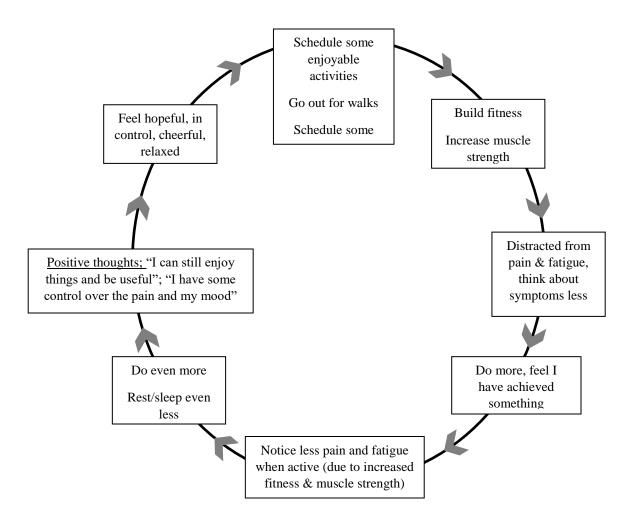
- Fresh air
- Spending time with others
- Having someone to talk to
- Distraction
- Safe place relaxation going to Cornwall
- Helping others
- Being in less pain

How could you build on the work you have done in therapy?

- Make use of the befriending service
- Set up regular Sunday activities with Lizzie
- Join social groups
- Set goals for myself
- Motivate myself to walk Coffee on my own
- Keep my therapy hour review therapy notes or do something nice for myself every Wednesday at 3pm

If you notice difficulties in the future, how will you help yourself?

- Use techniques learned in therapy
- Go for a walk
- Talk to someone



SERVICE RELATED PROJECT

FACTORS AFFECTING THERAPEUTIC OUTCOME FOLLOWING TREATMENT IN THE LEWISHAM INTEGRATED PSYCHOLOGICAL THERAPIES TEAM

Supervised by Jonathan Radcliffe

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ABSTRACT

This service evaluation project examined factors affecting therapeutic outcome following psychological intervention in the Integrated Psychological Therapies Team (IPTT). Fourteen people who had previously had therapy with the IPTT attended three focus groups; Group 1 (n = 4) comprised of people who experienced an increase in levels of distress following treatment; this was according to the Clinical Outcomes in Routine Evaluation outcome measure (CORE-OM). Participants in Group 2 (n = 8) and Group 3 (n = 2) experienced a decrease in their level of distress according to this measure. Thematic analysis was used to identify the themes and subthemes discussed by the groups. Across groups, it was noted that treatment within IPTT represented just one part of a recovery journey. Participants highlighted many factors that impacted on their capacity to benefit from therapeutic intervention, including the therapeutic relationship, expectations, stigma, relationships with other people in their lives and negative life events. It was also clear that discharge from IPTT did not mark the end of their recovery journey. Discussion focuses on possible areas for service development, as well as the limitations of this project and possible future directions.

INTRODUCTION

OVERVIEW

This service evaluation project sought to examine factors that might explain positive and negative outcomes following psychological treatment in the IPTT. More specifically, this was an examination of factors that patients found helpful or unhelpful in the therapy that they received. It was anticipated that this project would provide information with regards to improving service delivery and client outcome.

RATIONALE

It was predicted that the findings from these focus group would be useful in two key ways. First, highlighting factors that service users felt hindered improvement of their symptoms would shed light on ways in which the IPTT might improve therapeutic outcomes. Secondly, by determining service user opinion on the key elements of an effective therapeutic intervention to provide information to therapists about the impact of their interventions on their patients, to aid greater sensitivity to patients' experiences.

THE INTEGRATED PSYCHOLOGICAL THERAPIES TEAM

The IPTT is a secondary care psychological therapy service that specialises in the assessment and treatment of significant mental health problems in adults aged 18 and over. Referrals to the IPTT most often come from IAPT or community mental health teams for difficulties such as severe anxiety, severe depression and personality difficulties. The service provides a range of individual and group therapies that fall within eight areas: 1) cognitive behavioural therapy (CBT), 2) cognitive analytic therapy (CAT), 3) psychodynamic psychotherapy (individual and group), 4) trauma focused therapy, 5) mentalisation based therapy, 6) schema therapy, 7) group therapy and 8) family and couples

therapy. Each therapist working within the IPTT specialises in at least one of the eight modalities and some employ an integrated approach to individual treatments. Decisions regarding the acceptance of a referral and the type of therapy that a client receives are made following discussion in the weekly referral meeting.

In the context of cuts and a shrinking NHS budget, it is crucial for services to show that they are efficient and effective. The IPTT routinely administers the Clinical Outcomes in Routine Evaluation (CORE-OM; Evans et al., 2002) as a measure of effectiveness. As a minimum, the service aims for every client to complete the measure in the initial session and in the final session. A shorter version, the CORE-10 is a 10-item measure that is completed at monthly or three-monthly intervals to monitor clients' progress. CORE outcome data collected by the IPTT in the past two years show that the service is successful in delivering psychological interventions that reduce distress, as 56% of service users experienced reliable improvements in symptomatology following treatment, 26% experience non-reliable improvement and only 5% of service users experience reliable deterioration.

THE CORE-OM

The CORE-OM (Evans et al., 2002) is a measure of global psychological distress that was designed to provide 'an acceptable, standardized outcome measure to assess efficacy and effectiveness across multiple disciplines offering psychological therapies' (p. 51). It comprises of 34 items across four domains; well-being (4 items), symptoms (12 items), functioning (12 items) and risk (6 items). Each item is responded to on a 5-point Likert scale, ranging from 'not at all' to 'most or all of the time'. The client responds to the questions in relation to how they have been feeling over the past week and scores are averaged to produce a rating of distress that ranges from 'healthy' to 'severe'. Overall, a higher score represents a higher level of distress; more specifically, a score below 1.00

indicates a non-clinical/mild level of distress, a score between 1.00 and 2.49 is indicative of moderate distress and a score above 2.5 is indicative of severe distress. It is also possible to determine changes in levels of distress as an outcome of therapy by comparing distress ratings before and after therapeutic intervention. Comparison of CORE-OM scores yield information about the magnitude of change. A decrease of 0.5 shows reliable improvement and if this improvement also results in a client falling below the clinical range (1.00) it can be concluded that therapy brought about clinically significant change.

