University of Bath



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Research Portfolio submitted in partial fulfilment of the requirements for the degree of **Doctorate in Clinical Psychology**

Research Paper: Everyday experiences of intrusive thoughts and images in individuals with a diagnosis of bipolar disorder

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Award date: 2016

Awarding institution: University of Bath

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Research Portfolio submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

Volume 1 of 2

Rosie Oldham-Cooper

Doctorate in Clinical Psychology

University of Bath Department of Psychology

May 2016

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Word counts

Critical Review of the Literature	6,455
Service Improvement Project	4,965
Research Paper	4,992
Executive summary of research paper	525
Narrative overview of research components	2.073

Table of Contents

Abstract for main research project	6
Abstract for service improvement project	7
Abstract for critical review of the literature	8
Critical Review of the Literature: Disorder-specific versus generic cognitive-	
behavioural treatment of anxiety disorders in children and young people: A systematic	
narrative review of evidence for the effectiveness of disorder-specific CBT compared	
with the disorder-generic treatment Coping Cat	9
Service Improvement Project: Service-user and staff views on the provision of written	n
information in a memory service in the South West of England5	9
Research Paper: Everyday experiences of intrusive thoughts and images in	
individuals with a diagnosis of bipolar disorder8	5
Executive summary of research paper10	8
Narrative overview of research11	0
Acknowledgements11	5

List of Appendices

Appendix A. Search terms used, by database	116
Appendix B. Staff information sheet	.117
Appendix C. Service user information sheet	.120
Appendix D. Table summarizing the written information pack provided by the memo service and comparing against NICE (2006) guidance on topics to be covered within written information that is provided by clinicians alongside verbal communication of diagnosis of dementia	n a
Appendix E. Advertisements for participants in the Bipolar disorder group and the no clinical control group	
Appendix F. Participant information sheet	.127
Appendix G. Participant consent form	.130
Appendix H. Information sharing consent form	.131
Appendix I. Guide to sources of support for participants	.132
Appendix J. Guide to completing measures	.133
Appendix K. The 'representativeness rating scale'	.137
Appendix L. Debrief sheet	.139
Appendix M. Research ethics committee favourable opinion letter	.140
Appendix N. Recruitment approval letter from Avon and Wiltshire Mental Health Partnership NHS Trust	144
Appendix O. Recruitment approval letter from Birmingham and Solihull Mental Heal	
Appendix P. Recruitment approval letter from Everyone Included	.149
Appendix Q. Recruitment letter for Everyone Included	.150
Appendix R. Confirmation of approval from Avon and Wiltshire Mental Health Partnership Trust for Service Evaluation (service improvement project)	151
Appendix S. Author Guidelines for the Journal of Anxiety Disorders	.152
Appendix T. Author Guidelines for the journal Aging and Mental Health	.158
Appendix U. Author guidelines for the journal Behaviour Research and Therapy	160

List of Tables

Table 1. Search criteria14
Table 2. Characteristics of individual studies included in the review18
Table 3. Evidence of attempts to minimise risk of bias in 6 main areas, based on the Cochrane risk of bias assessment tool (Higgins et al, 2011)25
Table 4. Therapist details, including professional status, previous experience and supervision arrangements32
Table 5. Outcomes on various measures of anxiety severity across studies39
Table 6. NICE guidelines for the provision of written information to service-users alongside diagnostic feedback (NICE, 2006, p. 12)62
Table 7. Questions used in the service-user and staff focus-groups63
Table 8. Group comparisons on background variables and measures at initial interview
Table 9. Group comparisons on diary measures95
Table 10. Group comparisons on measures at final interview96
Table 11. Diagnosis-related information for participants in the bipolar disorder group,
with data for study completers and non-completers presented separately97

List of Figures

Figure 1. PRISMA flow diagram showing study selection and inclusion	15
Figure 2. Themes and sub-themes emerging from the two focus-groups	66
Figure 3. Model of mental imagery as an 'emotional amplifier' in bipolar disorder to	from
Holmes et al (2008)	88

Abstract for main research project (240 words)

Background: Holmes et al (2008) posited that mental imagery acts as an 'emotional amplifier' in bipolar disorder, leading to the shifts in mood that are a hallmark of the condition. Evidence for this idea comes largely from retrospective studies. No study has, to the author's knowledge, explored experiences of mental imagery as they occur in the day-to-day lives of individuals with bipolar disorder. This approach has the advantage of greater ecological validity, minimising confounds associated with retrospective recall.

Method: Twelve individuals with a diagnosis of Bipolar I or II disorder and 20 nonclinical controls completed a diary of intrusive mental images and verbal thoughts twice-daily for seven days. Thoughts and images were rated on a number of dimensions, including 'intensity' and 'vividness'.

Results: Individuals with bipolar disorder reported significantly more 'intense' experiences of intrusive mental imagery compared to controls, but there were no significant differences in frequency or intensity of verbal thoughts, although the small number of participants in the bipolar disorder group means the study may have lacked power to detect significant group differences. Vividness of mental images was also higher in the bipolar disorder group.

Conclusions: The findings provide support for Holmes et al's (2008) model, using assessment of intrusive verbal thoughts and mental images in a naturalistic setting. The main benefit was greater ecological validity compared to previous retrospective studies. The study also demonstrated that it is possible to elicit reports of these phenomena using diaries in a bipolar disorder population.

Abstract for service improvement project (199 words)

Background: Previous studies have suggested that memory service users generally report a desire for more information around a diagnosis of dementia.

Objective: To explore service user and staff views on written information provided following a diagnosis of dementia by a memory service in the South West of England.

Method: Service user and staff perspectives on the written information were explored through focus-groups in order to better understand their views and preferences on the type and quantity of written information that is provided around a diagnosis of dementia. The written information provided by the memory service was also assessed against the National Institute for Health and Care Excellence (NICE; 2006) guidelines for information provision.

Results: The provision of written information by the service covered all topics suggested in the NICE guidelines. Service users and staff generally agreed that there was 'too much' written information, and both parties highlighted a need for balance between written information and more direct support and information provision by staff.

Conclusion: The findings highlight potential barriers to service users accessing information relevant to their diagnosis and provide examples of how one service attempted to respond to such issues through some relatively simple adaptations to its practice.

Abstract for critical review of the literature (248 words)

Background: Coping Cat, a generic cognitive-behavioural intervention for childhood anxiety disorders, is recommended as a treatment of choice for social anxiety disorder (SAD), generalised anxiety disorder (GAD), separation anxiety (SA), and specific phobias (SP) in children and young people presenting in child and adolescent mental health services in England, in contrast with the disorder-specific approaches generally favoured in the treatment of anxiety disorders in adults. To date, little research has compared the effectiveness of Coping Cat versus disorder-specific approaches in the treatment of childhood anxiety disorders.

Objectives: To compare the effectiveness of Coping Cat with disorder-specific CBT interventions based on anxiety-related treatment outcomes using a narrative, systematic review to allow for flexible comparisons to be made.

Data sources: Science Direct and APA Psychnet were searched for relevant articles (April 2015), and reference lists of relevant review articles were searched by hand.

Study selection: Primary research articles describing treatment of children and young people aged 7-17 for SAD, GAD, SA, and SP, using either Coping Cat or disorder-specific CBT.

Results: Thirteen studies were included. Ten implemented Coping Cat and 4 implemented disorder-specific CBT. Only one study included a direct comparison of Coping Cat with a disorder-specific approach. There was a lack of data to support the use of Coping Cat in the treatment of SP. However, Coping Cat appeared to be at least equally effective as disorder-specific treatments for SA and SAD.

Conclusions: A lack of high quality data exists for disorder-specific treatment approaches. Implications for current practice and recommendations for future research are discussed.

Disorder-specific versus generic cognitive-behavioural treatment of anxiety disorders in children and young people: A systematic narrative review of evidence for the effectiveness of disorder-specific CBT compared with the disorder-generic treatment Coping Cat

Word count: 6,455

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A version of this paper is under review with the Journal of Anxiety Disorders

Abstract

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Introduction

Anxiety disorders are one of the most common mental health disorders occurring in childhood (Cartwright-Hatton, McNicol, & Doubleday, 2006). In a UK study conducted in 1999 the estimated prevalence of anxiety disorders in children aged 5–15 years was 3.8%, accounting for around 40% of all DSM-IV disorders in this group (Ford, Goodman, & Meltzer, 2003). Moreover, high comorbidity has been reported in children and young people (CYP), both among different anxiety disorders and between anxiety disorders and other DSM-IV disorders such as depression (Ford et al., 2003; Kendall et al., 2010). It has been suggested that in the majority of cases of anxiety disorders diagnosed in adulthood the disorder may have begun in childhood or adolescence (Ferdinand & Verhulst, 1995; Kim-Cohen et al., 2003; Pine, Cohen, Gurley, Brook, & Ma, 1998). Accordingly, researchers have stressed the importance of the early treatment of anxiety disorders in CYP (Kendall et al, 2004).

The Children and Young People's Improving Access to Psychological Therapies programme (CYP IAPT) was introduced in 2011 to improve existing Child and Adolescent Mental Health Services (CAMHS) in England. By March 2015, it was anticipated that CYP IAPT services would provide a service for 60% of children and adolescents in England (aged 0–19) with emotional disorders including depression, anxiety and behavioural problems. Indeed, as of April 2015, CYP-IAPT had surpassed this target, reaching 68% of services covering the 0-19 population (CYP IAPT Central Team; personal communication, 24.04.2015). The CYP IAPT National Curriculum (2013) outlines recommended treatments for anxiety disorders. The curriculum's authors highlight a lack of NICE guidance on the treatment of Generalised Anxiety Disorder (GAD), separation anxiety and social anxiety disorder in children and young people (p. 31, CYP IAPT Programme's Education and Curriculum Task and Finish Group, 2013). According to the authors, the 'most substantial' evidence for a treatment approach for the above disorders is for the Coping Cat programme. Coping Cat is also suggested as the treatment approach of choice for specific phobias in CYP.

Coping Cat is a manualised cognitive-behavioural treatment for anxiety disorders in children and adolescents developed by Kendall and colleagues (Kendall, 1994; Kendall et al., 1997; Kendall & Hedtke, 2006a; Kendall & Hedtke, 2006b). The treatment is recommended for children aged 7 to 13 years with GAD, separation anxiety, and/ or social anxiety disorder (Kendall, Hudson, Gosch, Flannery-Schroeder, & Suveg, 2008). A modified version of the treatment also exists for 14-17 year-olds. There are 16 hourlong sessions in total, consisting of 8 hours of 'skills training', and then 8 hours of 'exposure tasks', with the overall aim of equipping children with the skills to recognise

and confront, rather than avoid, the situations they find anxiety-provoking. An important feature of Coping Cat is that it is not targeted toward a specific anxiety disorder presentation. The authors justify this 'generalised' approach on the grounds that there is a high degree of comorbidity between anxiety disorders in CYP (Creswell, Waite, & Cooper, 2014; Kendall et al., 2010). In addition, well-validated maintenance models for specific anxiety disorders in CYP do not currently exist (Creswell et al., 2014).

In contrast, in the treatment of anxiety disorders in adult populations the use of disorder-specific approaches is commonplace and is supported by a strong evidence-base (e.g., Butler, Fennell, & Hackmann, 2010; Kendall, 1994; Reynolds, Wilson, Austin, & Hooper, 2012; though see Schulte, Künzel, Pepping, & Schulte-Bahrenberg, 1992). For example, treatments for specific phobia tend to focus largely on exposure to phobic stimuli and often some cognitive restructuring; treatment for GAD tends to incorporate exposure to worry, relaxation training, cognitive restructuring and coping strategies, and treatment for social anxiety disorder generally incorporates elements of exposure, cognitive restructuring, relaxation training, practice at reducing self-monitoring behaviours, and social skills training (see Olatunji, Cisler, & Deacon, 2010 for a review). Therefore, while many treatments share similar elements, some elements are disorder-specific (e.g. social skills training in social anxiety disorder, coping strategies in GAD).

As Kendall (1994) noted, the evidence for disorder-specific versus more general treatment approaches in CYP is lacking. Rapee, Schniering, and Hudson (2009) suggested that this is a question worthy of further investigation. Recently, knowledge has begun to advance in relation to this matter. For example, some studies have suggested poorer outcomes for generic CBT approaches in social anxiety disorder in CYP compared to disorder-specific approaches (e.g., Creswell et al., 2014; Kerns, Read, Klugman, & Kendall, 2013), although one study reported little advantage of a disorder-specific treatment approach compared to Coping Cat in the treatment of separation anxiety disorder (Schneider et al., 2013). Moreover, one recent study reported good outcomes for a single-session treatment of specific phobia (while the 16-session Coping Cat treatment is recommended by CYP IAPT; Ollendick et al., 2009). These findings highlight a need for systematic comparison of the outcomes for disorder-specific versus generic treatment approaches in anxiety disorders in CYP.

A recent meta-analysis conducted by Reynolds et al. (2012) included a comparison of a number of 'disorder-generic' and 'disorder-specific' cognitive behavioural treatments for anxiety disorders in CYP. Reynolds et al. (2012) reported that across 55 the randomised controlled trials they included the overall effect size was moderate for the

treatment of anxiety disorders with 'disorder-general' approaches (including, but not limited-to, Coping Cat), whereas for disorder-specific treatments the effect size was medium-to-large. In their discussion, the authors concluded that disorder-specific treatment approaches appeared to have a larger effect size, but noted that a confounding variable was the lack of availability of separate treatment outcome data for different disorders, which was problematic for the calculation of effect sizes.

An alternative approach to explore this important question further is the use of a critical, systematic, narrative review of the current literature. Specifically, the recommendations made by CYP IAPT's National Curriculum appear to favour a disorder-general treatment approach, Coping Cat, rather than disorder-specific approaches for the treatment of four different anxiety disorder presentations (GAD, social anxiety disorder, specific phobia and separation anxiety). The above-proposed alternative approach to the question of whether disorder-specific approaches are preferable to Coping Cat would allow for more flexible comparisons to be made for a relatively sparse literature, and could also highlight areas worthy of future research.

Therefore, our aim was to undertake a critical, narrative review of whether disorder-specific cognitive behavioural interventions, as favoured in the treatment of anxiety disorders in adults, are more effective compared to the disorder-generic Coping Cat treatment approach for the treatment of social anxiety disorder, GAD, separation anxiety, or specific phobia, in CYP aged 7-17 years, based on treatment outcomes assessed using validated measures relating to anxiety symptoms, including remission rates.

Following from this overall aim, the main objectives were as follows:

- To compare anxiety-related outcomes associated with treatment of four anxiety disorders using Coping Cat and disorder-specific cognitive behavioural interventions. Outcomes considered were remission rates and specific validated anxiety measures.
- To consider the quality of studies included to allow for exploration of any differences in overall quality of the evidence for disorder specific CBT interventions versus Coping Cat.

Methods

Search strategy

Searches were conducted by the primary author on 24th April 2015 using the research databases Science Direct and APA Psychnet (with each database accessing around 2500 peer-reviewed journals) to identify primary research articles describing the treatment, using individual psychological therapy, of anxiety disorders including GAD, social anxiety disorder, separation anxiety and specific phobia in children aged 7 – 17 years. The search was conducted according to the PRISMA guidelines for conducting systematic literature reviews (Moher, Liberati, Tetzlaff, & Altman, 2009). Initially, the search criteria to identify relevant primary research articles were entered into the two chosen databases. These criteria are included in Appendix A. The reference lists of recent review articles were also checked for further relevant articles. The review articles used were Reynolds et al. (2012), Davis, May, and Whiting (2011), Ishikawa, Okajima, Matsuoka, and Sakano (2007), and Cartwright-Hatton, Roberts, Chitsabesan, Fothergill, and Harrington (2004). The resulting articles were combined in a single list and duplicates were removed (see Figure 1).

Search criteria

Inclusion and exclusion criteria can be found in Table 1. In the case that the afore-mentioned disorders were included together with other disorders, such as obsessive-compulsive disorder, and results were not presented separately for the disorders of interest, these articles were also excluded. In some of the earliest studies of Coping Cat (Kendall, 1994; Kendall et al, 1997), diagnoses were based on DSM-III criteria. These studies included CYP with diagnoses of 'overanxious disorder', 'avoidant disorder' and separation anxiety. Kendall et al (1997) highlighted, however, that in the DSM-IV overanxious disorder was subsumed under the diagnosis of GAD, and avoidant disorder under the diagnosis of social anxiety disorder, with the characteristics of identified cases unchanged by the change in terminology. Therefore, these studies were included and interpreted according to the DSM-IV diagnostic categories.

Table 1.
Search criteria

Inclusion criteria	Exclusion criteria
English language articles	Non English language articles
Describes treatment of children aged 7-17 (for	Includes children younger than 7 years old or
children aged 14-17, use of age-appropriate	adults (i.e., 18 years and over).
version of Coping Cat must be explicitly	
stated)	
Cognitive behavioural treatment	Family therapy, EMDR, ACT,
	pharmacotherapy, behaviour therapy
Coping Cat (or adapted version of Coping Cat	FRIENDS, ECBT or BCBT disorder-generic
for a different population, e.g. Coping Koala in	treatment programmes
Australia) OR disorder-specific treatment	
Individual, face-to-face therapy	Computer-delivered therapies, group therapies
Treatment for social phobia, specific phobia,	Treatment for OCD, trauma, eating disorders,
separation anxiety or generalised anxiety	domestic violence, selective mutism,
disorder, with details of how diagnoses were	agoraphobia or panic, or no detail of how
made	diagnoses were made
Child anxiety is primary focus of treatment and	Child anxiety not primary focus of treatment or
outcome	outcome (e.g. parent training, outcome
	measures unrelated to child anxiety)
Primary research article describing treatment	Review, epidemiological study
of anxiety	
Treatment according to original model	Adapted treatment, e.g. for individuals with an
	Autism Spectrum condition
Use of a validated outcome measure of	Use of an unvalidated outcome measure of
anxiety	anxiety

Data extraction

Data extraction was conducted using a standardised data extraction form. The primary author, RO-C, performed all data extraction and the resulting summary forms were checked by the second author, ML. Discrepancies in judgement were resolved by consensus.

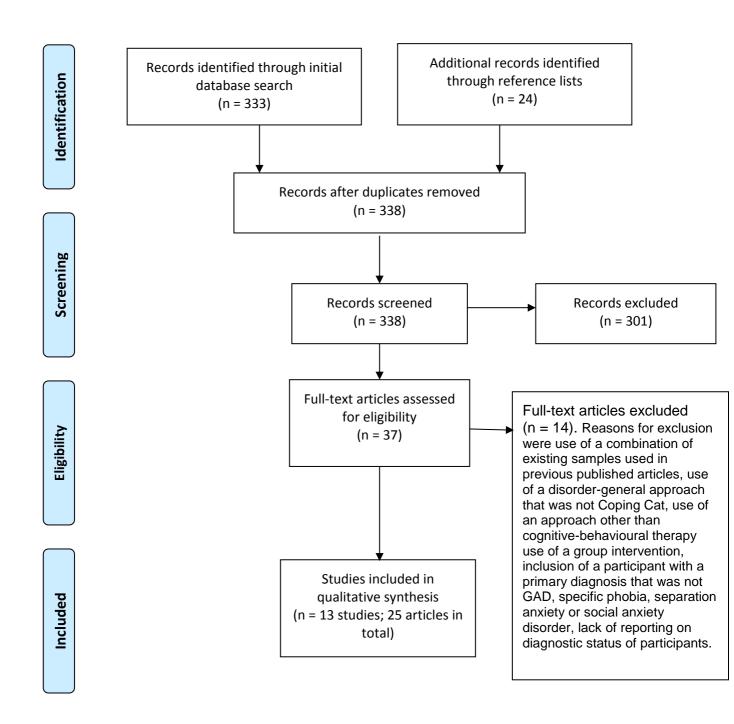


Figure 1. PRISMA flow diagram showing study selection and inclusion

Quality assessment

The articles were assessed for quality using the Cochrane Collaboration's tool for assessing risk of bias, recently updated by Higgins et al (2011). This tool allows the researcher to assess randomised controlled trials for risk of bias based on six different sources of possible bias, including selection bias (random sequence generation and allocation concealment), performance bias (blinding of participants and personnel),

detection bias (blinding of outcome assessment), attrition bias (incomplete outcome data), reporting bias (selective reporting) and 'other' bias. The tool was used to guide the consideration of potential sources of bias affecting the studies included in the present review, and for a comparison between Coping Cat and disorder-specific treatment studies to be made, although no studies were removed from the review based on the identification of possible bias.

Data analysis

In order to explore whether there is any difference between disorder-specific cognitive-behavioural interventions and the disorder-generic Coping Cat programme for the treatment of social anxiety disorder, GAD, separation anxiety, or specific phobia in CYP aged 7-17 years, the outcomes assessed were remission rates (i.e., the number of cases who were diagnosis-free at end of treatment), and anxiety symptom severity, if assessed using a validated measure. The analysis strategy was a narrative review, which included assessment of study quality as well as outcome (remission rates and validated measures of anxiety). The assessment of study quality was an important aspect of the review, as it allowed for study outcomes to be assessed in the context of aspects of their design, methodology and reporting. A meta-analysis was not conducted because of the very small number of disorder-specific intervention studies available; narrative review was considered to be a more appropriate and meaningful way of synthesising the information to address the review question.

Results

Twenty-four published articles were included in the present review. All were randomised-controlled trials. Seventeen articles reported outcomes for only six original samples – six from the CAMS trial (original study by Walkup et al., 2008), two from an original study by Kendall et al. (2008), two from Kendall (1994), two from a trial conducted by Barrett, Dadds, and Rapee (1996), three from Kendall et al. (1997), and two from an original trial by Ollendick et al. (2009), and so these are considered as only six single sets of data. This left 13 data sets or 'studies' for inclusion in the present review. One study compared a disorder-specific treatment approach with Coping Cat for the treatment of separation anxiety (Schneider et al, 2013). Therefore, this study is included in both the 'Coping Cat' and 'disorder-specific' categories for the purpose of this review. Overall, there were 10 data sets, comprising 20 individual articles with 1076 participants in total that described the use of Coping Cat in the treatment of the childhood anxiety disorders of interest, and 4 data sets, comprising 5 articles and a total of 393 participants that described a disorder-specific approach to the treatment of one of the disorders of interest. Of the four data sets relating to a disorder-specific

approach, two described the treatment of specific phobias, one described the treatment of separation anxiety disorder, and one described the treatment of social anxiety disorder. No studies relating to the treatment of GAD met the inclusion criteria for this review. The studies were undertaken in North America, Sweden and Switzerland. No UK-based studies met the inclusion criteria for this review. Table 2, below, provides a summary of the data sets included.

Table 2.

Characteristics of individual studies included in the review

Authors, date	Country of	Sample	Age	%	Ethnic	Primary	Comorbid	Comorbidity	Experimental	Control	Primary	Length of	Outcome	Effect size
	origin	size	range	girls	background	diagnosi	diagnoses	rates	group	group	outcome	follow up		
			(years)			S			treatment		measure			
Kendall	North	47	9-13	40%	76%	OAD,	Depression,	32%	CC	WL	RCAMS	1 year,	CC > WL	Not reported
(1994)	America				Caucasian	SAD, AD	ADHD,	depression,			t-score	3.35 years		
Kendall &							ODD, CD,	15% ADHD,						
Southam-							specific	13% ODD, 2%						
Gerow (1996)							phobias	CD, 60%						
								simple phobias						
Barrett,	Australia	79	7-14	43%	Information	SAD,	Depression,	6% depression,	Coping	Coping	ADIS-C	6 months,	Coping	Not reported
Dadds &					not	SOP,	specific	22% simple	Koala	Koala +	& ADIS-	1 year,	Koala +	
Rapee (1996)					available	OAD	phobias,	phobias, 2%		family	Р	6.17 years	FAM >	
Barrett, Duffy,							ODD	ODD		anxiety			Coping	
Dadds &										management			Koala	
Rapee (2001)										(FAM) and				
										WL				
Kendall,	North	94	9-13	38%	85%	OAD,	Specific	48% simple	CC	WL	ADIS-C	1 year, 7.4	CC > WL	Not reported
Flannery-	America				Caucasian,	SAD, AD	phobias,	phobias, 14%			& ADIS-	years		
Schroeder,					5% African		ADHD,	ADHD, 8%			Р			
Panichelli-					American		ODD,	ODD, 6%						
Mindel,							depression,	depression, 1%						
Southam-							CD	CD						
Gerow, Henin														
& Warman														

Kendall, Safford, Flannery- Schroeder & Webb (2004) Kerns, Read, Klugman & Kendall (2013)														
Flannery- Schroeder & Kendall (2000)	North America	37	8-14	49%	Information not available	GAD, SOP, SAD	Specific phobia, ADHD, dysthymia, depression, ODD	30% specific phobia, 25% ADHD, 8% ODD, 5% dysthymia, 3% depression	СС	WL	ADIS-C & ADIS- P	3 months	CC > WL	Not reported
Siqueland, Rynn & Diamond (2005)	North America	11	12-17	27%	91%	GAD, SOP, SAD	Depression, panic, GAD, SOP, SAD, specific phobia	36% depression, 18% social phobia, 9% specific phobia, panic	СС	CC + attachment based family therapy (ABFT)	ADIS-C-R	6-9 months	CC = CC = ABFT	Not reported
Kendall, Hudson, Gosch, Flannery- Schroeder & Suveg (2008) Suveg, Hudson,	North America	161	7-14	44%	85% Caucasian, 9% African American	GAD, SOP, SAD	GAD, SAD, SOP, specific phobia, ADHD, ODD, dysthymia, depression,	24% GAD, 32% SAD, 37% SOP, 53% specific phobia, 32% ADHD, 14% ODD, 6% dysthymia, 5% depression	CC	Family- based education/ support/ attention active control (FESA)	ADIS C/P	1 year	CC > FESA	Not reported

Desires							CD							
Brewer, Flannery- Schroeder, Gosch & Kendall (2009)							CD							
Southam- Gerow, Weisz, Chu, McLeod, Gordis & Connor-Smith (2010)	North America	48	8-15	56%	38.5% Caucasian, 33.3% Latino/ Hispanic, 15.4% African American	GAD, SOP, SAD, SP	Specific phobias, SAD, SOP, GAD, panic disorder, PTSD, OCD, ADHD, ODD, CD, depression, dysthymia	73% specific phobias, 52% SAD, 44% SOP, 27% GAD, 13% panic, 6% PTSD, 4% OCD, 42% ADHD, 38% ODD, 8% CD, 8% depression, 2% dysthymia	CC	Usual care	DISC 4.0 child & parent report		CC = Usual care	Odds ratio = 0.71
Walkup, Albano, Piacentini, Birmaher, Compton et al (2008) Ginsburg, Sakolsky, Piacentini, Walkup, Coffey, et al (2011)	North America	488	7-17	50%	78.9% Caucasian, 9% African American, 12.1 % Hispanic	GAD, SOP, SAD	SAD, GAD, SOP, specific phobia, dysthymia, ODD, CD, tic disorder	43.6% internalising disorder, 11.9% ADHD, 9.4% ODD or CD, 2.7% tic disorder	СС	Sertraline, sertraline + CBT	ADIS-C	12 weeks, 24 weeks	CBT + sertraline > CBT, sertraline	Hedges g = 0.31 CBT, vs 0.86 combination and 0.45 sertraline

Caporino, Brodman, Kendall,

Albano, Sherrill et al

(2013)

Piacentini,

Bennett,

Compton,

Kendall,

Birmaher et al

(2014)

Compton,

Peris,

Almirall,

Birmaher,

Sherrill et al

(2014)

Beidas,

Lindheim,

Brodman,

Swan, Carper

et al (2014)

Herbert,	North	73	12-17	56%	47 %	SOP	GAD,	59% had at	Disorder	Educational/	CGI &	6 months	Disorder	r = 0.13
Gaudiano,	America				Caucasian		dysthymia,	least 1	specific	supportive	SPAI-C		specific	
Rheingold	,				and 44%		specific	comorbid	CBT, CC	psychothera			CBT =	
Moitra, My	vers .				African		phobia,	disorder, 26%		ру			ESP	
et al (2009	9)				American		depression,	had 2 or more						
							SAD, OCD<	comorbidities						
							panic,							

21

							PTSD,							
							ADHD							
Silk, Sheeber,	North	47	9-13	52%	88%	GAD,	Not reported	Not reported	CC	Manualised	K-SADS		CC = CCT	Not reported
Tan,	America				Caucasian,	SOP,				non-directive	PL			
Ladouceur,					8% African	SAD				supportive				
Forbes, et al					American					psychothera				
(2013)										py (CCT)				
Disorder-specif	fic intervention	n studies												
Authors, date	Country of	Sampl	Age	%	Ethnic	Primary	Comorbid	Comorbidity	Experimental	Control group	Primary	Length	Outcome	Effect size
7.00.00, 00.00	origin	e size	range	girls	background	diagnosis	diagnoses	rates	group	Gormon group	outcome	of follow	0 41001110	2.1001 0.20
	og	0 0.20	(years)	90	2 dong o dina	alag. loolo	u.ugooo	raioo	treatment		measure	up		
Öst,	Sweden	60	7-17	61%	Information	SP	Specific	42% had at	Disorder-	WL	ADIS-C	1 year	Disorder	Not reported
Svensson,					not		phobias,	least one	specific CBT		independe		specific >	
Hellström &					available		depression,	comorbid			nt		WL	
Lindwall							SOP, SAD,	condition			assessor			
(2001)							GAD,				rating of			
							enuresis				severity			
Herbert,	North	73	12-17	56%	47 %	SOP	GAD,	59% had at	Disorder	Educational/	CGI &	6	Disorder	CGI $d = 0.13$;
Gaudiano,	America				Caucasian		dysthymia,	least 1	specific CBT,	supportive	SPAI-C	months	specific	SPAI-C d =
Rheingold,					and 44%		specific	comorbid	CC	psychotherap			CBT =	0.16
Moitra, Myers					African		phobia,	disorder, 26%		y (ESP)			ESP	
et al (2009)					American		depression,	had 2 or more						
							SAD, OCD<	comorbidities						
							panic,							
							panic, PTSD,							

Ollendick, Öst, Reuterskiöld, Costa, Cederlund et al (2009) Ollendick, Öst, Reuterskiöld & Costa (2010)	North America, Sweden	196	7-16	54%	88% of North American participants and 94% of Swedish participants Caucasian	SP	Specific phobias, SAD, GAD, SOP, depression, ADHD, OCD, enuresis, PTSD, ODD	68% had at least 1 comorbid disorder, 41% had 2 or more comorbidities	Disorder specific CBT	WL or education support treatment	ADIS-C/P	6 months	Disorder specific CBT > education support treatment > WL	Not reported
Schneider, Blatter- Meunier, Herren, In- Albon, Adornetto et al (2013)	Switzerland	64	8-13	52%	Information not available	SAD	Not reported	55% had at least 1 comorbid condition	Disorder specific CBT	СС	DSM-IV- TR diagnostic interview - parent and child versions	1 month and 1 year	Disorder specific CBT = CC	Not reported

CC = Coping Cat; OAD = overanxious disorder; SAD = separation anxiety disorder; AD = avoidant disorder; SOP = social phobia; SP = specific phobia; GAD = generalised anxiety disorder; WL = waiting list control group

Quality assessment

An assessment of the quality of these studies, based on the Cochrane risk of bias assessment tool, suggested that there was an unclear or possibly increased risk of bias for many of the studies included in the review. It would appear that some aspects of quality improved over time, with many of the earlier studies not reporting the randomisation strategy used or describing any blinding of assessor to outcome, for example, while many later studies specifically addressed these issues. Treatment integrity was assessed in most cases, although assessment of treatment integrity varied considerably, from ratings made for 10%, 15% or an unspecified percentage of sessions, to 30% and 60% of available recorded sessions, and often using a standardised assessment of integrity such as a checklist. Dropouts were clearly reported in all cases, therefore reducing the risk of attrition bias, and relatively clear and well-defined analysis strategies in all studies meant that risk of reporting bias could be estimated as low in all cases. Because of the nature of the intervention, it was not possible in any case to blind clinicians or participants themselves to the treatment (performance bias). The evidence used to assess the risk of bias in each of the 6 areas is outlined in Table 3. Comparison of Coping Cat and disorder-specific intervention studies suggests that, as noted previously, study quality has generally improved over time, with more recent studies addressing most of the possible sources of bias considered, while earlier studies, such as the first studies of Coping Cat, had unclear or increased risk of bias due to, for example, a lack of reporting around the randomisation strategy used, lack of blinding and independent raters in assessment of outcome, and unclear methods for monitoring treatment integrity. In addition, there appears to have been a general move from using a non-active, waiting-list control to comparison with active treatments in more recent studies. Despite this, the small number of studies of disorder-specific CBT interventions mean that despite a generally low risk of bias among these studies, the available evidence for disorder-specific CBT remains extremely limited compared to that for Coping Cat.