The CORE system also collates data into an anonymised, central database, which allows services to request overall outcome data, thus providing service feedback at the group level. In the developmental phases of the CORE-OM, the authors report that the measure has good reliability and validity, as well as good sensitivity to detect change (Evans et al., 2002). Much research has supported these findings. For instance, the CORE-OM has been shown to be sensitive in detecting large and significant differences between clinical and non-clinical samples (Barkham et al., 2001; Barkham, Gilbert, Connell, Marshall & Twigg, 2005) and good test-retest reliability (> 0.8) has been shown (Barkham, Mullin, Leach, Stiles & Lucock, 2007). However, there are critics of quantitative outcome measures, particularly with regards to whether or not they effectively capture the gains that clients experience following therapeutic intervention. For instance, Marzillier (2004) highlighted that outcome measures fail to capture the nuances of mental health difficulties. Quantitative measures have also been citicised for lacking cross-cultural validity, which is crucial in the context of a service meeting the needs of significant numbers of patients from ethnic minority backgrounds. By running focus groups with ex-service users, it was hoped that a more nuanced picture of therapy outcomes would be gathered, as well as information regarding the process of therapy to supplement quantitative outcome data.

FACTORS AFFECTING THERAPEUTIC OUTCOME

Decades of research have sought to determine the effectiveness of psychological therapy (Norcross & Lambert, 2011). Much of this research has yielded positive and encouraging results – approximately 75-80% of people who receive therapy experience an improvement in their presenting difficulties (Lambert & Ogles, 2009). Notably, therapy has been found to be as effective as antidepressant medication and its effects more long-lasting (Blackburn, Bishop, Glen, Whalley & Christie, 1981; Blackburn, Eunson & Bishop, 1986; Evans et al., 1992; Hollon & Shelton, 2001; Kovacs, Rush, Beck & Hollon, 1981; Murphy, Simons, Wetzel & Lustman, 1984; Rush, Beck, Kovacs & Hollon, 1977; Simons, Murphy, Levine & Wetzel, 1986).

Following on from research that strongly supports the efficacy of psychological intervention, psychologists have attempted to determine the particular aspects of therapy that lead to positive change. Such research has largely fallen into one of two categories; the "common factors" approach and the "empirically supported treatments" approach. The empirically supported treatments approach seeks to match a particular therapeutic approach to a presenting difficulty, in order to provide treatment that is most efficacious.

In contrast to approaches that examine the overall effectiveness of therapeutic modalities, the common factors approach seeks to elucidate generic elements of psychological intervention that are not specific to any particular modality, such as, client expectations, therapist confidence and the therapeutic relationship. Following review of more than 100 studies that reported on predictors of outcomes, it was documented that common factors account for 30% of the variance in treatment outcome, whereas specific therapeutic techniques account for just 15%; the remaining variance was attributed to extratherapeutic change (40%) and expectancy (15%) (Lambert & Barley, 2002).

The aim of this project was to determine the factors that previous service users felt were helpful or unhelpful aspects of therapy. The most notable common factors are considered below.

THE THERAPEUTIC RELATIONSHIP

The therapeutic relationship is probably the most widely researched and well-substantiated common factor that is known to predict therapeutic outcome (e.g. Horvath, Bedi & Norcross, 2002; Shirk & Karver, 2003; Wampold, 2001). Indeed, the American Psychological Association (APA) set up the Task Force on Empirically Supported Therapy Relationships to explore this particular common factor in detail (Norcross, 2002). With regards to factors that were demonstrably effective in the one-to-one treatment of adults, the Task Force identified goal consensus and collaboration, the therapeutic alliance and therapist empathy. More specifically, goal consensus refers to the importance of the client and the therapist agreeing on the goals that will be worked towards during treatment and of ensuring that such goals are important and meaningful to the client. Collaboration describes the importance of the client and the therapist working together to address the client's difficulties and of the client taking an active role in their therapy. With regards to therapist empathy, Carl Rogers has guided much of the research in this area. He defined the concept as the capacity to 'perceive the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person' (Rogers, 1959, p. 210). Additional therapist qualities that have been found to be important in predicting positive change following therapy include positive regard, openness, genuineness and effective communication, as well as being flexible, honest, respectful, trustworthy, confident, warm and interested (e.g. Ackerman & Hilsenroth, 2001, 2003; Keijsers, Schaap & Hoogduin, 2000; Lambert & Barley, 2001). Research also shows a negative correlation between therapeutic outcome and the frequency of hostile interactions

(Binder & Strupp, 1997). In relation to therapy, a context in which clients discuss topics that trigger negative emotions and therapists seek to challenge clients, it is not uncommon for clients to feel hostile towards their therapist. Thus, a factor that is also shown to be important is the therapist's capacity to repair therapeutic ruptures (for reviews, see Ackerman & Hilsenroth, 2001, 2003).

It is important to note that many IPTT service users present with long-standing personality difficulties, typically, borderline personality disorder (BPD). According to criteria outlined by the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013), symptoms of BPD commonly include impairments in interpersonal functioning (e.g. intense and unstable relationships that are often experienced in extremes of idealisation and devaluation), emotional liability and antagonism characterized by persistent or frequent angry feelings (American Psychiatric Association, 2013). In this context, it might be expected that the therapeutic relationship will be unsettled. However, some approaches, such as psychodynamic approaches, see the expression of negative affect by the patient in the relationship as an important part of therapy (Yeomans et al., 2015).

TIMING: STAGE OF ILLNESS AND STAGE OF CHANGE

Given that service users are required to play an active role in the therapeutic process, it is relevant to consider that their willingness to do so will be dependent on their positioning with regards to stages of change. The Transtheoretical Model of change describes the stages that unfold in the context of changing a behavior (Prochaska & DiClemente, 1982). The model outlines the following six stages of behavior change; 1) precontemplation, in which the individual does not intend to act on changing the behavior, 2) contemplation, in which the pros and cons of changing the behavior begin to be weighed, 3) preparation, describes

the stage immediately before change, in which some significant step has been taken towards action 4) action, in this stage overt modifications to behavior can be seen 5) maintenance, this is a key stage in which people work to prevent relapse and 6) termination, which describes the point at which there is no longer any temptation to engage in the original, unhelpful behavior. The principles of this model are relevant across therapeutic approaches; hence it being referred to as transtheoretical. According to the Transtheoretical Model, the time at which therapeutic intervention takes place is likely to be a predictive factor in terms of outcome.

The stage of illness (i.e. acute vs. chronic) is also shown to be of predictive importance. Research into common factors has found a significant negative correlation between level of impairment and treatment outcome (Norcross, 2004). Research shows a significant negative correlation between outcome and the length of time that psychosis, bipolar disorder, major depressive disorder or anxiety disorders are left untreated (Boonstra et al., 2012; Dell'Osso, Glick, Baldwin & Altamura, 2013). Several factors may contribute towards the duration of untreated illness, including increasingly long waiting times and reluctance to seek support from mental health services. Of course, there is stigma associated with receiving treatment from mental health services, which could result in people seeking help as a very last resort, when their difficulties are most severe. In 2015, Clement and colleagues carried out a systematic review to explore the impact of mental health stigma on help-seeking behavior. They found a small to moderate negative effect of stigma on help-seeking for mental health needs. The impact of stigma was also found by them to be disproportionately larger for ethnic minorities, men, youth and those in military and health professions. In particular, selfstigma (holding stigmatising views about oneself) was most often associated with reduced help seeking and has also been found to be negatively associated with adherence to

psychological treatment (e.g. Livingston and Boyd 2010; Fung, Tsang, Corrigan, Lam & Cheng, 2007).

Just as the content and process of therapeutic intervention differs for each individual who engages with psychological therapy, the factors that impact on their particular outcome will also vary from case to case. The list of common factors described above is therefore not exhaustive. It is also likely that the factors described above will interact to predict therapeutic outcome, for instance, therapeutic alliance might mediate the relationship between expectations and outcome in some instances. However, for the purposes of improving and increasing positive outcomes following therapy with the IPTT, this project aims to extract common processes impacting on service user experience.

AIMS

- 1) To gain qualitative feedback on factors affecting therapeutic outcomes
- 2) To provide guidance on factors that might improve IPTT treatment outcomes
- To highlight the factors that are effective in bringing about positive change for people receiving treatment in IPTT

METHOD

Comparison of pre- and post- therapy CORE-OM scores provides an indication of whether treatment was effective in reducing distress. This information was used to invite previous service users to a series of focus groups that explored factors affecting positive and negative therapeutic outcomes.

PARTICIPANTS

The 70 'best improvers' and the 70 'worst improvers' since 2016 were identified based on the IPTT CORE-OM outcome data. These people were invited to take part in focus groups in tranches i.e. if not enough from the first batch responded than more were invited.

Following the recruitment process, three focus groups were run. Focus Group 1 consisted of four female participants who had CORE-OM scores that had worsened following treatment in the IPTT. The second and third groups consisted of ex-service users whose CORE-OM score had improved following treatment; Group 2 consisted of two males and six females, and Group 3 consisted of two female participants.

SERVICE USER INVOLVEMENT

Service users played a role in the design of the questions and led on the recruitment of focus group participants. The groups were facilitated by a peer support development coordinator with lived experience of mental health difficulties, who was employed in the IPTT to deliver peer support. The second and third facilitators were volunteer peer support workers in the IPTT and both were former IPTT service users. This was made explicit to participants during the consent gaining process to maximise the validity of the responses generated, and to reduce social desirability (Adams et al., 1999). Two male facilitators (C.D. and H.N.) led Group 1 and these facilitators were joined by a female facilitator (A. B.) in Group 2 and Group 3.

DESIGN AND PROCEDURE

Two of the focus groups were run in a neutral setting where service users could feel more able of speak freely, namely a hired room in a local library, and a third was held in the services. Each focus group lasted approximately 90 minutes. Written consent was gained

from each participant prior to the start of the interview. Participants were reimbursed for giving up their time to take part in this project with a £15 shopping voucher, and tea and biscuits were provided to create an informal atmosphere.

At the start of the session the focus group facilitators introduced themselves and reminded participants of the topic of discussion. Participants were informed that the interview would be voice recorded, but that anonymity and confidentiality would be maintained. They were also assured that the information that they provided would not be fed back to individual therapists.

The interviewers used predefined questions as a guide to ensure that all important topic areas were covered (see Appendix 1) but adopted an open and curious style. All questions asked were open-ended and non-directive, and participants who were less forthcoming were asked directly about their thoughts, where appropriate. Interviewees were assured that there were no right or wrong answers to the questions being asked. The focus group facilitator moved on to the next topic only when it was felt that the discussion came to a natural conclusion or no new answers were forthcoming.

ANALYSIS

Interviews were digitally recorded and transcribed verbatim. The first focus group was transcribed by one of the researchers (L.A.C.), the second was transcribed by a paid professional and the third focus group was transcribed by a member of the IPTT administration team. Thematic analysis was carried out twice. First of all, on data from Group 1 i.e. CORE non-improvers, and secondly, data from Group 2 and Group 3 was collapsed to allow for thematic analysis of the data provided by CORE improvers.

Each transcript was re-read several times by L.A.C. and thematic analysis began once the researcher was familiar with the data. Stage 1 involved the researcher noting general

patterns and themes that encapsulated the ideas conveyed by the participants. Stage 2 involved the grouping of subthemes that seemed related and Stage 3 involved the extracting of participant quotes into subthemes in an Excel spreadsheet. The research supervisors examined themes and subthemes for evaluation and feedback on appropriateness.