Table 3.

Evidence of attempts to minimise risk of bias in 6 main areas, based on the Cochrane risk of bias assessment tool (Higgins et al, 2011)

Coping cat intervention studies Authors, date Selection bias Reporting bias Other bias Overall rating of Treatment Performance bias **Detection bias** Attrition bias risk of bias (low, medium or high) Kendall (1994) Coping Cat vs WL Randomisation Blinding of Attempts to blind Comparisons made Clear and well-Treatment integrity Medium strategies not reported participants or outcome between remainers defined assessed via Kendall & Southamin sufficient detail to personnel to and drop outs, no ratings of an assessments were analysis Gerow (1996) allow assessment of treatment condition not specifically significant unspecified strategy risk of bias, but was not possible discussed differences reported percentage of comparisons between audiotaped treatment groups sessions reported and no significant differences on any demographic variables considered Barrett, Dadds & Coping Koala vs Randomisation Blinding of Attempts to blind Comparisons made Clear and well-Treatment integrity Medium Rapee (1996) Coping Koala + family strategies not reported participants or outcome between remainers defined assessed via anxiety management in sufficient detail to personnel to assessments were and drop outs, no analysis random selection Barrett, Duffy, (FAM) vs WL allow assessment of treatment condition not specifically significant strategy and audiotaping of Dadds & Rapee risk of bias, but was not possible discussed differences reported 60% of therapy (2001)possible confounding sessions using a standardised factors due to between-group checklist differences taken into consideration Kendall, Flannery-Coping Cat vs WL Randomisation Blinding of Attempts to blind Comparisons made Clear and well-Treatment integrity Medium Schroeder, defined assessed via strategies not reported participants or outcome between remainers Panichelli-Mindel. in sufficient detail to personnel to assessments were and drop outs, analysis ratings made for Southam-Gerow. allow assessment of treatment condition not specifically confounding factors strategy 15% of audiotaped

Henin & Warman (1997) Kendall, Safford, Flannery-Schroeder & Webb (2004) Kerns, Read, Klugman & Kendall (2013)		risk of bias, but comparisons between treatment groups reported and no significant differences on any demographic variables considered	was not possible	discussed	taken into account in analysis		sessions, out of an unspecified percentage of all sessions	
Flannery-Schroeder & Kendall (2000)	Coping Cat individual vs WL	Randomisation strategies reported and treatment groups compared and possible confounding factors taken into consideration	Blinding of participants or personnel to treatment condition was not possible	Attempts to blind outcome assessments were not specifically discussed	Comparisons made between remainers and drop outs, confounding factors taken into account in analysis	Clear and well- defined analysis strategy	Treatment integrity assessed via review of 10% of randomly selected video- and audio- taped sessions using checklists	Medium
Siqueland, Rynn & Diamond (2005)	Coping Cat vs Coping Cat + attachment based family therapy (ABFT)	Randomisation strategies reported and comparisons between treatment groups reported and no significant differences on any demographic variables considered	Blinding of participants or personnel to treatment condition was not possible	Attempts to blind outcome assessments were not specifically discussed	Drop outs were stated	Clear and well- defined analysis strategy	Treatment integrity assessed via ratings of an unspecified percentage of audiotaped sessions	Low
Kendall, Hudson, Gosch, Flannery- Schroeder & Suveg (2008) Suveg, Hudson,	Coping Cat vs Family- based education/ support/ attention active control (FESA)	Randomisation strategies reported and comparisons between treatment groups reported and	Blinding of participants or personnel to treatment condition was not possible	Blinding of outcome assessors to treatment condition	Comparisons made between remainers and drop outs, confounding factors taken into account	Clear and well- defined analysis strategy	Treatment integrity assessed via ratings of 15- minute sections of 30% of randomly-	Low

Brewer, Flannery-		no significant			in analysis		selected recordings	
Schroeder, Gosch		differences on any					of sessions using a	
& Kendall (2009)		demographic variables					standardised	
		considered					checklist	
Walkup, Albano,	Coping Cat vs	Randomisation	Blinding of	Independent raters	Comparisons made	Clear and well-	A clear method for	Low
Piacentini,	Sertraline, sertraline +	strategies reported	participants or	of outcome	between remainers	defined	monitoring	
Birmaher, Compton	CBT	and comparisons	personnel to		and drop outs,	analysis	treatment integrity	
et al (2008)		between treatment	treatment condition		confounding factors	strategy	was not identified	
Ginsburg, Sakolsky,		groups reported and	was not possible		taken into account			
Piacentini, Walkup,		no significant			in analysis			
Coffey, et al (2011)		differences on any						
Colley, et al (2011)		demographic variables						
Caporino,		considered						
Brodman, Kendall,								
Albano, Sherrill et								
al (2013)								
Piacentini, Bennett,								
Compton, Kendall,								
Birmaher et al								
(2014)								
Compton, Peris,								
Almirall, Birmaher,								
Sherrill et al (2014)								
Beidas, Lindheim,								
Brodman, Swan,								
Carper et al (2014)								
Southam-Gerow,	Coping Cat vs Usual	Randomisation	Blinding of	Blinding of outcome	Dropouts and	Clear and well-	Treatment integrity	Low
Weisz, Chu,	care	strategies reported	participants or	assessors to	missing data were	defined	was assessed	
McLeod, Gordis &		and comparisons	personnel to	treatment condition	taken into	analysis	using a	
Connor-Smith		between treatment	treatment condition		consideration in the		standardised	

(2010)		groups reported and no significant differences on any demographic variable considered	was not possible		analysis	strategy	checklist	
Schneider, Blatter- Meunier, Herren, In-Albon, Adornetto et al (2013)	Disorder specific CBT vs Coping Cat	Randomisation strategies reported and comparisons between treatment groups reported and no significant differences on any demographic variable considered	Blinding of participants or personnel to treatment condition was not possible	Blinding of outcom assessors to treatment condition and independent raters of outcome	between remainer	defined analysis strategy	Treatment integrity was assessed for 10 randomly- selected participants in each condition using a standardised checklist	Low
Silk, Sheeber, Tan, Ladouceur, Forbes, et al (2013)	Coping Cat vs Manualised non- directive supportive psychotherapy (CCT)	Randomisation strategies reported and treatment groups compared and possible confounding factors taken into consideration	Blinding of participants or personnel to treatment condition was not possible	Independent raters of outcome	Reporting of dropouts was not sufficiently clear for the risk of bias due to attrition bias to estimated	e strategy	Treatment integrity was assessed by 'experts' for 20% of sessions using standardised rating scales	Low
Disorder-specific inte	rvention studies							
Authors, date	Treatment	Selection bias P	erformance bias l	Detection bias A	ttrition bias F	Reporting bias	Other bias	Overall rating of risk of bias (low, medium or high)
Öst, Svensson, Hellström &			· ·	·		Clear and well- defined analysis	A clear method for monitoring	Medium

Lindwall (2001)		reported in sufficient detail to allow assessment of risk of bias, but possible confounding factors due to between- group differences taken into consideration	personnel to treatment condition was not possible	outcome		strategy	treatment integrity was not identified	
Herbert, Gaudiano, Rheingold, Moitra, Myers et al (2009)	Disorder specific CBT vs Disorder specific group CBT, educational/ supportive psychotherapy	Randomisation strategies reported and comparisons between treatment groups reported and no significant differences on any demographic variables considered	Blinding of participants or personnel to treatment condition was not possible	Blinding of outcome assessors to treatment condition and assessment occasion	Comparisons made between remainers and drop outs, no significant differences reported	Clear and well- defined analysis strategy	Treatment integrity was assessed by independent raters completing standardised checklists for around 25% of sessions	Low
Ollendick, Öst, Reuterskiöld, Costa, Cederlund et al (2009) Ollendick, Öst, Reuterskiöld & Costa (2010)	Disorder specific CBT vs WL or education support treatment	Randomisation strategies reported and comparisons between treatment groups reported and no significant differences on any demographic variables considered	Blinding of participants or personnel to treatment condition was not possible	Blinding of outcome assessors to treatment condition for some measures and assessment reliability ratings made for others	No dropouts were reported for post-treatment; drop outs at follow-up were compared and differences were taken into consideration in analysis	Clear and well- defined analysis strategy	Treatment integrity was assessed by 'experts' for 20% of each therapist's sessions using standardised rating scales	Low

Schneider, Blatter-	Disorder specific	Randomisation	Blinding of	Blinding of outcome	Comparisons made	Clear and well-	Treatment integrity	Low
Meunier, Herren,	CBT vs Coping Cat	strategies reported	participants or	assessors to	between remainers	defined analysis	was assessed for	
In-Albon, Adornetto		and comparisons	personnel to	treatment condition	and drop outs, no	strategy	10 randomly-	
et al (2013)		between treatment	treatment condition	and independent	significant		selected	
		groups reported	was not possible	raters of outcome	differences reported		participants in each	
		and no significant					condition using a	
		differences on any					standardised	
		demographic					checklist	
		variables						
		considered						

CBT delivery

In the 10 studies describing the implementation of Coping Cat as an intervention for GAD, separation anxiety, social anxiety and specific phobia, the number of sessions provided ranged between 12 and 20 approximately weekly sessions of 50 to 80 minutes, and all reported following the Coping Cat (or Coping Koala) manual, with at least some monitoring of treatment integrity, excepting Walkup et al (2008). Some studies specifically reported modification of an existing manual to make it more suitable for adolescents (Siqueland et al, 2005; Walkup et al, 2008), for example by including visualisation techniques in addition to breathing and progressive muscle relaxation exercises and increased use of cognitive restructuring and socratic questioning (Siqueland et al, 2005).

In the four disorder-specific treatment studies, length of intervention ranged between a single session of up to three hours (Ost et al, 2001; Ollendick et al, 2010) and 12-16 sessions of 50-60 minutes each approximately once per week (Herbert et al, 2009; Schneider et al, 2013). All disorder-specific interventions were based on an existing manual or published treatment protocol, and treatment integrity was explicitly attended to in all studies excepting Ost et al (2001).

As outlined in Table 3, most of the studies attended to treatment integrity by assessing CBT delivery against pre-defined standards. In addition, many of the studies also provided details of therapist training, supervision and competence, which may be relevant to outcome. These are briefly summarised in Table 4, below. There was an increase in reporting of supervision and training practice over time. In addition, it is worth noting that the early trials of Coping Cat were conducted in university, rather than community, clinics. However, overall there were no major differences found in therapist professional status, experience and training, or supervision, between Coping Cat and disorder-specific studies.

Table 4.

Therapist details, including professional status, previous experience and supervision arrangements

Coping Cat intervention studies

Authors, date	Professional status of	Previous experience of	Supervision
	therapists	therapists	arrangements
Kendall (1994)	Doctoral candidates	Not reported	Not reported
Kendall & Southam-	within a university clinic		
Gerow (1996)			
Barrett, Dadds & Rapee	Clinical psychologists	Not reported	Not reported
(1996)	within a university clinic		
Barrett, Duffy, Dadds &			
Rapee (2001)			
Kendall, Flannery-	Doctoral candidates	Not reported	Not reported
Schroeder, Panichelli-	within a university clinic		
Mindel, Southam-			
Gerow, Henin &			
Warman (1997)			
Kendall, Safford,			
Flannery-Schroeder &			
Webb (2004)			
Kerns, Read, Klugman			
& Kendall (2013)	D ()	.	
Flannery-Schroeder &	Doctoral candidates	Received training in	2 hours' weekly
Kendall (2000)	within a university clinic	Coping Cat	supervision
Siqueland, Rynn &	Doctoral and masters	Training and	1 hour of supervision
Diamond (2005)	level therapists	certification of	for every 2 hours'
		therapists in the	therapy
Kendall, Hudson,	Doctoral and masters	approach Training and pilot	Weekly 2 hour group
Gosch, Flannery-	level therapists,	experience in Coping	supervision
Schroeder & Suveg	supervised by doctoral	Cat	Capol Violoti
(2008)	level therapists	Cat	
Suveg, Hudson,			
Brewer, Flannery-			
Schroeder, Gosch &			
Kendall (2009)			
Walkup, Albano,	Experienced	Certified in Coping Cat	Regular site level and
Piacentini, Birmaher,	psychotherapists	protocol	cross-site supervision

Compton et al (2008)			
Ginsburg, Sakolsky,			
Piacentini, Walkup,			
Coffey, et al (2011)			
Caporino, Brodman,			
Kendall, Albano, Sherrill			
et al (2013)			
Piacentini, Bennett,			
Compton, Kendall,			
Birmaher et al (2014)			
Compton, Peris,			
Almirall, Birmaher,			
Sherrill et al (2014)			
Beidas, Lindheim,			
Brodman, Swan, Carper			
et al (2014)			
Southam-Gerow,	Social workers, doctoral	6 hours' training in	Weekly supervision
Weisz, Chu, McLeod,	level psychologists,	Coping Cat	
Gordis & Connor-Smith	masters level		
(2010)	psychologists, family		
	therapists with an		
	average of 4.4 years		
	training and 4.9 years		
	additional professional		
	experience		
Schneider, Blatter-	Fully qualified	Specialised training in	Not reported
Meunier, Herren, In-	psychotherapist,	CBT	
Albon, Adornetto et al	advanced clinical		
(2013)	psychologists		
Silk, Sheeber, Tan,	Doctoral and masters	Training by experts in	Weekly expert
Ladouceur, Forbes, et	level therapists	the Coping Cat	supervision
al (2013)	•	protocol	·

Disorder-specific intervention studies

Authors, date	Professional status of	Previous experience of	Supervision
	therapists	therapists	arrangements
Öst, Svensson,	Clinical psychologists 6-	Extensive experience	Not reported
Hellström & Lindwall	11 years post-CBT	of treating children with	
(2001)	training	specific phobias and	
		had treated around 40	

		children prior to study	
		using OST	
Herbert, Gaudiano,	Advanced doctoral	Trained by first author	Weekly individual and
Rheingold, Moitra,	candidates in clinical	in the protocol	group supervision,
Myers et al (2009)	psychology		provided by the first
			author
Ollendick, Öst,	Masters and doctorate	Approximately 10	Weekly supervision
Reuterskiöld, Costa,	level therapists with 1-4	hours' training	
Cederlund et al (2009)	years of experience,		
Ollendick, Öst,	limited experience		
Reuterskiöld & Costa	treating specific phobias		
(2010)			
,			
		_	
Schneider, Blatter-	Fully qualified	Specialised training in	Not reported
Meunier, Herren, In-	psychotherapist,	CBT	
Albon, Adornetto et al	advanced clinical		
(2013)	psychologists		

Diagnostic status after treatment

Across studies of Coping Cat, the percentage of individuals classified as no longer meeting criteria for their primary diagnosis at post-treatment was between 53% and 87%, across all studies where these data were available. In the Walkup et al (2008) study, these data were only available at 12-week follow-up, and for all disorders rather than the primary diagnosis only, and suggested a slightly poorer outcome (46.2%). Where long-term follow-up data were available in addition to post-treatment data, these suggested slight increases in remission rates of primary diagnosis after the Coping Cat intervention. For example, the percentage of participants who no longer met criteria for their primary diagnosis after Coping Cat in Flannery-Schroeder and Kendall's (2000) study was 73% at post treatment and 79% at 3 month follow up. Similarly, Barrett et al (1996, 2001) reported that 57.1% of their sample no longer met criteria for any anxiety disorder immediately after the Coping Cat intervention, and this increased to 71.4% at 6-month follow-up and 70.3% at 1-year follow up, and Siqueland et al (2005) reported that 100% of their sample no longer met criteria for their primary diagnosis at 6-9

month follow-up, an increase from 67% at post-treatment. In the only study to report a decrease in the percentage of the sample who were diagnosis-free after treatment with Coping Cat, this decrease occurred between 4 weeks and one year post-treatment, and no diagnostic data were available immediately post-treatment (Schneider et al, 2013). In addition, it is worth noting here that there was variability across studies in the way diagnostic status was assessed, not only in terms of the measure used to determine diagnostic status, but also in the method of determining presence or absence of diagnosis, the reporting of diagnostic status (i.e., freedom from primary diagnosis versus all diagnoses) and also the analysis strategy used (e.g., intention-to-treat, as treated, or both), and all of these may have an impact on the apparent effectiveness or otherwise of a treatment.