RESULTS

A total of fourteen people who received psychological therapy with the IPTT attended the focus groups. Of these fourteen people, four were classified as non-improvers (Group 1) and ten were classified as CORE-OM improvers (Group 2 and Group 3). Findings from thematic analysis are reported below.

CORE "Non-Improvers"

Thematic analysis of the focus group that was run with people whose CORE-OM scores did not improve following treatment yielded a total of ten subthemes and five general themes: perceived stigma, expectations, the therapeutic relationship, resources and outcomes.

GENERAL THEME 1: PERCEIVED STIGMA

SELF-STIGMA

The participants themselves made assumptions about what it meant to be mental health service users ("I was terrified of getting involved in anything that was encapsulated as mental health, it made me feel bad about myself"). Participants described being confronted by this when arriving at the mental health unit where the team was located ("people were outside with their pyjamas on and you felt a bit scared going in there"; "they were obviously unwell people, sometimes sitting outside on the wall in dressing gowns"). It was evident that participants were fearful of their own assumptions being adopted by others ("I felt that I was going to get labelled crazy"; "it's going to be on my doctors' records, I'm not going to be

able to emigrate, get a job – anything"; "I thought I could be stopped from seeing my grandson").

STIGMA

Participants experienced others discriminating against them following their involvement with mental health services ("my family decided that I was so crazy and vulnerable that they would sell my flat without telling me"; "when I told my son's school that I was having therapy they told me it's all my fault that my son had problems"). Stigma from others was also described as having contributed towards relapse ("I remitted after that because it was so stressful to be told that it's all my fault"). As well as experiencing stigma from people who knew the participants, examples of stigma from strangers were also shared ("that's where the crazy people are, you're not crazy").

DELAYED HELP SEEKING

Participants had a shared experience of having delayed help-seeking due to perceived stigma ("I just felt like the minute I put myself forward and said there's something wrong my whole life would fall apart so I just carried on in misery"). This resulted in participants seeking help only when their difficulties were at their most severe ("I went on for maybe 20 years. It's only when it did get impossible and it did all crumble and I didn't really have a choice that I got help").

A number of participants described the fact that positive portrayals of mental health in the media had facilitated help seeking ("that gave me quite a bit of encouragement because it's a straight laced person who wears a suit every day and he's come out and said this") and support from significant others also emerged as being key ("everyone said you've got to do it, so I did it").

THE IPTT SETTING

Accessing the building where the IPTT unit was located was stressful for most of the participants, who felt uncomfortable about the level of security and meeting inpatient service users at the Hospital entrance ("it was scary coming in to the front"; "going back out of the building, I didn't really enjoy that part").

Reference was made to the attitudes of administrative staff in the IPTT and at the entrance to the building. Participants described negative interactions with a member of staff on the building's reception desk ("that lady wasn't actually very friendly"), but very positive interactions with IPTT administrative staff in the IPTT unit ("they were very welcoming"; "they always made you feel like you had nothing to worry about"). One participant was also unsettled by security alarms that ring periodically in the hospital; she referred to these reminding her of her own inpatient stay ("the alarm brought back memories of when I was admitted").

GENERAL THEME 2: EXPECTATIONS

Expectations regarding the likelihood of change were low ("I was always resistant to therapy because I just thought it's not going to change"). Participants were not sure what to expect from therapy and this led to anxiety ("I was scared that I wasn't going to understand therapy") and the tendency to approach treatment from a passive position ("just said yes and went along with everything I thought you had to do it."). As described above, expectations regarding societal reactions towards mental health patients also hindered engagement ("I felt that I was going to get labelled crazy").

GENERAL THEME 3: THE THERAPEUTIC RELATIONSHIP

PERCEPTIONS OF POWER

It was evident that some participants experienced themselves as lacking power in a therapeutic context ("we're almost like little children"; "I was really scared, I thought if I say this or that I'll get locked away"; "if I put up any resistance I'm going to get shut in a cell"). One participant also described how receiving a letter that listed the therapist's qualifications intimidated her ("On his letter it had all these senior such and such... it was a lot of pressure"). There was a sense of feeling from some patients that they had to agree to the assessor's decision regarding the type of therapy to be delivered ("someone just puts you into therapy that they think is best"). In contrast, one participant reflected positively on her experience of ownership ("my therapist was providing me with lots of tools and it was up to me to use the tools to help myself — I was the boss").

OPENNESS

In some cases, participants felt that they weren't able to be open with their therapist ("I was very scared to tell the truth about how I really felt and behaved because I was worrying that I would lose my child"; "I held a lot back"; "I started lying because I felt like I had to perform and do these things"). The idea of wanting to please one's therapist was also shared by members of the group ("I was trying to present myself in a way that would please her"; "I was trying to make her happy, so I didn't want to admit that I still had panic attacks").

Some members of the group described their lack of understanding regarding therapy following treatment ("I don't know what kind of therapy it was"; "I didn't know if that was normal"; "I didn't know if this is what therapy should be"), as well as anxieties about asking for clarification ("I thought for a long time that if I start to question it too much it's going to look like I'm arguing"; "I was thinking that a lot of other things might be helpful, but I

thought that if I refused then I might not be offered another option so I just said yes"). In contrast, one member described a positive experience alongside good understanding of her treatment ("everything was making sense to me").

GOAL SETTING

Participants described how positive change was hindered in the absence of shared goals ("I ended it earlier, I just said there's no point in coming, I'm not going to do what you think I should do"). They felt that some goals set by therapists were too challenging ("he put me under too much pressure"; "you can't put me into somewhere where you push me to go out and get a job"). In contrast, one participant described a positive experience of therapy being tailored to her needs ("I was incredibly lucky because my therapist in CBT/schema therapy really met my needs").

PERCEPTIONS OF THERAPISTS' REACTIONS

Participants commented on their perceptions of negative reactions from therapists ("I felt like she got kind of impatient or irritated"; "I could see him a couple of times getting a bit uptight"). This had a negative impact on the therapeutic alliance, leading clients to feel that there were certain topics that could not be discussed ("I just left it after that").