Of the 10 studies of Coping Cat, 4 compared treatment with Coping Cat to a wait-list control (Kendall, 1994; Kendall et al, 1997; Barrett, Dadds & Rapee, 1996; Flannery-Schroeder & Kendall, 2000). In each of these studies, Coping Cat was found to be significantly more effective, in terms of the percentage of the sample considered diagnosis-free at the end of treatment, compared to no treatment. In studies that included an active control, outcomes were more variable. Only one study compared Coping Cat to a disorder-specific intervention. In this study, discussed in greater detail below, no significant differences in terms of the percentage of the sample who were free of their primary separation anxiety disorder diagnosis were found between the Coping Cat and disorder-specific groups at either 4-weeks or 1-year post-treatment (Schneider et al, 2013). Three studies included a comparison group who received Coping Cat plus a family-based intervention, rather than Coping Cat alone. In these studies, Coping Cat + family-based intervention outperformed Coping Cat alone in terms of post-treatment diagnostic status in one study (Barrett, Dadds & Rapee, 1996), but did not produce significantly different outcomes in two others (Kendall et al, 2008; Sigueland et al. 2005). Flannery-Schroeder and Kendall (2000) compared the original individual Coping Cat treatment to a group format, and reported no significant differences between the treatment formats in terms of remission rate for the primary diagnosis at post-treatment. Silk et al (2013) compared Coping Cat with a non-directive 'child centred therapy' and Southam-Gerow et al (2010) compared Coping Cat with 'usual care' in a public community mental health clinic setting, and both studies reported no significant differences between the treatments in terms of remission rates of primary diagnoses.

Some studies were able to compare the effectiveness of Coping Cat across different disorders within their samples. No significant differences in primary outcomes across

different primary diagnoses were reported by Barrett, Dadds and Rapee, (1996) or Kendall et al (1997). However, both Kerns et al (2013) and Ginsburg et al (2011; CAMS trial) reported significantly poorer remission rates for children with social anxiety disorder compared to GAD and separation anxiety at 7.4 year and 12-week follow-up, respectively, although Ginsburg et al.'s study analysis included participants who received CBT+sertraline, sertraline only, and placebo-only, and so individual outcomes for Coping Cat alone could not be assessed.

Across studies of disorder-specific interventions there was also variability in the percentage of individuals who no longer met criteria for their primary anxiety disorder, or were considered to be 'clinically improved'. Rates were reported to be 55% by Ollendick et al. (2009) for specific phobia, 87.5% by Schneider et al. (2013) for separation anxiety disorder, 29% by Herbert et al. (2009) for social anxiety disorder and 90% by Öst et al. (2001) for specific phobia. As above, there were differences between studies in terms of the way that diagnostic outcomes were assessed. For example, Herbert et al. (2009) did not report the percentage of their sample who were free of their primary diagnosis post-treatment using the ADIS-C, but instead utilised a perhaps more stringent criterion, stating that patients were considered 'recovered' only if they had both a SPAIC-C total score <18 and a CGI rating <4. Although it is impossible to estimate what proportion of the sample would be likely to be considered recovered according to the more commonly utilised diagnostic assessment (e.g., ADIS-C/P), it is possible that the use of a different outcome assessment may have affected these results. Similarly, the proportion of participants who no longer met diagnostic criteria for their primary diagnosis of separation anxiety post-treatment reported by Schneider et al (2013) was based on analysis of completers only, and when an intentto-treat analysis was conducted this percentage was reduced to 67.7%. Finally, the two published trials assessing a single-session treatment (OST) of specific phobia included in this review produced markedly different rates of remission (Öst et al., 2001; Ollendick et al., 2009). Ollendick et al. offered few possible explanations for this finding, except for the experience of the clinicians delivering the treatment (see Table 4 for further information), and so the reason for this difference remains elusive, although one difference appeared to be in the means by which the study authors had arrived at their definition of 'clinically significant improvement', which in Ollendick et al.'s study was being 'diagnosis free' (a CSR <4 on the ADIS) and in Öst et al.'s study was based on three scores: ratings of phobic severity, the Behavioural Approach Test (BAT) score, and the self-rating of anxiety during the BAT. Despite this, as Ollendick et al. identify, the remission rates achieved within their study were comparable to those achieved in a number of studies of Coping Cat. Follow-up periods for these disorderspecific studies varied between 6 months and 1 year. In three cases the rates of remission or clinically significant improvement were stable from post-treatment to follow-up, though did not increase significantly between these points (Öst et al.; Ollendick et al.; Schneider et al.), and in Herbert et al.'s study the percentage of 'remitted' patients who received the individual disorder-specific treatment dropped between post-treatment and 6-month follow up, from 29% to 15%, though the authors did not state whether this represented a significant decrease.

Measures of post-treatment severity

The studies utilised a number of different measures of anxiety symptom severity. These included self-report, parent and teacher report, and clinician/ assessor ratings. Of the self-report measures a number of studies utilised the 37-item Revised Children's Manifest Anxiety Scales (RCAMS) measure of trait anxiety; the State-Trait Anxiety Inventory for Children (STAIC), a measure consisting of two 20-item scales measuring state (situation-specific) and trait (stable, longer-term) anxiety in children; the Fear Survey Schedule for Children (FSSC-R), an 80-item measure assessing specific fears in children; the individualised Coping Questionnaire-Child (CQ-C), which assesses the child's perceived ability to cope with anxiety-provoking situations; the Multidimensional Anxiety Scale for Children (MASC), a 39-item assessment of anxiety symptoms; the 21-item Beck Anxiety Inventory (BAI); and the 11-31 item (age-dependent) children's Negative Affectivity Self-Statement Questionnaire (NASSQ), which assesses frequency of occurrence of negative self-statements associated with negative affectivity. One study utilised a Global Success Rating – a modified version of the Sheehan-Marks Impairment Rating – a single item measure of therapy outcome, with a child version, parent version and therapist version. Some studies utilised disorder-specific measures, including the Social Anxiety Scale for Children (SAS-C), a 22-item measure of social anxiety, the 26-item Social Phobia Anxiety Inventory for Children (SPAI-C), the 12-item Separation Anxiety Avoidance Inventory for Children (SAAI-C) and the 22-item Social Anxiety Scale for Children-Revised (SASC-R). Parent measures included parent versions of the STAIC (the STAIC-A-Trait-P/STAIC-P), the Coping Questionnaire (CQ-P), the Social Anxiety Scale (SAS-P) and the Separation Anxiety Avoidance Inventory (SAAI-P). The Child Behaviour Checklist (CBCL) was also included as a parent-report measure in a number of studies, requiring responses for 120 statements about a child's emotional, behavioural and social functioning. The CBCL was also utilised for teacher reports – using the Teacher Report Form (TRF) version of the measure. Finally, clinician report was obtained via a number of measures in different studies including severity and improvement ratings on the ADIS C/P versions, the Clinical Global Impression-Improvement and Severity rating scale (CGI-I/ CGI-S), the Paediatric

Anxiety Rating Scale (PARS), used to determine severity of anxiety symptoms, the Children's Global Assessment Scale (CGAS), which also allows clinicians to rate the general functioning of the child on a single scale, and the Hamilton Anxiety Rating Scale (HAM-A), a 14-item inventory assessing severity of common anxiety symptoms. The findings were mixed, demonstrating in some cases advantages of both Coping Cat and disorder-specific interventions, particularly over waiting-list control conditions, yet in many cases did not demonstrate advantages of Coping Cat or Disorder-Specific treatments over other interventions, and in the only study assessing outcomes for both Coping Cat and a disorder-specific intervention for the treatment of separation anxiety disorder, little difference in outcomes was demonstrated. The outcomes are summarised in Table 5, below.

Table 5.

Outcomes on various measures of anxiety severity across studies

Coping Cat intervention studies

Authors, date	Treatment	Respondent	Measure	Outcome pre-post treatment	Outcome at follow-up
Kendall (1994) Kendall & Southam-Gerow	Coping Cat vs WL	Child	RCAMS	Significant reduction in anxiety after Coping Cat, significantly lower post-treatment scores for Coping Cat than WLC	Maintenance of scores post-treatment at follow-up 1 year and around 3.35 years later
(1996)		Child	STAIC	Significant reductions in state and trait anxiety for Coping Cat, significantly reduced scores for Coping Cat group compared to WL at post-treatment	Reductions maintained after Coping Cat intervention at 1 year
		Child	FSSC-R	Significant reductions in scores for the Coping Cat group and significantly lower scores at post- treatment compared to the WL control group	Reductions maintained after Coping Cat intervention at 1 year
		Child	CQ-C	Significant improvements on this measures for Coping Cat group and significantly greater improvement compared to the control group at post-treatment	Improvements for Coping Cat group maintained at 1 year follow-up and around 3.35 years
		Child	NASSQ	Significant reductions in anxious self-talk after Coping Cat intervention, and at post-treatment scores were significantly improved compared to controls	Improvements for the Coping Cat group were maintained at 1-year and around 3.35 years later
		Parent	CBCL	Internalising, Externalising, Health and Social T- scores were significantly improved for the Coping Cat group and significantly more improved for the Coping Cat group compared to WL at post-treatment	Improvements for the Coping Cat group were maintained at 1-year and around 3.35 years later
		Parent	STAIC-A-Trait-P	Significant improvements during treatment for both WL and Coping Cat groups but Coping Cat	Improvements for the Coping Cat group were

				group had significantly lower scores post- treatment than the WL group	maintained at 1-year and around 3.35 years later
		Teacher	CBCL-TRF	Significant improvements in Internalising and Externalising T-scores for both groups, no significant difference between groups at post-treatment	Improvements for the Coping Cat group were maintained at 1-year
Barrett, Dadds & Coping Koala vs Rapee (1996) Coping Koala + family anxiety management (FAM) vs WL	Child	RCAMS	Significant decreases in scores for all conditions, no significant difference between WL, Coping Cat or Coping Cat + FAM at post treatment	Scores maintained for both Coping Cat and Coping Cat + FAM at 6-months and 12 months, but slight increases at 6 years. No between-condition differences	
	vs WL	Child	FSSC-R	Significant decreases in scores for all conditions, no significant difference between WL and Coping Cat or Coping Cat and Coping Cat + FAM at post treatment, but Coping Cat + FAM had significantly lower scores than WL at post-treatment	No difference between conditions at 6-month follow up but Coping Cat + FAM group had significantly lower scores than Coping Cat at 12-month follow up
		Parent	CBCL	For mother and father report there were significant reductions for Coping Cat on Internalising and Externalising scales, and Coping Cat was significantly lower than WL at post-treatment for Internalising (mother-reported), but not Externalising. No significant differences between Coping Cat and Coping Cat + FAM except for father-reported externalising scores for CC+FAM were significantly lower than for the Coping Cat group at post-treatment	Significant reductions in mother- and father-reported Internalising and Externalising scores at 6-month and 12-month follow-up for Coping Cat, although for Coping Cat + FAM scores were significantly lower than for Coping Cat alone
		Clinician	CGI-I, general scales assessing	Coping Cat + FAM outperformed Coping Cat when assessed across all measures of improvement at post-treatment, including	Differences were maintained at 6- and 12-month follow-up

		improvement	significantly greater improvement on the CGI-I	
			compared to Coping Cat at post-treatment,	
			although whether Coping Cat scores were	
			significantly improved at post-treatment	
			compared to baseline was not reported	
Kendall, Flannery- Coping Cat vs WL	Child	RCAMS	Significant reduction in anxiety after Coping Cat,	Gains maintained at 1 year follow up, but significant
Schroeder,			sig lower post-treatment scores for Coping Cat	increase in RCAMS scores an average of 7.4 years
Panichelli-Mindel,			than WLC	post-treatment with Coping Cat although means
Southam-Gerow,				remained significantly lower than at pre treatment
Henin & Warman	Child	STAIC	Significant reduction in state and trait anxiety,	Gains maintained at 1 year follow up
(1997)	Orma	017110	no significant differences between WL and	Gains maintained at 1 year follow up
Kendall, Safford,			Coping Cat groups at post-treatment	
Flannery-				
Schroeder &	Child	FSSC-R	Scores for both the Coping Cat and WL	Gains maintained at 1 year follow up
Webb (2004)			conditions reduced significantly between pre-	
Webb (2004)			and post treatment, but no significant between-	
Kerns, Read,			condition differences at post-treatment	
Klugman &	Child	CQ-C	Significant improvements after Coping Cat, sig	Gains maintained at 1 year follow up and significant
Kendall (2013)			higher post-treatment coping scores for Coping	increases in self-reported coping were found at 7.4
			Cat than WLC	year follow-up after Coping Cat intervention compared
				to post-treatment
	Child	NASSQ	Significant reduction in anxiety after Coping Cat,	Gains maintained at 1 year follow up
	Orma	11/1000	sig lower post-treatment scores for Coping Cat	Came mamamod at 1 your lonow up
			than WLC	
	Parent	CBCL	For mother and father reported Internalising,	Gains maintained at 1 year follow up, with the
			significant reductions after Coping Cat, sig lower	exception that mother-reported Internalising was
			post-treatment scores for Coping Cat than WLC,	significantly reduced between post-treatment and
			and similar patterns for mother reported	follow-up after Coping Cat intervention and further
			Anxious-Depressed subscale and 'Anxiety', but	reductions for Internalising and Externalising scores
			effects of time only for father reports on these	found at 7.4 year follow-up compared to post-treatment

				measures	
		Parent	STAIC-A-Trait-P	Significant improvements after Coping Cat, sig lower post-treatment coping scores for Coping Cat than WLC for mother and father report	Gains maintained at 1 year follow up
		Parent	CQ-P	Significant improvements after Coping Cat, sig higher post-treatment coping scores for Coping Cat than WLC for mother and father report	Gains maintained at 1 year follow up and significant increases in parent-reported coping were found at 7.4 year follow-up after Coping Cat intervention
		Teacher	CBCL-TRF	Significant improvements in teacher-reported internalising in both conditions, and significant improvements for both conditions on the Anxiety-Depressed scale but significantly greater improvements for Coping Cat compared to WL at post-treatment	Gains maintained at 1 year follow up
Flannery- Schroeder & Kendall (2000)	Coping Cat individual vs WL	Child	RCAMS	Outcome reported in combination with STAIC. No significant main effects or interactions reported for this measure alone	At 3 month follow-up scores were not significantly different for the Coping Cat group
		Child	STAIC	Significant reductions in state and trait anxiety for children who received Coping Cat, but not for waiting list controls, after treatment	At 3 month follow-up scores were not significantly different for the Coping Cat group
		Child	CQ-C	Significantly improved after Coping Cat intervention at post-treatment, but not after WL	At 3 month follow-up scores were not significantly different for the Coping Cat group
		Child	SASC-R	There were significant reductions anxiety on this measure for both the WL and Coping Cat group.	At 3 month follow-up scores were not significantly different for the Coping Cat group
		Parent	CBCL Internalising	No significant differences in mother reported internalising of distress were found, but significant reductions in father reports were found at post-treatment for the Coping Cat but not WL group	At 3 month follow-up scores were not significantly different for the Coping Cat group

		Parent	STAIC-P	Anxiety on this measure for mother and father report combined was significantly reduced at post-treatment after Coping Cat and significantly lower than WL controls	At 3 month follow-up scores were not significantly different for the Coping Cat group
		Parent	CQ-P	Significant improvements for both mother and father reports for the Coping Cat group but not WL group at post-treatment	At 3 month follow-up scores were not significantly different for the Coping Cat group
		Teacher	CBCL-TRF Internalising	No significant differences in teacher reported internalising of distress were found for either group at post-treatment	At 3 month follow-up scores were not significantly different for the Coping Cat group
Siqueland, Rynn & Diamond (2005)	Coping Cat vs Coping Cat + attachment based	Child	BAI	Significant reduction in scores between pre-and post-treatment but no significant between-condition differences at post-treatment	Significant reduction in scores between post-treatment and 6-9 month follow up but no significant between-condition differences at follow-up
	family therapy (ABFT)	Clinician	HAM-A	Significant reduction in scores between pre-and post-treatment but no significant between-condition differences at post-treatment	Significant reduction in scores between post-treatment and 6-9 month follow up but no significant between- condition differences at follow-up
Kendall, Hudson, Gosch, Flannery- Schroeder & Suveg (2008)	Coping Cat vs Family-based education/ support/ attention active	Child	MASC	Significant reduction in scores between pre-and post-treatment after Coping Cat and WL, no significant between-condition differences at post-treatment	Significant reduction in scores between post-treatment and 1 year follow-up
Suveg, Hudson, Brewer, Flannery- Schroeder, Gosch & Kendall (2009)	control (FESA)	Child	CQ-C	Significant improvement in scores between pre- and post-treatment after Coping Cat and WL, no significant between-condition differences at post-treatment	Significant improvement in scores between post- treatment and 1 year follow-up
		Parent	CBCL	Significant improvement in scores between preand post-treatment after Coping Cat and WL, no	Significant improvement in scores between post- treatment and 1 year follow-up

				significant between-condition differences at post-treatment for mother and father reports on Internalising and Anxiety symptoms	
		Parent	CQ-P	Significant improvement in scores between pre- and post-treatment after Coping Cat and WL, no significant between-condition differences at post-treatment mother and father reports	Significant improvement in scores between post- treatment and 1 year follow-up
		Teacher	CBCL-TRF	Significant improvement in scores between pre- and post-treatment after Coping Cat, no significant between-condition differences at post-treatment	Improvements in teacher-reported Internalising and Anxiety maintained at 1 year follow-up
		Clinician	ADIS C/P clinician severity rating	Significant reduction in scores between pre-and post-treatment and significantly lower scores at post-treatment for Coping Cat versus FESA	Improvements maintained at 1-year follow-up
Walkup, Albano, Piacentini, Birmaher, Compton et al (2008) Ginsburg, Sakolsky, Piacentini,	Coping Cat vs Sertraline, sertraline + CBT	Clinician	CGAS	Significant improvement in scores for Coping Cat between pre-and post-treatment, and significantly greater improvement compared to placebo. No significant differences in scores at post-treatment between Coping Cat and sertraline but combination therapy associated with significantly better scores on this measure than Coping Cat alone	Significant improvement in scores for Coping Cat between post-treatment and 3- and 6-month follow-up, and although significant advantage of combination therapy over Coping Cat remained at 3- and 6-month follow-up
Walkup, Coffey, et al (2011)		Clinician	PARS	Significant improvement in scores for Coping Cat between pre-and post-treatment, and	Significant improvement in scores for Coping Cat between post-treatment and 3- and 6-month follow-up,
Caporino, Brodman, Kendall, Albano, Sherrill et al (2013)				significantly greater improvement compared to placebo. No significant differences in scores at post-treatment between Coping Cat and sertraline but combination therapy associated with significantly better scores on this measure	and although significant advantage of combination therapy over Coping Cat remained at 3- and 6-month follow-up

Piacentini,				than Coping Cat alone	
Bennett, Compton,					
Kendall, Birmaher et al (2014)		Clinician	CGI-S – severity score	Significant improvement in scores for Coping Cat between pre-and post-treatment, and	Significant improvement in scores for Coping Cat between post-treatment and 3- and 6-month follow-up,
Compton, Peris, Almirall, Birmaher, Sherrill et al (2014)				significantly greater improvement compared to placebo. No significant differences in scores at post-treatment between Coping Cat and sertraline but combination therapy associated	and although significant advantage of combination therapy over Coping Cat remained at 3- and 6-month follow-up
Beidas, Lindheim, Brodman, Swan, Carper et al (2014)				with significantly better scores on this measure than Coping Cat alone	
Southam-Gerow, Weisz, Chu, McLeod, Gordis & Connor-Smith (2010)	Coping Cat vs Usual care	Child	STAIC	No significant differences between children who received Coping Cat or Usual care, although both groups demonstrated significant reductions in anxiety on this measure between pre- and post-treatment	-
		Parent	STAIC-P-T	Analysed outcomes on the STAIC-PT for their sample together with the Child Behaviour Checklist and reported no significant differences between children who received Coping Cat or Usual care, although both groups demonstrated significant reductions in anxiety on this measure between pre- and post-treatment	
		Parent	CBCL	As above	-
Schneider, Blatter- Meunier, Herren, In-Albon,	Disorder specific CBT vs Coping Cat	Child	RCAMS	Significant reductions in score for Coping Cat and disorder-specific treatment. No significant	Gains maintained at 1-year and no significant between-group differences

Adornetto et al			differences between groups at post-treatment	
(2013)				
	Child	Global Success Rating, Child	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
	Child	Global Success Rating, Child	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
	Parent	SAAI-P	No significant differences between conditions at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
	Parent	Global Success Rating, Parent	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1- month or 1-year follow-up with the exception of father- reported success at 1-year follow-up, with significantly higher ratings for children in the disorder-specific group compared to the Coping Cat group
	Clinician	Global Success Rating, Therapist	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
Silk, Sheeber, Tan, Ladouceur,	Parent	SAAI-P	No significant differences between conditions at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
Forbes, et al (2013)	Parent	Global Success Rating, Parent	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1- month or 1-year follow-up with the exception of father- reported success at 1-year follow-up, with significantly higher ratings for children in the disorder-specific group

			compared to the Coping Cat group
Clinician	Global Success Rating, Therapist	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
Parent	Global Success Rating, Parent	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up with the exception of father-reported success at 1-year follow-up, with significantly higher ratings for children in the disorder-specific group compared to the Coping Cat group
Clinician	Global Success Rating, Therapist	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up

Disorder specific intervention studies

Authors, date	Treatment	Respondent	Measure	Outcome pre-post treatment	Outcome at follow-up
Öst, Svensson, Hellström & Lindwall (2001)	Disorder-specific CBT vs WL	Child	RCAMS	Significant reduction in scores when waitlist included in treatment analysis, difference not significant when WL analysed separately	Scores maintained at 1 year post-treament
		Child	STAIC	Significant reductions on the STAIC-Trait scale for the group who received the disorder-specific treatment for specific phobia, but no significant differences compared to WL at post-treatment	Improvements maintained at 1-year follow-up
		Child	FSSC-R	Significant reductions for the group who received the disorder-specific treatment for specific phobia, but no significant differences compared to WL at post-treatment	Improvements maintained at 1-year follow-up

		Clinician	Phobia severity rating, ADIS-C	One-session treatment yielded significant reductions in severity between pre- and post-treatment and significantly lower phobic severity ratings compared to WL at post-treatment	Improvements maintained at 1-year follow-up
Herbert, Gaudiano, Rheingold, Moitra, Myers et al (2009)	Disorder specific CBT vs Disorder specific group CBT, educational/ supportive psychotherapy	Child	SPAIC-C	Significant decreases between baseline and post-treatment, but no significant between-condition differences	Improvements maintained at 6-month follow-up
		Child	SAS-C	Significant decreases between baseline and post-treatment but no significant between-condition differences	Improvements maintained at 6-month follow-up
		Parent	SAS-P	Significant decreases between baseline and post-treatment, but no significant between-condition differences	Improvements maintained at 6-month follow-up
		Clinician	CGI-S severity scale	Significant decreases between baseline and post-treatment, but no significant between-condition differences	Improvements maintained at 6-month follow-up
Ollendick, Öst, Reuterskiöld, Costa, Cederlund et al (2009)	Disorder specific CBT vs WL or education support treatment	Child	FSSC-R	Significant reductions in scores between baseline and post-treatment, but no significant differences between treatment groups at post-treatment	Improvements maintained at 6-month follow-up
Ollendick, Öst, Reuterskiöld & Costa (2010)		Child	MASC	Significant reductions in scores between baseline and post-treatment, but no significant differences between treatment groups at post-treatment	Improvements maintained at 6-month follow-up
		Parent	CBCL	Significant reductions in scores between baseline and post-treatment, but no significant	Improvements maintained at 6-month follow-up

				differences between treatment groups at post-treatment	
		Clinician	ADIS C/P clinician severity rating	Significant reductions in severity ratings between baseline and post-treatment, and significantly lower scores for disorder-specific treatment at post-treatment compared to WL or education support treatment	Gains maintained at 6-month follow up and scores for disorder-specific CBT group significantly lower than for education support treatment group
Schneider, Blatter-Meunier, Herren, In-Albon,	Disorder specific CBT vs Coping Cat	Child	RCAMS	Significant reductions in score for Coping Cat and disorder-specific treatment. No significant differences between groups at post-treatment	Gains maintained at 1-year and no significant between-group differences
Adornetto et al (2013)		Child	SAAI-C	No significant differences between conditions at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
		Child	Global Success Rating, Child	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
		Parent	SAAI-P	No significant differences between conditions at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up
		Parent	Global Success Rating, Parent	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1- month or 1-year follow-up with the exception of father- reported success at 1-year follow-up, with significantly higher ratings for children in the disorder-specific gro
		Clinician	Global Success Rating, Therapist	Overall improvement for both groups between baseline and post-treatment, no significant difference between groups at post-treatment	No significant differences between conditions at 1-month or 1-year follow-up

Discussion

The present review addressed the following research question: are disorder-specific cognitive behavioural interventions, as favoured in the treatment of anxiety disorders in adults, more effective compared to the disorder-generic Coping Cat treatment approach for the treatment of social anxiety disorder, GAD, separation anxiety, or specific phobias in CYP aged 7 to 17? The review produced limited evidence that disorder-specific approaches produce better outcomes compared to the disorder-generic approach Coping Cat currently recommended in England for the treatment of these anxiety disorder presentations. This held true for both diagnostic outcome and assessment of anxiety severity.

Our finding contrasts with that of a similar review conducted by Reynolds, Wilson, Austin and Hooper (2012), who reported that larger effect sizes were achieved for disorder-specific compared to disorder-generic treatment approaches. However, the present review differed from that of Reynolds et al. (2012) in a number of ways. First, as mentioned previously, Reynolds et al. compared a number of different disorder-generic treatment approaches with disorder-specific interventions, while the present review included only disorder-generic studies that employed Coping Cat. Second, Reynolds et al. included studies that employed a range of interventions, including CBT, narrative therapy and EMDR, whereas the present review included studies of CBT only. Third, Reynolds et al. included a broader range of anxiety disorder presentations than the present study, for example OCD and panic disorder. Fourth, the age-range of participants included in Reynolds et al's review was wider than in the present study. Finally, the review conducted by Reynolds and colleagues included studies of group and individual interventions, whereas group interventions were not considered here.

In summary, the present review differed from that of Reynolds and colleagues in a number of ways, and is therefore able to provide a more detailed and flexible comparison of disorder-specific CBT with Coping Cat in treatment of disorders for which Coping Cat has been recommended as a treatment of choice for CYP presenting in CAMHS services in England. For these disorders, as mentioned above, there does not seem to be a clear overall advantage of disorder-specific CBT interventions over the currently recommended Coping Cat.

However, the picture is less clear when each anxiety disorder presentation is considered in turn. Although one previous study (Kerns et al., 2013) reported poorer outcomes after treatment with Coping Cat for children with social anxiety compared to GAD or separation anxiety, in Herbert et al's (2009) study the outcomes reported for an alternative disorder-specific treatment of social anxiety disorder were not particularly

striking, and certainly did not provide strong evidence that a disorder-specific intervention is more efficacious than a disorder-generic approach. Similarly, in the only study reporting outcomes of a disorder-specific CBT intervention for separation anxiety (Schneider et al., 2013), which included a direct comparison with Coping Cat, no clear advantages of either treatment over the other were found for remission rates or validated measures of anxiety symptom severity at post-treatment or follow-up at 1 month or 12 months. The evidence for effectiveness of Coping Cat compared to disorder-specific approaches in the treatment of GAD cannot be commented on here, since no disorder-specific treatment of GAD met inclusion criteria for the present review. However, the evidence for the effectiveness of Coping Cat in the treatment of specific phobias is far less compelling than that for the other disorders included in this review. Just 11 participants with a primary diagnosis of specific phobia made up the total 1076 participants contributed by studies that utilised the Coping Cat intervention. These 11 participants came from a single study – the only study to have included participants with a diagnosis of specific phobia in an RCT involving Coping Cat (Southam-Gerow et al, 2010). In Southam-Gerow et al's study there were 48 participants in total. Twenty-four were allocated to receive Coping Cat, and only 18 of these completed post-treatment assessments. The exact number of participants with a specific phobia who entered the Coping Cat intervention arm was not reported, but it is anticipated that not all of the 11 children with a specific phobia who entered the study would have received Coping Cat. Therefore, given the far greater sample sizes of the two studies exploring the effectiveness of a disorder-specific treatment for specific phobia (combined N = 256), it is not clear that the best available evidence supports the use of Coping Cat.