One participant described how the reaction from the therapist in the initial session had made her feel less anxious and embarrassed ("embarrassment evaporated when I could see that the person wasn't really being affected by what I was saying. If I had had somebody who was feeling uncomfortable that would have made me just clam up").

GENERAL THEME 4: CLIENT RESOURCES

Several participants described social factors in their lives affecting them. This involved family members ("they started making decisions for me because they just classified me as crazy"), unemployment issues ("the whole process was disturbed by the job centre") and

arranging childcare ("during any school holiday I can't got for treatment"). Participants referred to the personal resources necessary to attend therapy, particularly energy and motivation ("because I was really depressed I couldn't get up in the morning"; "people with no mental issues might be able to organise something, but mentally I'm not able to do it").

A number of participants also commented on the need for personal resources to deal with the unsettling emotions stirred up by therapy ("scared"; "stressed"; "vulnerable").

GENERAL THEME 5: OUTCOMES

BENEFICIAL OUTCOMES IN CORE NON-IMPROVERS

Two participants described therapeutic gains that contradicted lack of improvement on the CORE-OM ("I'm a lot more happy, stable, it has made a big difference to me, but I don't know how it has done it"; "in general I have seen huge progress"). Several participants made reference to practical CBT techniques that they found helpful.

POST-THERAPY OUTCOMES

One participant reported that the therapy they received in the IPTT was helpful in preparing them for further intervention ("allowed me to join the group therapy, because before that I would never have been able to talk to other people") and another felt ready to approach more entrenched difficulties ("I feel now I can approach my deep problems that are causing depression").

CORE "IMPROVERS"

Thematic analysis of the CORE-OM improvers yielded a total of fifteen sub-themes and six general themes; therapeutic relationship, client factors, expectations, pre-therapy factors, post-therapy factors and positive experiences.

GENERAL THEME 1: THE THERAPEUTIC RELATIONSHIP

PERCEPTIONS OF POWER

There were discrepancies among CORE improvers with regards to whether they perceived the relationship with their therapist to be collaborative or not. One group member described a positive experience of feeling that she took the lead during sessions ("I felt like I was almost leading, that was really helpful"). Other members reflected positively on relationships in which they experienced an absence of conflict and an ability to freely disagree with their therapist ("I didn't get told to be anything or do anything at all"; "I felt comfortable enough to battle with her, rather than be like bow down"; "I was able to go no, I disagree with you, and stand my ground").

As with the previous group of non-improvers, some clients felt that they lacked power within the therapeutic relationship. One participant resented the therapist placing stringent conditions for continued attendance at therapy ("He blackmailed me by saying if you don't do this therapy just cuts there and then") and others found their therapist intimidating ("I found him very intimidating").

SHARED UNDERSTANDINGS

When describing aspects of therapy that were most crucial in leading to positive outcomes, two group members described having a therapist with a good understanding of them and their needs ("She could gauge very well if I was feeling that I didn't want to talk about something, this was so helpful"; "if I was finding something difficult she would know and we'd talk about something else until I was ready"). These participants developed trust and confidence in their therapists as a consequence ("I felt like I trusted her and could talk to her which was really important").

Some group members felt misunderstood and judged by their therapist ("you don't need to judge me"). Others described discontent with therapists who took a different view about therapeutic goals ("at the time I was thinking you're not listening to me, this isn't what I want to focus on for my therapy"). Several group members disagreed with the emphasis on obtaining suitable work ("Get a better job, work longer hours, but my difficulties are about severe trust issues"; "Get a job. That's their answer to everything") and finding a relationship ("he wanted to focus on me getting a boyfriend"; "my therapist had really strange perspectives on things, like being in a relationship might help my mental health"). In these instances, participants experienced feelings of animosity and anger towards therapists ("I hate him"; "I'm not going to have a conversation with you if you continue to tell me that this is who I need to be").

Two group members shared their views on therapists being unable to understand what it is like to experience mental health difficulties ("I think the only people that can truly understand is someone that's suffered the same things"; "he couldn't tell you how it feels when you're going through a stage of self-harming"). Overall, members of this group agreed about the importance of having a therapist who they "connected" with ("I really clicked with her, I was extremely lucky"; "it is so important to find one that you like and connect with").

GENERAL THEME 2: CLIENT FACTORS

COMPLEXITY

Participants described longstanding mental health difficulties ("I've been in and out of services for like 12 years"; "I am suffering from PTSD from a traumatic experience I had 25 years ago") and there was a sense of IPTT therapy being their final hope ("I've tried to go to counselling and things online, and they actually told me you have a lot of things wrong with you"; "I've had several bouts of therapy over a number of years"). Participants described

comorbid mental health difficulties ("I struggle with anxiety as well as depression"; "I have a history of drug and alcohol use") and the fact that previous therapy had "opened a can of worms" and then failed to address all of their difficulties in the context of time limited interventions ("they open up a can of worms, it's like you only have so many sessions to deal with them").

RISK

There was a history of high risk amongst members of this group who described suicide attempts and crisis points ("after they messed up my assessment appointment I had to phone Samaritans because I was in a really bad way"; "I attempted suicide and was seen by the crisis team"; "I've overdosed in the past"), presentations to A&E ("until I was in A&E all the time, until the police got involved, then I finally got proper therapy here"), psychiatric inpatient stays ("it was two years ago when I got admitted") and deliberate self-harm ("I might have like three months and then self-harm").

RELATIONSHIP WITH MENTAL HEALTH SERVICES

Participants often digressed from focusing on their experience with the IPTT to discuss their experience of the wider mental health system. Some participants described negative experiences of services and some staff affecting their feelings towards the whole mental health service ("I think a lot of people, myself included, have felt like disappointment and anger and frustration towards mental health services"). Feelings of anger, dissatisfaction and disappointment were evident ("I think I'd rather kill myself than go back into the hospital, because it's pointless"; "I need a little more trust and a little more faith and compassion from services"; "I've got to still be willing to engage with people who are not treating me the way I need to be treated, and not fulfilling a duty of care in how that's handled"; "I was

getting worse when I got admitted into that hospital"; "I do have a lot of anger towards the

mental health service").