Quality of the evidence and strengths and limitations of the review

The strengths of the present review include the consideration of a variety of outcomes, including remission rates and anxiety symptom severity, the consideration of only validated measures of outcome, and the use of a standardised quality assessment tool. The systematic narrative approach allowed for flexible comparisons to be made for studies that used a wide variety of measures, designs, implementations of interventions and follow-up periods. The approach also allowed for comparisons to be made where the existing literature was sparse – i.e., for disorder-specific approaches. However, a number of limitations should also be addressed here. The present review included only studies involving individual CBT implemented using either the disorder-general Coping Cat programme or a disorder-specific cognitive-behavioural protocol. This decision was made on the basis of the research question posed, and facilitated direct comparison of disorder-specific treatments with Coping Cat, which was originally

devised as an individual intervention. The present review did not aim to explore the effectiveness of different variations of Coping Cat, such as augmentation with a familybased approach or implemented via a group, and inclusion of a variety of formats such as group interventions was beyond the scope of the review, although where included as an additional treatment arm alongside an individual intervention, outcomes were compared. However, the exclusion of group-only studies, and also those utilising behavioural interventions only, meant that a number of disorder-specific studies could not be considered here. For example, Spence, Donovan and Brechman-Toussaint (2000) reported very positive outcomes for group-based CBT for social anxiety disorder in 7-14 year-olds, Beidel, Turner and Morris (2000) reported positive outcomes for a behavioural treatment of social anxiety disorder in 8-12 year-olds, and Clementi and Alfano (2014) reported positive outcomes in a small sample of 7-12 year-olds for a behavioural treatment of GAD. The ability to include a greater number of studies that explored different disorder-specific treatment approaches in the review would have been useful in that it would increase the amount of data on which conclusions could be drawn, and would also have allowed for the consideration of disorder-general vs. specific treatments for GAD, which was not possible in the present review. In addition, comparing different disorder-specific treatment approaches could have allowed for cross-comparisons between different approaches for a single disorder to be made. In addition, a number of trials were rejected based to their inclusion of CYP outside of the 7-17 year age bracket set. Although this could have affected the findings, it was felt that the imposition of this age bracket was important to ensure that a fair comparison was made for Coping Cat, which was developed for this age group only. Thus, the inclusion of studies of Coping Cat that reported outcomes for children outside of this bracket may not have provided a fair representation of the effectiveness of Coping Cat, and the inclusion of disorder-specific studies reporting outcomes for children not aged 7-17 would have been an inappropriate comparison for Coping Cat studies.

Other factors which may affect the conclusions drawn include the country of origin (with no study including participants from England or the United Kingdom, for example), the different outcome measures utilised, variation in analysis strategy used, the lack of analysis-by-disorder for Coping Cat in many of the studies, and relative paucity of studies describing the implementation of disorder-specific approaches. This final limitation could perhaps be viewed as evidence that disorder-generic approaches are simply most suited to the treatment of childhood anxiety, for example due to the high degree of comorbidity between anxiety disorders that is found in this population. Another possibility is that the findings for the studies included in the present review, of minimal differences between different approaches in terms of anxiety-related

outcomes, is due to flexibility in the implementation of different interventions. It is possible that clinicians delivering disorder-generic treatment approaches such as Coping Cat will naturally make small adjustments according to the child's presentation, meaning that in practice there is little difference between disorder-specific and disorder-generic approaches. Such flexibility could mean that a disorder-generic treatment such as Coping Cat is a more pragmatic intervention because it would likely require less staff training and therefore allow a greater throughput of patients compared to employment of a number of separate disorder-specific treatments by a service. This is particularly relevant given the finding that no treatment approach appeared to 'stand out' against any other in the present review in terms of outcomes.

Policy and practice implications

The present review was motivated by the observation of a difference in approach to the treatment of anxiety disorders in children vs. adults. While the adult literature generally supports disorder-specific approaches, disorder-generic treatments are often utilised in treatment of child anxiety disorders. This is reflected in the CYP IAPT National Curriculum (2013), which outlines recommended treatments for anxiety disorders in CYP, and suggests that Coping Cat is used to inform the treatment of GAD, separation anxiety disorder, social anxiety disorder and specific phobia, whilst acknowledging the limited evidence base for treatment of these disorders in CYP.

As noted above, for the treatment of GAD, separation anxiety and social anxiety, the evidence does not appear to favour either a disorder-specific or a disorder-general treatment approach. Nor does it appear to favour one mode of delivery of Coping Cat (i.e., individual versus group, Coping Cat augmented with specific family interventions) or even, in many cases, Coping Cat rather than alternative interventions such as 'usual care' or 'non-directive supportive psychotherapy'. Therefore, in the absence of a clear alternative to Coping Cat, no changes are recommended for the guidelines on treatment of these disorders, nor for general practice, although recommendations for future research are discussed below. For the treatment of specific phobias, however, it is suggested that the evidence for the use of Coping Cat to inform intervention is not sufficiently compelling at present. Therefore, we suggest that alternative treatment approaches be considered for the CYP IAPT National Curriculum, and that clinicians consider the weight of the evidence for different approaches to inform their practice. A detailed review of alternatives for the treatment of specific phobias was beyond the scope of this project, although it is suggested that Öst and colleagues' One Session Treatment for specific phobias is one possible alternative. Indeed, a clear benefit of the use of such a package for treatment of specific phobias is the relatively small amount of time required for the treatment – a single session of up to three hours - compared to 16 hours of Coping Cat, if delivered according to the manual: a large potential saving in clinician hours.

Recommendations for future research

A key recommendation is that further studies should compare outcomes for the disorder-generic treatment, Coping Cat, with disorder-specific approaches. In addition, it is recommended that a review be conducted of the current evidence base for different disorder-specific approaches to the treatment of specific phobias in CYP, given the finding that the evidence base for use of Coping Cat in the treatment of specific phobias appears extremely limited. It is also recommended that future studies consider disorder-specific and disorder-generic approaches in terms of their ability to provide cost-efficiency as well as positive outcomes, by assessing factors such as treatment duration and use of additional services, and by implementing the treatment approaches in community settings rather than university clinics, as described in the study by Southam-Gerow and colleagues (2010) included in this review.

Conclusions

The disorder-generic treatment for childhood anxiety disorders, Coping Cat, appears to be equally effective compared to disorder-specific treatments for social anxiety disorder and separation anxiety. Across the studies included, conclusions about disorder-specific treatments for GAD could not be drawn. However, for specific phobias the current evidence appears to favour disorder-specific treatments over Coping Cat. Study quality appears to have improved over time, based on those studies included in this review, although future studies should begin to utilise direct comparisons of Coping Cat with alternative disorder-specific treatments and assess effectiveness for treatments in terms of cost and time, in community, rather than university clinic, settings. A useful direction for future reviews would be to consider evidence for disorder specific versus generic approaches for particular disorders.

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Service improvement project, October 2015

Service-user and staff views on the provision of written information in a memory

service in the South West of England

Word count: 4,970

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A version of this paper is in preparation for submission to the journal 'Aging and mental

health'

Abstract

Background: Previous studies have suggested that memory service users generally

report a desire for more information around a diagnosis of dementia.

Objective: To explore service user and staff views on written information provided

following a diagnosis of dementia by a memory service in the South West of England.

Method: Service user and staff perspectives on the written information were explored

through focus-groups in order to better understand their views and preferences on the

type and quantity of written information that is provided around a diagnosis of

dementia. The written information provided by the memory service was also assessed

against the National Institute for Health and Care Excellence (NICE; 2006) guidelines

for information provision.

Results: The provision of written information by the service covered all topics

suggested in the NICE guidelines. Service users and staff generally agreed that there

was 'too much' written information, and both parties highlighted a need for balance

between written information and more direct support and information provision by staff.

Conclusion: The findings highlight potential barriers to service-users accessing

information relevant to their diagnosis and provide examples of how one service

attempted to respond to such issues through some relatively simple adaptations to its

practice.

59

Introduction

The impact of receiving a diagnosis of a dementia and living with this progressive condition can be tremendous both for the individual with dementia and those around them (Husband, 1999; Husband, 2000; Pratt & Wilkinson, 2003; Joling et al, 2010; Schulz et al, 1995). An important consideration for a service that assesses and diagnoses such individuals is whether its patients and their families and carers understand the diagnosis and receive appropriate information about sources of support.

This project was undertaken in a specialist memory service in the South West of England that conducts assessments, makes diagnoses, and provides information for patients and their family members and caregivers. The service hoped to understand whether written information provided to service-users (the service's patients, and their family and carers) around diagnosis, about dementia and sources of support, was useful and relevant. The enquiry was motivated by concerns about the *timing* of the information (was the information experienced as overwhelming if provided when the diagnosis was shared verbally?) and the *content* of the information (was it both sufficient and relevant?). A further concern was a possible lack of attention to the 'emotional journey' experienced after a diagnosis: it was highlighted that much of the information provided was more 'practical' than 'emotional' in nature, and some staff felt that more information on emotional aspects of adjustment and coming to terms with a diagnosis could be beneficial.

The provision of information has been highlighted as an essential element of patient-centred care. For example, the NHS Plan stated a commitment to improving information for patients (Department of Health, 2010, p. 88), and the National Dementia Strategy described one of its objectives as, "good quality information for those diagnosed with dementia and their carers... on the illness and on the services available both at diagnosis and throughout the course of their care" (Department of Health, 2009, p. 38). However, only a handful of studies have investigated information provision in dementia assessment and treatment (Vernooj-Dassen et al., 2003).

One study, conducted in the Netherlands, reviewed clinician-reported type and quantity of information provided to 51 patients of a memory service and their caregivers. The authors used 14 different categories to summarise information that could be provided. These included 'diagnosis told to patient', 'diagnosis told to carer', 'information on

medication', and 'information on care'. Only 8% of patient/carer dyads were provided with written information. The authors noted large variation in amount and type of information provided, and suggested that healthcare professionals tailor provision according to the information needs of clients and caregivers (Vernooj-Dassen et al., 2003). However, the views of patients and carers were not sought for this study. In another study, 30 patients with dementia and their caregivers who received both written and verbal information from a memory service expressed a desire for more information about dementia after diagnosis (Byszewski et al., 2007). The authors conducted interviews within one week of diagnosis, and focus-groups with carers one month later. A key outcome was the suggestion of 'progressive disclosure', allowing a gradual 'coming to terms' with the diagnosis, and for important elements of information to be revisited. Finally, van Hout et al. (2001) explored information provision in a memory clinic in the Netherlands, using a questionnaire measure to probe opinions of 81 caregivers and 31 patients who were recently assessed. Van Hout et al. reported that service-users' feedback was generally that information and advice could be more detailed and provided in greater quantity. In particular, both patients and caregivers agreed that the information provided around diagnosis was often 'vague', and caregivers reported dissatisfaction with advice around care support and handling behaviour, and insufficient discussion of carer distress.

In a related field, an intervention that included the refinement of a service's written information to promote increased understanding and improved adjustment around a diagnosis of cancer resulted in positive outcomes for patient satisfaction, symptom management, knowledge about the condition, and affective state (McPherson, Higginson & Hearn, 2001). This finding suggests that focusing on the improvement of written information provision within a memory service could have beneficial outcomes for service-users.

This study addressed the following questions by giving service-users and staff the opportunity to share their views through focus-groups, and reviewing written information provided:

- 1) Do service-users and staff consider the written information provided around diagnosis to be i) sufficient and relevant, and ii) well-timed?
- 2) Do service-users and staff consider that enough attention is given to the 'emotional journey' after diagnosis?

3) Does the information provided meet the National Institute for Health and Clinical Excellence (NICE; 2006) guidelines for provision of information by memory services?

Method

Overview

Focus-groups were utilised to explore the opinions of service-users and staff. Focus-groups were considered to be an appropriate method of data collection because they could allow for the flexible capture of richer information compared to quantitative methodologies, and were less time-intensive than individual interviews. Focus-groups have been employed for data collection in similar studies previously. Two focus-groups were held: one for memory service staff and one for service-users. In addition, a brief review of written information provided around diagnosis was conducted to assess provision against NICE guidelines (NICE, 2006, Table 6). The protocol received ethical approval from the University of Bath Department of Psychology Ethics Committee (received 16/01/15, reference number: 14-227) and the NHS Trust (06/01/15, reference number: 2014.E022).

Table 6.

NICE guidelines for provision of written information to service-users alongside diagnostic feedback (NICE, 2006, p. 12)

Topics recommended for inclusion in written information offered to users of memory services alongside verbal information about diagnosis of a dementia

Signs and symptoms

Course and prognosis

Treatments

Local care and support services

Support groups

Sources of financial and legal advice and advocacy

Medico-legal issues, including driving

Local information sources including libraries and voluntary organisations

Review of written information

The standard information pack was reviewed by the lead researcher and compared with the standards outlined in the NICE guidelines (NICE, 2006). Specifically, the researcher assessed whether the information addressed the 8 recommended topics. In addition, staff reports of the information they provided and service-user reports of the

information they received were taken into account in the focus-groups.

Focus-groups

Questions were formulated through consultation with the staff team and are presented in Table 7. Focus-groups lasted 90 minutes. Approximately 60 minutes were spent on discussion of the focus group questions. Prior to this, participants had time to re-read the information sheet (Appendices B and C), ask questions, sign the consent form, complete a brief demographic questionnaire, and indicate the written information they generally provided (staff) or had received (service-users). All possible leaflets and other informational documents from the memory service's information pack were on the table during this time and throughout the focus-group for participants to look at as a memory aid. After the focus-group discussion verbal and written debriefs were provided. Service-user participants were asked to write down their name and address if they wished to receive a brief written summary of the findings.

Table 7.

Questions asked in the service-user and staff focus-groups

- 1. Is enough written information given at diagnosis, or is there too much? Is it all relevant, and is everything covered that needs to be covered?
- 2. Is the information well-timed, or does it seem to come too early or too late?
- 3. Is there scope for more written information on the emotional side of things, about coming to terms and what to expect in your relationships and how you're feeling after receiving a diagnosis?

All staff were emailed with a brief invitation to the study. Staff who registered an interest were given an information sheet and invited to take part. The staff focus-group included 9 participants comprising four nurses (including the service manager), one speciality doctor, one occupational therapist, two clinical psychologists, and an assistant psychologist. The participants were all female, aged between 33 and 59 years, and had worked in the service for an average of 2.7 years (range = 8 months to 5 years).

Service-users were recruited by a brightly-coloured study invitation sheet included in the information pack at diagnosis, which clinicians were asked to highlight to serviceusers. Fifty-two service users were given an invitation. Service-users who expressed an interest were contacted by telephone and sent an information sheet. The serviceuser focus-group was attended by 5 service-users, including two married couples, who had all attended the service's 'Finding a Way' group previously¹. The group was facilitated by the researcher and two clinicians who provided field supervision for the project. The clinicians provided additional support, ensured that conversations remained on track, and were available in the event that any participant became distressed by the topics discussed. There were three male and two female attendees, of whom two had recently received a diagnosis of dementia and three had a spouse who had recently been diagnosed by the service. The mean age of attendees was 72 years (range = 70 to 74 years). Diagnoses had been received between 1-2 years previously, and included Alzheimer's disease and fronto-temporal dementia.

Analysis strategy

Data from the staff and service-user focus-groups were analysed separately using the qualitative thematic analysis approach outlined in Braun and Clarke (2006). Specifically, recordings for each focus-group were carefully transcribed by the lead researcher, who then undertook a process of familiarisation with the data (by repeated reading), generation of initial codes, searching for initial themes, and naming of themes. The transcripts were separately read and coded by an independent rater (a second-year trainee clinical psychologist with previous experience of conducting thematic analysis) who noted key emerging themes, which were then compared for agreement with the themes generated by the lead researcher. The transcripts, codes and final themes were also read and agreed by the two field supervisors involved in the project. A data trail was kept so that the researcher could identify how themes had developed over time.

Findings

Review of written information

The standard information pack contained 14 separate information sources in the form of booklets, pamphlets and advertisements. Perhaps the most comprehensive source of information (covering 5 of the 8 categories outlined in the NICE guidance, see appendix D) was the 128-page Dementia Guide. The remaining 13 sources included information about local groups and services, charitable organisations, and research opportunities. The information packs covered all the areas outlined in the NICE (2006)

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¹ The 'Finding a Way' group is a 6-week post-diagnostic course for patients and their spouses who experienced difficulties in accepting or adjusting to their diagnosis

guidelines. Review of questionnaire responses from the focus-groups suggested that service-users were unsure of which pieces of information they had received, with one service-user writing, "too much information!" Service-users estimated that they had received between 3 and 11 of the 15 possible pieces of information (although considerable uncertainty was expressed) and staff reported that they generally provided between 4 and 13 items, although they reported considerable variation within their own practice. Additional items of information provided by some staff included a 'telephone support referral form', additional information on Attendance Allowance, information on the Positive Step support service, medication information leaflets, and information on 'living with mild memory difficulties'.