GENERAL THEME 3: EXPECTATIONS

THERAPY

Some of the participants presented with expectations regarding what being in therapy would

involve and it was evident that several engaged in therapy from an initial position of both

needing help and feeling helpless ("please fix this"; "tell me what to do"; "If I knew how to

help myself I wouldn't be here").

RESOURCES

There were mixed expectations with regards to resources. Those who reflected more

positively on their experience with the IPTT had started therapy with the expectation that

resources were limited ("I also understood that for free, it does come to an end"), whereas

some participants felt that resources should be unlimited ("they fund me for 15 weeks to

start, and then hopefully I'll get funding for another 15 weeks, and another however long it

needs to go on").

RELAPSE

There was a sense of some participants feeling that they needed to be in therapy to feel well

and such individuals expected that they would relapse once sessions ended ("I just knew that

after the sessions ended, that I was going to be just going back to what I was doing before";

"I'll be back").

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WAITING TIMES

The participants described the pathway through mental health services to the IPTT as being long and arduous ("about two, three years to get into therapy and get help properly"). They felt that their difficulties changed ("I was in a different space by then") and worsened ("You have difficulties because you're waiting for it") during the time they waited. Participants cited poor communication between NHS teams as one reason for the delay in them accessing therapy ("communication between my GP and then from this team going over to the Maudsley and all of that stuff, ended up taking like five months. Five months in which I then deteriorated very fast").

ADMINISTRATION

Participants reported experiencing administration errors by NHS teams ahead of starting therapy with the IPTT ("Things just getting lost in the post constantly"). This was particularly true in instances where multiple mental health teams were involved ("awful communication between the Southbrook Road people, the Crisis and the A&L team, and here, and then doctors").

ASSESSMENT

Generally, participants found the assessment stage challenging ("After the first one I basically spent a week crying"). Participants struggled to describe their difficulties ("The pressure that I think that those assessments put on you to present with your illness is really immense") and to do so before having built trust with the assessor ("At assessment I felt that I was being pushed to say things that I wasn't comfortable with and it made me close up"). In response, one participant recommended that the IPTT combine assessment with treatment ("it would have been better to just start the therapy, and not have this assessment").

GENERAL THEME 5: POST-THERAPY FACTORS

THE IMPACT OF ENDING

The majority of this group described finding the ending of therapy difficult. One participant described feeing abandoned when sessions ended ("abandonment at the end, that was really difficult."). Some participants felt that the treatment was too short ("I inevitably needed to go back for more help, because I've been discharged when I probably shouldn't have been") and others felt that they were not sufficiently prepared for sessions to end ("it came to the final session and I'm like so what's going to happen now?"; "you kind of need to give us time to adjust"). Several participants highlighted that one thing they appreciated at the end was the therapeutic letter ("Those letters are really helpful, I've still got mine").

Overall, the group was in agreement that the service would benefit from offering follow up or a "refresher" session ("I still feel it would be beneficial to maybe have a follow up, even a phone call"; "a refresher two or three months later might have helped").

POST-THERAPY OUTCOMES

There were mixed experiences with regards to using what had been learned in therapy once sessions ended. Two participants described being able to put what they learned into practice in order to stay well ("I'm definitely still able to use the techniques"; "I'm still using what she taught me"). Whereas others forgot what they had learned ("I know I've forgotten everything that she told me to do") and found it difficult to generalise ("it doesn't really have any relevance after it finishes").

One member of the group described having continued to experience improvements in her quality of life following the end of treatment ("I'm continuing to build confidence in myself, I cook, clean, go out of the house, I love life so much now"), but others described ongoing difficulties ("I was discharged with like a whole host of problems"). One participant

described experiencing relapses since sessions with the IPTT ended ("I had like a relapse three times since my sessions ended, where I had to go back to the crisis centre") and one participant was back in therapy ("I now have therapy elsewhere").

GENERAL THEME 6: POSITIVE EXPERIENCES

HELPFUL FACTORS

During therapy, participants described benefitting from gaining a different perspective on their difficulties ("I can see past it, where I couldn't see past it before"; "when I get unhappy, is it such a bad thing, actually? I just need to sit with it"). Some participants also gained an understanding of their difficulties, particularly their triggers ("I've realised what makes me anxious and what kind of triggers my sort of negativeness") and learned helpful coping strategies ("they do give us skills"; "breathing techniques and the mindfulness were helpful").

Some participants described the regularity of attending therapy as being particularly helpful ("routine of coming here was like something that helped to maintain me") and this was something that they missed once sessions ended ("therapy ended about six weeks ago, and I'm really missing it, that was a day just for me").

POSITIVE OUTCOMES

All the CORE improvers described some positive outcomes following their treatment with the IPTT ("It was the best time of my life – wouldn't change anything about it"; "it did help me, I really enjoyed it"; "my therapist here is lovely, I enjoyed it"; "I've been getting the longer gaps between self-harming"; "I felt quite empowered for a while after finishing"; "My experience was really good!"; "I'm amazed at how grounded I seem to be at the moment"; "I felt like my needs were met").

DISCUSSION

SUMMARY AND IMPLICATIONS

Across groups, it was notable that treatment within the IPTT represented just one part of a multi-faceted recovery journey and that discharge from the IPTT did not mark the end of this journey. Both groups highlighted many factors that impacted on their capacity to benefit from therapeutic intervention, including the therapeutic relationship, stigma and negative life events (e.g. being homeless, financial difficulties).

Both groups emphasised the importance of the therapeutic relationship, which is in keeping with the idea that it is a central common factor (e.g. Horvath & Bedi, 2002; Lambert, 2003; Shirk & Karver, 2003; Wampold, 2001). Many of the participants highlighted the importance of the client and therapist having shared and agreed upon goals, but participants in both groups felt that this was sometimes lacking in their treatment with the IPTT. Interestingly, some particiants with improved CORE scores had clashes with their therapist and even described hating them. As highlighted by Yeomans et al. (2015), this could indicate that being able to have conflict in therapy may in some cases be helpful, or alternatively, that gains were in spite of these conflicts.