Focus-group themes

Themes for the service-user and staff focus-groups were found to overlap to a relatively large extent. Therefore, to aid direct comparison, they are presented in parallel. Three main themes emerged across the two focus-groups (Figure 2). Quotes from staff are coded 'S' together with a participant number. Quotes from service users are coded 'SU".

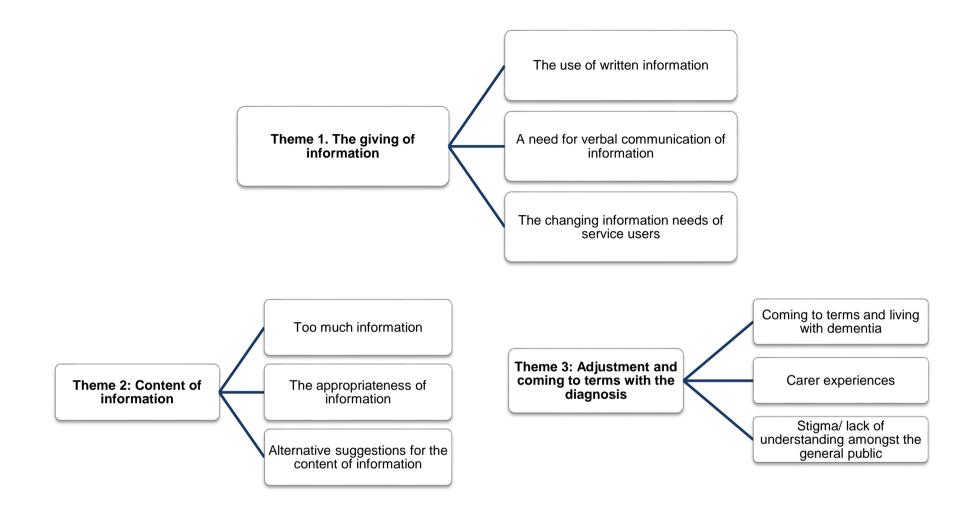


Figure 2. Themes and sub-themes emerging from the two focus-groups

Theme 1: The giving of information

Subtheme 1A. The use of written information

Participants in the staff focus-group spoke about the importance of written information provision, commenting that some information can be 'empowering' (S4) for services users, that they can refer to the written information if needed, and digest information better if it is available in writing.

"I think it's important to have written information as part of the diagnosis because I don't think people always take it in straight away when they are told things.. I think it's nice for them to be able to go home and actually look at stuff and read it through and digest it a bit better" (S1).

Service users did not generally express this view, instead reporting an urge to dispose of information, or saying that they would probably not refer to it later on.

"you feel like binning it" (SU2)

"you probably wont go back to it [written information]" (SU4)

Some participants reported attempts to 'shield' a spouse with a diagnosis of dementia from the information by managing the information themselves and removing it from their spouse's view.

"I try not to let it get to her because to let her see it its.. oh whats this about, you know, and then we're talking about dementia and Alzheimers again" (SU4).

Staff also commented on the importance of written information in the context of constraints on the time staff can spend with service-users, allowing clinicians to feel they can 'do something':

"if you think of the transaction that you're having with the person... it's not a feel good situation um but lots of information, ...it kind of makes you feel a bit better if I'm honest" (S6)

"You feel you're not leaving them on their own" (S4).

Some staff suggested that written information was potentially not utilised by service users:

"...my sense is that kind of what's important gets lost under what they don't feel is relevant um and the whole lot gets swept aside..." (S2)

"quite often what will happen is we know this information just goes in a drawer somewhere..." (S6)

Service users echoed this view, commenting that they had not made use of the written information ("...we haven't had time to look at it", SU4).

Subtheme 1B. A need for verbal communication of information

Staff commented that constraints on the service including limited patient contact time and pressure to discharge patients after the diagnostic appointment leave clinicians feeling unable to 'be there' for their patients as much as they would like. Staff spoke about the gap in service provision after diagnosis, with patients unable to seek support from the service but instead directed to charities whose staff may not be able to offer the highly specialist support required.

"you feel you want to do something and of course we are limited in what we can do because of the boundaries of the service primarily" (S3)

"...knowing that there's a gap in the service, that a lot of people will be discharged..." (S7)

"we're able to do less and less because of [financial] constraints and I think a lot of it's been farmed out to [charities]" (S2)

Clinicians felt that offering patients the opportunity to telephone them after discharge from the service could be helpful and did not represent a large time burden for the clinician, since in many cases this offer was not taken up.

"...if I was in this position, I'd like somebody to perhaps give me this information and then say if you've got any questions just give me a ring, I'm at the end of the phone, and to know that, which as a service we can't..." (S2)

"...that's what I've done... sometimes people just want to think there's somebody on the end of the phone and I think the majority don't choose to use

that but also hopefully it makes the patient feel better and it certainly makes me feel better..." (S3)

Participants in the service-user group also spoke of the importance of being able to speak to somebody.

"I got given so much... written information, and it's not quite what you want... you really just want to talk to somebody." (SU1).

Service-users preferred to contact the service and service-user groups.

"I was talking just now about this little lunch club, one that runs in [nearby town] to do with the Alzheimer's society... I've found that really, really helpful because you're able to talk with people in exactly the same position..." (SU4).

Service-users also commented that asking questions was generally easier than consulting the written information, often allowing for more personally-relevant answers.

"if you've got a service here like the lady on reception says oh I'll just bring up your file and she says oh yes, Mr X, fine, and she just keys in and they immediately know who you're talking about and what your need is..." (SU1)

"you cant have everybody's personal problems in [writing]" (SU3)

Subtheme 1C. Changing information needs

Staff considered the different needs of service-users at different times – for example that patients in the earlier stages of dementia and their carers may not require much information, but their need would change as the dementia progressed. This was also discussed in the context of the service beginning to diagnose dementia earlier, meaning many patients are relatively unimpaired when they are diagnosed and may require very different information at this stage compared to the more advanced stages.

"when we see people ... in the earlier stages of their cognitive change... they don't see themselves as that person, so its that sort of lack of connection when people are talking about there are services there and the Alzheimers society and there's this and that..." (S3)

"...especially if people have a like big be strong um they'll say no, we're fine, we're coping ok, and it's trying to meet them in a timely way..." (S6)

This view was echoed by service users:

"I think also when you have your original diagnosis you're pretty strong and life is relatively straightforward, it's a year down the road or 18 months down the road... and it's as time progresses..." (SU1)

Staff also discussed the possibility of two different packs of written information, one for the early stages of dementia, and one for the later stages. Some service-users talked about a preference for relevant information to be 'drip-fed' (SU1), or available closer to the point where it becomes relevant. The importance of GPs in providing post-diagnostic support was raised by service users, and this group also suggested that a follow-up with the service, individually or in a group to address their needs – particularly in relation to emotional support – could be useful.

"it's almost like [you need] an earlier and a later pack isn't it" (S2)

"...I know we have that group where we all come together but in a way you just, ideally, could do with a drop in type meeting where you can just drop in and stay 10 minutes..." (SU1)

Staff raised concerns that service-users revisiting information later may find it no longer relevant, or up-to-date.

"Is it still relevant, have things changed?" (S3)

Staff generally agreed on the benefits of providing information about participating in research, not only for the advancement of knowledge but also more direct benefits for service-users such as gaining access to medications. However, some staff commented that providing this information at the time of diagnosis felt unhelpful.

"...it is so important, research" (S4)

"...there's also some people where that's really the first thing they want...
to know about ...to get more help I guess" (S4)

"you've just spent an hour with somebody going through everything [in the diagnostic appointment] and then you're sort of talking about that [research] and it's a bit of a negative at the end." (S1),

and suggested changes such as adding information about research to the diagnostic letter, adding an appointment after diagnosis to discuss research, or passing the responsibility for discussing research to GPs.

"...even if it isn't touched upon at the diagnostic appointment, whether it's something we could put into a diagnostic letter... you know... I've included some information that you may choose to engage with..." (S3)

Different modes of service delivery were also discussed in terms of the 'gap' in service provision post-diagnostically, and possible adaptations to address this such as the use of 'dementia navigators' who are able to provide information as it becomes relevant, the addition of 6-week review appointments for all patients after diagnosis, or use of a post-diagnostic group format to address information needs.

"it was different where I was [previously]... they'd have a [dementia] navigator for life and so they'd gradually feed them a lot of the post-diagnostic information that would be more appropriate to the individual" (S9)

Theme 2: Content of information

Subtheme 2A. Too much information

Staff unanimously agreed that there is 'too much' written information ("...we continually have people saying there's just too much information...", S2), but also spoke about the struggle to achieve a balance between too much and 'enough'. Staff suggested that the presentation of information in a 'bundle' could add to service-users' experiences of 'information overload'.

"...I might be able to look at one leaflet if I got just one thing to take away but if I'm getting a bundle of them it's gonna be hard for me to know which ones to pick out, so which ones are relevant" (S5)

Service-users spoke of feeling they had received too much information ("...I think we were quietly bombarded from the start", SU2), and that the amount of information had acted as a barrier to utilising it because it was difficult to find relevant information,

difficult to remember the information, and because they did not have time to read it ("...we've got so much paperwork, I've got a big file [full]...", SU4). Service-users commented that they felt unable to digest the information all at once, particularly in the context of recent diagnosis.

Subtheme 2B. The appropriateness of information

Staff talked about the possibility that some of the information – the diagnostic letter in particular - included too much 'jargon', and was not all relevant to patients in the early stages of dementia, and staff felt that much of the information focused on 'older' and more impaired individuals.

"... we have to put [in the report] severely impaired for this, severely impaired for that, and sometimes it feels like you're battering people with it." (S7).

"...the person that comes through the door... particularly more as we see people... in the earlier stages... they don't see themselves as that person, so it's that sort of lack of connection when people are talking about 'there are services there and the Alzheimer's society and there's this and that' – that's not me...", \$3).

There was general consensus that the diagnostic letter was one means by which information and service provision could be improved easily and with a potentially large impact for service-users. Staff suggestions included splitting the letter into two parts, making the assessment report optional, and writing separate letters to GP and service-user rather than attempting to meet the needs of different audiences with a single letter.

"it strikes me the importance of the letter... that's the next place I suppose we can really kind of make a difference... that's the thing that people might actually pick up again and look at if it's got quite a lot of important information in" (S5)

"Perhaps in the diagnostic letter we should be selective about what we provide and say if you wish to have a full report of your assessment we are happy to provide it ..." (S3)

Service-users also talked about feeling that some information had been too 'professional' (SU1), feeling 'cowed' (SU1) by professionals, feeling 'clobbered' (SU2) with information about their diagnosis, having too many reminders of the diagnosis,

and not wanting to know about it. Participants discussed the use of language in the written information, commenting that they struggled to relate to the words 'Alzheimer's' and 'dementia' and disliked their frequent use within the information they had received. This seemed to motivate the removal of information from view and to be related to the lack of engagement with the written information participants reported

"...it's that clobbering all the time with information and ... you don't necessarily need that... you already know there is a problem, you're not 100% right, but you don't need it in your face, you don't want to keep knowing about it.", SU2)

Discussion of the diagnostic letter in the service-user focus group centred largely on the wording used: service-users spoke of seeing the diagnosis in bold at the top of the diagnostic letter and feeling that this was not necessary or particularly useful ("...why do we need to see the clinician's wording to the doctor...?", SU2). Instead, participants agreed that splitting the diagnostic letter and report may be useful, as well as considering the language used in the diagnostic letter, and perhaps having a separate letter for the GP.

Subtheme 2C. Alternative suggestions for the content of information

Some participants in the staff focus-group felt that more written information could be provided in some areas, including practical issues (e.g., 'Power of Attorney' and attendance allowance), increasing the provision of information for people at different stages of dementia, or younger patients, and ensuring that information reflects the 'reality' of a diagnosis of dementia rather than being 'overly positive'

"...while it's [the written information] good and it's positive, it's all a bit cheery and I think when we have our encounter with people it's not... they don't really want to feel cheery, you know, and sort of like cheeriness is a bit of a snub... and kind of undermines and undervalues... where they really are" (S6).

There was unanimous agreement among staff that written information on the emotional impact of a diagnosis could be useful, although staff returned to the importance of personal contact in addressing the emotional impact.

"I think its very important really to have something written I think when somebody's quite emotional, feeling very tearful, very anxious, sometimes its quite you know refreshing sort of you know to be able to say there's something written that you can read and saying yep this is quite normal and I think that's quite grounding for somebody" (S9)

"...if we had that availability it is also then revisiting that emotional impact that you know we have given you information and actually how do you feel now and it's that sort of 6 week period where people are, if you like, to the best of their ability coming to terms, so its bridging that initial emotional impact and knowing that there's going to be somebody coming back again in 6 weeks time that can talk through if you actually emotionally, if you are feeling a real struggle with this" (S3)

Although some service-users agreed that there might be scope for the inclusion of more information about coming to terms with a diagnosis, many participants commented that they probably already had this information somewhere within the information packs, and the general consensus was that it would not be useful to add any extra written information

"... we could pick up all these leaflets that we've been given and we'll find a way somewhere or other in all this that might deal with our emotions and our things have progressed but it would take an awful lot of time to go through all that lot wouldn't it?" (SU2)

Theme 3: Adjustment and coming to terms with the diagnosis

Staff made a number of comments about their understanding of the process of adjustment to a diagnosis, both in terms of the emotional journey for the service-user and also the impact on their ability to make use of the written information. Themes included 'feeling overwhelmed' ("It comes back to what people can absorb at that time..., S5), 'talking about feelings', 'shock' and 'denial', and 'self-image' ("I'm not that person that I've got in my head that you're telling me I am, and that's the hard thing", S3).

"I just wonder about the client group as well and the generational thing, you know, not kind of really wanting to talk about how you feel about things and that, you know, if you say you're struggling is that perceived as a sign of weakness and I've heard lots of... just pull your socks up... just get on with it, keep going..." (S5)

"If people are in that shock or denial stage where they don't want to accept what's happening or the reality of having a diagnosis, are they going to be able to, um, absorb and take in the information that's given actually if they just want to push it away" (S5)

Staff talked about adaptations to their practice in response to service-users' needs in this domain, such as addressing the emotional impact of the diagnosis in their consultations whilst also instilling hope, and considered changes to service provision, including adapting the focus of the existing 'memory matters' group to incorporate attention to the emotional impact of receiving a diagnosis.

Service-users spoke about the challenges surrounding 'coming to terms' and living with a diagnosis of dementia, both for the patient and their spouse. These challenges included accepting and incorporating the diagnosis into their view of themselves and daily life, overcoming the initial shock of the diagnosis, and their own negative reactions to terms such as 'Dementia' and 'Alzheimer's'

"I think it's the thought as well of the word, I never in a million years thought that would apply to me, you know, in the past I never would have even dreamed of it cos I didn't know much about it at all either, so it did come as a bit of a shock" (SU3)

This was described as a gradual process, happening in the context of a variety of changes and perturbations in the service-users' lives

"... the patient, the person with the diagnosis, it's difficult to get them to understand what's going on; this denial thing, they don't want to hear it... we've got to the stage after a 12 month where actually we can talk about it more, it's now been accepted that there is a problem, but it's a short term memory problem only and that's where we're at." (SU4)

Subtheme 3B. Carer experiences

The spouses who participated in the focus-group spoke of the practical and emotional tasks that they faced around their partner's diagnosis and living with dementia

"...it's [dementia] what you all dread, but quietly you already know. I mean, I knew that [my husband] was unwell about 2 or 3 years before I actually got him to the appointment." (SU1)

They spoke of changing responsibilities and the burden associated with becoming a carer. One burden they described was paperwork, and they felt that the written information had added to this.