The notion of the therapist as "being in the driving seat" and the client having to go along with what they said, was referred to by some members of both groups. In particular, members commented on the fact that they felt disempowered by therapists who asked them to stop using drugs and alcohol and resorted to dishonesty when asked about this directly. However, at least one person was able to recognise that therapy did not work when they were abusing substances. Many participants described a collaborative relationship in which they felt empowered and more able to challenge or disagree with their therapist. These findings are consistent with those reported by the Task Force on Empirically Supported

Therapy Relationships (Norcross, 2002), which identified that goal consensus, collaboration, and therapist empathy are associated with a strong therapeutic alliance.

Both groups described longstanding mental health difficulties, which is unsurprising in that the IPTT is a secondary care service for clients who have severe and complex difficulties. Research shows a significant negative correlation between level of impairment and treatment outcome (Norcross, 2004), which suggests that, as a service, the IPTT might not expect to discharge people who no longer meet clinical threshold for any mental health diagnoses. This could explain the ongoing difficulties described by participants across groups. In addition, a negative association has been found between treatment outcome and the length of time that mental health difficulties are left untreated (Boonstra *et al.*, 2012; Dell'Osso *et al.*, 2013), which is relevant to CORE non-improvers, who delayed helpseeking as a consequence of stigma and negative expectations. Self-stigma was particularly apparent amongst this group and has been found to be negatively associated with adherence to psychological treatment (e.g. Livingston and Boyd 2010; Fung, Tsang, Corrigan, Lam & Cheng, 2007). This could provide one explanation for the fact that their CORE scores were unimproved following intervention with the IPTT.

There was a notable group difference in terms of participants' experience with mental health services. Several of the CORE improvers described a long history of help seeking behaviour and contact with mental health services. There was a high level of animosity among some participants, which they described as resulting from poor administration, long waiting times, poor communication between health professionals and a perception of lack of compassion from mental health sector staff. These participants also tended to make negative predications about their capacity to make and maintain therapeutic gains, which is perhaps unsurprising in the context of a history of multiple experiences of intervention followed by poor outcomes or relapse. This could either reflect a poor response to their condition, or highly

treatment resistant conditions, but nonetheless, research into the impact of expectations tends to show that very low expectations are a predictor of poor therapeutic outcome (e.g. Greenberg, Constantino & Bruce, 2006).

CORE improvers described a higher level of risk than non-improvers; crisis points, deliberate self-harm, inpatient stays and suicide attempts were reflected on by all members of this group. In the context of this level of distress, it is important to note that this group experienced improvements following treatment with the IPTT. Across groups, aspects of therapy that participants highlighted as being particularly helpful included a positive and collaborative relationship with their therapist, gaining a greater understanding of their difficulties (particularly triggers), seeing their difficulties from a new perspective and learning coping strategies.

It was evident that both groups experienced outcomes that were not captured by the CORE, which is a noted criticism of quantitative outcome measures (e.g. Bannister, 1998; Marzillier, 2004). Some of the participants in the non-improved group described experiencing benefits following treatment with the IPTT and some CORE improvers highlighted ongoing difficulties at the end of treatment, implying that therapy was too short, and the gains were not always sustained. This finding highlights the value of carrying out longer term follow-up of response to therapy, which has previously been trialed within IPTT, but with poor response rates.

What is evident from these findings it that more severe patients felt that they needed longer in therapy to improve. Due to constraints on funding and resources, many IPTT patients receive relatively short therapies given the severity of their difficulties. Indeed, there are large numbers of patients with severe psychological difficulties who would benefit from longer-term treatment were it available.

Possible Service Recommendations

These focus groups highlighted several possible service recommendations. These related to monitoring the therapeutic relationship, exploring expectations, and considering endings.

MONITORING THE THERAPEUTIC RELATIONSHIP

Several participants highlighted that ruptures in the therapeutic relationship impacted on their capacity to benefit fully from treatment with the IPTT. Qualities that have been found to be important in predicting positive change following therapy include positive regard, openness, genuineness and effective communication, as well as being flexible, honest, respectful, trustworthy, confident, warm and interested (e.g. Ackerman & Hilsenroth, 2001, 2003; Keijsers, Schaap & Hoogduin, 2000; Lambert & Barley, 2001). It is difficult to know whether these factors were absent or whether the psychological make-up of participants led them to perceive interactions with their therapist in this way. However, failure to mend ruptures predicts negative outcome (for reviews, see Ackerman & Hilsenroth, 2001, 2003) and it is therefore important for therapists to provide regular opportunities for client feedback on their experience of the therapeutic relationship.

The theme of participants feeling that they had to go along with the views of therapists was evident in both groups, which demonstrates the usefulness of therapists being explicit about the collaborative nature of therapy. Indeed, a collaborative relationship provides clients with the opportunity to feel that they have been actively involved in ameliorating their difficulties.

EXPLORING EXPECTATIONS AND ENCOURAGING TRANSPARENCY

Several expectations seemingly impacted on participants' capacity to benefit from therapy.

Many CORE non-improvers expressed anxieties about the wider implications of being a

patient in a mental health service. Three participants were fearful of being sectioned and

chose to withhold information from their therapists for this reason. This finding highlights the value of therapists allowing time during the assessment period to encourage the service user to speak freely and openly in order for therapy to work well. The assessment period might also be used to explore clients' reservations and anxieities about therapy and what it means to them to be IPTT service users. Participants in both groups highlighted the fact that attending appointments in the Ladywell Unit was distressing. This was due to panic alarms, past experiences of being an inpatient and also seeing inpatients in the entrance area. In response, it might be helpful for this to be explored and acknowledged with first time patients. Some participant expectations resulted from previously unhelpful experiences of mental health services. Again, discussing this could improve rapport.

PRE AND POST-THERAPY FACTORS

Many participants described the assessment period as being difficult. It may be useful for a staff discussion about their practice regarding allowing enough time in the first meeting for clients to express concerns and ask questions. The service leaflet that is sent to clients before the first meeting could also highlight the value of service users asking questions and sharing their views during the assessment.

The period preceding assessment was difficult for many of the participants. In general, participants accepted that there was a long waiting time for therapy that was being offered within the NHS. Perceived administrative errors and poor communication between teams had a powerful impact on some clients, although these errors may have happened before they were referred to the IPTT, which has an excellent reputation for efficiency. Indeed, IPTT service users are likely to have had assessments and treatment elsewhere so it could be relevant for the IPTT staff to reflect on how communication between teams could be further improved.

There was disparity between groups with regards to satisfaction with endings. One patient in the non-improvers group was encouraged by the fact that she was being offered further treatment in the service in the form of group therapy. There was much discussion of the impact of endings, which is perhaps not surprising given that some participants said that therapy in the service was their final hope after many previous treatments, and it was perhaps inevitable that all of their long-standing difficulties were not ameliorated. There is also the impact of loss and sadness at the ending of what was a significant relationship where the patient may have talked about what mattered to them the most. Indeed, for those who showed improvement, the end of sessions with the IPTT might signal the end of their involvement with mental health services. Many participants reported finding the CAT therapeutic letter to be helpful and therapists from other modalities might consider this, perhaps as a subject of further research. Three participants also felt that the IPTT should offer a follow up session or phone call to address feelings left over after therapy ended.

LIMITATIONS AND FUTURE DIRECTIONS

There are several limitations of the current project. One issue relates to the validity and reliability of the data collected. With regards to validity, issues such as social desirability and "group think" can hinder focus group data. It was hoped that having service users who were not involved in delivering individual treatment within the IPTT would allow participants to feel able to provide honest opinions, yet it is important to acknowledge that the facilitators' positions of having had a positive experience of therapy could have led to participants being less inclined to share negative views. However, findings indicated that the participants did engage in sharing negative experiences and responses across the groups demonstrated internal coherence, suggesting that findings were valid. In both groups, particular group members dominated the conversation and their opinions and views could have shaped responses from others and subsequent themes. Indeed, these participants

represent a small proportion of the people who have received treatment within the IPTT and therefore it cannot be presumed that the responses are reflective of overall service user perspective.

With regards to reliability, it is important to consider the characteristics of people who agreed to attend the focus groups versus those who declined. There was a tendency to focus on negative features of treatment, even among CORE improvers thus preventing the opportunity to gain valuable information about the aspects of therapy that are most helpful. One possible explanation for this is that those who gained the greatest benefits were more reluctant to re-engage with mental health services. Indeed, this could explain why several CORE improvers described relapse and ongoing difficulties. The IPTT would benefit from ascertaining more views of those who maintained gains following discharge. The service could consider piloting qualitative feedback questionnaires alongside the CORE to see whether this added useful information about the process and efficacy of therapy.

Alternatively, the service might benefit from carrying out focus groups regularly, or from having a service user employed to interview clients about their experiences following their final session with the IPTT.

The qualitative findings from both focus groups highlighted that important outcomes may not have been captured by the CORE-OM, although there was a time lag between the outcome of the final CORE, and the focus groups which were held several months later, so it is possible that there had been changes. Future research might repeat the CORE at the time of the focus groups, to be able to compare quantitative outcome data with the qualitative data described in the focus groups.

CONCLUSION

Overall, these focus groups provided useful information regarding factors that affect therapeutic outcome following treatment in the IPTT. This project highlighted the importance and value of involving service users in service development, both through employment in mental health teams and through collecting and implementing their feedback. The findings were fed back to therapists and it is hoped that they lead to improved experiences and outcomes for future IPTT service users.

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APPENDIX

Appendix 1. Focus group facilitators prompt sheet (including questions asked)

Introduction

Greet participants and introduce facilitators

C.D.

My name is C.D. and I'm the peer support development coordinator for the service, my role is focused on enabling former clients of the service to provide peer support to current clients. Welcome to today's focus group and thank you for giving your time and expertise today. The department values your views and expertise and wants to thank you for attending today's meeting.

H.N.

Good afternoon and welcome to today's group, my name is H.N. and I was a patient her, I'm now volunteering with the service. The service values your expertise and knowledge and wants to listen to your feedback. Your experience of the service can help us to make improvements to our service and place the client at the centre of what we do.

Thanks for attending and their time

Flip Chart exercise.

Contracting/ground rules – mutual respect, confidentiality, everyone has chance to contribute, no right/wrong answer, please turn off phones, talk to each other etc.

Restate the purpose of the group – to hear about people's thoughts on what contributed to the outcome of their psychological therapy in IPTT, interested in your experience of therapy what helped and what hindered you benefitting from therapy.

Restate framework – including timeframe

Outline role of facilitators – guide the discussion, give everyone chance to talk, ensure we stay on topic

Opportunity for questions

General Discussion

Go round, introduce self, and briefly summarise what you feel the outcome was of your therapy in IPTT.

What were the things that you can think of that made it possible for you to get ome benefit from treatment?

What were things that meant you did not benefit from therapy in the way you would like to have done?

<u>Prompts</u> appointment time, travel expenses, length of therapy.

Specific Questions

1. Thinking about your relationship with your therapist, how did this affect things?

Prompts: were you listened to, Did you feel you actively involved in the process.

2. Thinking about what happened in your life outside of therapy at the time, how did this affect things?

Prompts: Financial difficulties, child care issues, housing difficulties.

3. Thinking about the setting of the therapy, how did this affect things?

Prompts: alarms sounding, attending an in-patient unit.

Anything else that has been important to the outcome of their therapy that they want to mention before finishing up.

Rounding up

Everyone to identify out of all the reasons affecting therapy outcome discussed, which stands out for you as the most important?

Facilitator to summarise key issues and points raised during the discussion

Explain what will happen next with the information and what action will be taken — recording will be transcribed, and themes extracted, fed back to the team's clinicians, the wider service to help up think about how to improve our service for patients Invite people to write with further feedback if they have additional comments after the session.