"... because my wife used to do my books and all the paperwork at home and all the banking and all this sort of thing, and all that went clunk... stop... and I'm thinking woah, I've got to take this on now" (SU4)

"really, paperwork is the bane of my life" (SU1)

They also alluded to an awareness of the impact of budget cuts in the NHS on the availability of services, and the increased reliance on carers to fill gaps in provision, as well as speaking about the importance of charitable organisations for supporting them in their role as a carer.

"for us as carers the responsibility is absolutely enormous and it's saving the government 87 billion pounds a year because we are caring" (SU1)

"they're [charities] your lifeline because they provide lots of things that the NHS cant provide" (SU1)

Subtheme 3C. Stigma/ lack of understanding amongst the general public
Staff spoke about the negative media image of dementia. They discussed negative
attitudes toward dementia in the context of service-users struggling to accept and
adjust to their diagnosis, and the problems this can produce for the service in providing
support to individuals around their diagnosis (including written information)

"Well people don't recognize the diagnosis in themselves do they? Because I think the media image of Alzheimer's disease particularly is this very negative image and, we know all the sorts of things, you know, of there's somebody not able to do anything for themselves, possibly in 24-hour care, sat there unengaged..." (S3)

"It's that identity" (S5)

Service-users spoke at length about the negative connotations of 'Dementia' and 'Alzheimer's', and of their experiences and perceptions of a lack of understanding in the general public about these terms

"... they sort of start shying away from you – oh my God!" [Describing the experience of sharing the diagnosis of dementia with others] (SU2)

Participants also spoke about their changing understanding of dementia since receiving the diagnosis and of their hope that the public will also develop a better understanding of the disease through education campaigns.

"... it... dementia, it does bother me. I can't, that's not me, you know, I'm not demented in the respect of walking around completely out of my tree" (SU3)

Feedback to the service

A feedback meeting was held with four staff members including the service manager. In general, the findings were felt to be consistent with what staff had already encountered in their contacts with service-users (e.g., dislike of the words 'Dementia' and 'Alzheimer's' and a preference for face-to-face contact with the service).

Key recommendations fed-back to the service were:

- Offer service-users the option to delay receiving the written information pack
- Send a separate diagnostic letter (report optional) to the service-user, and word this letter sensitively (e.g., not stating the diagnosis in bold text at the top of the letter)
- Providing more opportunities for follow up for service-users, in the form of a post-diagnostic group or drop-in service
- Addressing the 'emotional journey' after a diagnosis of dementia verbally with the service-user (this may be achieved as part of a post-diagnostic group)

Changes agreed during the meeting were, i) the diagnosis at the top of the diagnostic letter will not be written in bold text; ii) service-users will be given the option to receive the information pack at the diagnostic appointment or at a later time; iii) plans to change the format of the post-diagnostic 'finding a way' group to include more service-users will be followed-up; and iv) the emotional impact of diagnosis will be addressed by an optional information leaflet for service-users and greater staff training and support around this issue. The service planned to probe the views of a greater number and wider range of service-users via a questionnaire.

The service subsequently decided to provide the written information pack at the first contact with service-users, with a warning that some information may not be relevant but is provided for reference in case it is needed later. This was intended to minimise the administrative burden associated with providing information at different times for different individuals, while avoiding the 'overload' of receiving written information as well as verbal information at the point of diagnosis. If specifically requested, arrangements are made to send the written information to a service-user after diagnosis. In addition, service-users are now encouraged to make contact with the service at a later date if they require further information. In terms of the diagnostic letter, the service have addressed the content of letters in terms of reducing 'jargon' and attending to presenting potentially challenging information more sensitively, although time-pressures have meant that the service are unable to write separate letters to the service-user and GP in most cases. Following the feedback, the service

renamed their post-diagnostic 'Finding a Way' group 'Living Well with Dementia' and offer the group to most service-users. In addition, a group for service-users with a diagnosis of Mild Cognitive Impairment has been piloted. Finally, the need for support around the 'emotional journey' after a diagnosis of dementia has been addressed to some extent by referring as many service-users as possible for telephone support from the Alzheimer's Society after diagnosis.

Discussion

The aims were i) to explore service-user and staff views on whether written information provided around diagnosis is useful and relevant, ii) whether written information pays sufficient attention to the 'emotional journey' after diagnosis; and iii) to assess the written information provided by the memory service against the NICE (2006) recommendations.

The review of the information pack provides a useful context for the focus-group discussions and recommendations, and is therefore attended-to first. The information pack covered all 8 categories of information recommended by NICE (2006), and for many categories provided more than one source of information. However, there was variability in the amount of information actually provided by staff, and accurate reports from service-users were difficult to obtain because service-users had difficulty remembering what they had received.

In relation to the first and second aims, the feedback provided by the service-user and staff focus-groups suggested the amount of written information provided is sufficient. Indeed, a resounding finding was that there was 'too much'. Both service-users and staff cited the amount of information as a barrier to utilisation. Both groups agreed that written information is not sufficient alone, and service-users in particular suggested the 'emotional journey' after diagnosis could be addressed verbally. The need for face-to-face contacts was a major theme of both groups, and appeared to be a particular challenge in the face of funding constraints. In terms of timing, there was agreement that information comes too early; that often need increases over time - perhaps due to progression of the dementia and an increasing need for external support. In addition, both groups felt that service-users' ability to absorb information at the point of diagnosis was limited, and could be another barrier to making use of information initially. Other issues covered by both groups included the impact of adjustment and 'coming to terms' on engagement with the written information, and the problems with writing a diagnostic report and letter to the GP and copying these directly to service-

users. Although staff and service-users felt that written information was important and potentially useful, staff were uncertain about the extent to which the written information is utilised, and feared that it is often 'discarded' or put aside. This was corroborated by service-user reports that they had not yet made use of the written information, despite receiving it between 1 and 2 years previously.

These findings indicate that staff who took part in the focus-group were well-informed and sensitive to the needs and views of service-users, at least in terms of the small number of service-users who took part in the focus-group. Staff in the feedback session said that service-users' dislike of the terms 'Dementia' and 'Alzheimer's' resonated with their experiences. This could present a barrier to service-users accessing written information, and is therefore an important consideration for the service and other organisations that provide similar written information. Previous studies have noted a tendency for professionals to use euphemistic terms in diagnosis, particularly when disclosing this information to the person with dementia (Bamford et al., 2004; Gove, Downs, Vernooj-Dassen & Small, 2015). This might be understood as a response to patients' dislike of particular terms, as observed within the service-user focus group. A number of studies have identified shame and perceived stigma (noted within both the service-user and staff focus groups) as common reactions to a diagnosis of dementia (e.g., Frank et al., 2006; Moniz-Cook et al., 2006; Aminzadeh et al., 2007; Langdon et al., 2007). These emotions, among others, may take time to process and are considered to be relevant to a period of denial after diagnosis (Steeman et al., 2006). Steeman et al. have suggested that moving toward acceptance may be thwarted by the attempts of family members to 'cover up' the problems, and this is consistent with the comments from the service-users focus group. Rabinowitz and Peirson (2006) summarised suggestions for clinicians for the management of 'denial' and encouraging acceptance in the context of a diagnosis of cancer. These included maintaining a non-judgemental and non-confrontational stance, ensuring that adequate information has been provided, using active and empathic listening, encouraging use of adaptive (i.e., not harmful) coping strategies, and being available to the patient at a later time, after diagnosis. Such adjustments may also be relevant to service-users receiving a diagnosis of dementia. In addition, it may also be useful for the service to consider how to support its users in disclosing their diagnosis and managing reactions from others, for example through skills training, advice or support groups. A need for staff availability after the diagnosis was also highlighted as a result of the focus groups. Staff reported a number of existing practices that are consistent with the above ideas, such as giving patients the option to contact them by telephone after diagnosis and normalising negative reactions to diagnosis. During the feedback

session a number of other changes to service provision were discussed, including communicating the diagnosis on the diagnostic letter more sensitively (not presenting it in bold type), extending the availability and scope of post-diagnostic support via drop-in group sessions, and allowing service-users to delay receiving post-diagnostic written information. This is consistent with recommendations from a number of previous studies (e.g., Byzewski et al, 2007; Vernooj-Dassen et al, 2006).

Although the project provided some useful insights, the scope of the findings may also be limited by a number of issues. For example, one service-user was able to contribute only minimally to discussions due to the relatively advanced nature of their dementia. The inclusion of individuals with dementia in studies attempting to evaluate the provision of dementia services is commonplace, and considered important (e.g. Bamford et al, 2004). However the possible limitations associated with asking individuals with cognitive impairments to comment on their experiences of services from memory is not without limitations. Moreover, all of the service-users had taken part in a post-diagnostic support group specifically for individuals who had initially struggled to come to terms with their diagnosis. Therefore, the 'voice' of service-users may have been relatively unrepresentative of the service-user population as a whole, privileging the views of those within a small age bracket, within 1-2 years of receiving their diagnosis, currently living with their spouse, and who struggled to adjust after diagnosis. However, this limitation was addressed by the service with the intention to continue to gather the views of its service-users via alternative means such as questionnaires.

In summary, in spite of some limitations associated with the study methodology and sample, the findings were felt by the service to be useful. They allowed for staff and service-user views to be fed-into changes in service delivery and information provision, and provided reassurance that the service was meeting the NICE (2006) guidelines for the information provision relating to a diagnosis of dementia. The findings also have implications for wider practice in highlighting possible barriers to utilisation of written information, such as shame and perceived stigma, and providing examples of how one service attempted to respond through some relatively simple adaptations to their practice.

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Research paper, June 2016

Everyday experiences of intrusive thoughts and images in individuals with a diagnosis of bipolar disorder

Word count: 4,992

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Target Journal: Behaviour Research and Therapy (5000 word maximum including abstract, text and references). This journal focuses on emotional and behavioural disorders in terms of working towards a better understanding of their aetiology, prevention and treatment.

Background: Holmes et al (2008) posited that mental imagery acts as an 'emotional amplifier' in bipolar disorder, leading to the shifts in mood that are a hallmark of the condition. Evidence for this idea comes largely from retrospective studies. No study has, to the author's knowledge, explored experiences of mental imagery as they occur in the day-to-day lives of individuals with bipolar disorder. This approach has the advantage of greater ecological validity, minimising confounds associated with retrospective recall.

Method: Twelve individuals with a diagnosis of Bipolar I or II disorder and 20 nonclinical controls completed a diary of intrusive mental images and verbal thoughts twice-daily for seven days. Thoughts and images were rated on a number of dimensions, including 'intensity' and 'vividness'.

Results: Individuals with bipolar disorder reported significantly more 'intense' experiences of intrusive mental imagery compared to controls, but there were no significant differences in frequency or intensity of verbal thoughts, although the small number of participants in the bipolar disorder group means the study may have lacked power to detect significant group differences. Vividness of mental images was also higher in the bipolar disorder group.

Conclusions: The findings provide support for Holmes et al's (2008) model, using assessment of intrusive verbal thoughts and mental images in a naturalistic setting. The main benefit was greater ecological validity compared to previous retrospective studies. The study also demonstrated that it is possible to elicit reports of these phenomena using diaries in a bipolar disorder population.

Introduction

Bipolar disorder is a severe and enduring mental health condition that is characterised by episodes of extreme disruption in mood, behaviour, and cognitive functioning, and affects around 1-2% of the world's population (Merikangas et al, 2007; Geddes & Miklowitz, 2013). Mood fluctuations involve depression and elevated mood ((hypo)mania) in addition to periods of relatively stable mood (euthymia). Sufferers may have mood swings and sub-clinical symptoms during euthymia (Mansell, Morrison, Reid, Lowens, & Tai, 2007).

The treatment approach for bipolar disorder recommended by the National Institute for Health and Care Excellence (NICE, 2014 and updated 2015, guideline CG185: Bipolar Disorder: assessment and management) and other bodies (see Geddes & Miklowitz, 2013) is, broadly, a combination of pharmacological and psychological interventions. Evidence-based psychological interventions include cognitive-behavioural therapy, family-focused therapy, and group psycho-education (Geddes & Miklowitz, 2013). A focus on improving outcomes of psychological interventions has led some researchers to explore the role of mental imagery in mood instability in bipolar disorder (Geddes & Miklowitz, 2013).

Intrusive mental imagery has been highlighted as an important feature of a number of disorders, including post-traumatic stress disorder, social phobia, and depression (Hackmann & Holmes, 2004; Hirsch & Holmes, 2007; Holmes, Arntz & Smucker, 2007; Moulds & Holmes, 2011; Brewin, Gregory, Lipton & Burgess, 2010). Accordingly, psychological therapy interventions that incorporate a focus on mental imagery are becoming more commonplace (e.g., Holmes et al, 2007; Moulds & Holmes, 2011).

A number of studies provide evidence that experiences of mental imagery are relevant in bipolar disorder and may provide a useful target for psychological interventions. For example, Holmes, Deeprose, Fairburn, Wallace-Hadrill, Bonsall, et al (2011) found that people with a diagnosis of bipolar disorder reported greater general use of mental imagery on the 12-item Spontaneous Use of Imagery Scale (SUIS; Reisberg, Pearson, & Kosslyn, 2003), a more imagery-based and less verbal processing style (Holmes, Mathews, Mackintosh, & Dalgleish, 2008), more 'vivid' and frequent imagery of future events, and a more extreme bias in the way they interpreted these images compared to non-clinical controls. In addition, within the bipolar disorder group greater 'mood instability' - more changeable mood over a 6-month period - was associated with more frequent mental images. Ivins, Di Simplicio, Close, Goodwin and Holmes (2014) reported that people with bipolar disorder experienced positive imagery as more

'powerful' (vivid, intense) compared to positive verbal thoughts, and Mansell and Lam (2004) found that a group with remitted bipolar disorder reported high levels of mental imagery associated with recall of specific memories. Hales, Deeprose, Goodwin and Holmes (2011) reported that individuals with bipolar disorder were more likely to experience mental imagery compared to individuals with unipolar depression, and also experienced greater preoccupation with 'flashforward' mental imagery relating to suicide. They rated these images as more compelling and more likely to foster motivation to act compared to individuals with unipolar depression. In another recent study, Gregory, Brewin, Mansell and Donaldson (2010) explored intrusive memories and mental images associated with recent episodes of hypomania, depression, and euthymia in individuals with bipolar disorder who were currently euthymic. In their reports of previous depressed and hypomanic states intrusive mental images featured heavily, but having a different theme in each (e.g., death- or suicide-related imagery in depression and positive, goal-directed future events in hypomania; Gregory et al, 2010). Researchers have also noted that greater frequency of intrusive mental imagery (rather than greater use of imagery per se) was associated with higher levels of hypomania in a non-clinical sample, which in-turn is associated with greater likelihood of meeting diagnostic criteria for bipolar disorder in the future, while intrusive verbal thoughts showed no association (McCarthy-Jones, Knowles & Rowse, 2012). Similarly, Deeprose, Malik and Holmes (2011) found that higher levels of intrusive prospective imagery were associated with greater risk for bipolar disorder as measured by the Mood Disorders Questionnaire (Hirschfield, Williams, Spitzer et al., 2000) in a nonclinical sample.

It has been suggested that mental imagery acts as an 'emotional amplifier' in bipolar disorder (Holmes, Geddes, Colom & Goodwin, 2008; Holmes & Matthews, 2005). According to this account, mental images can act to amplify or escalate both anxiety and positive mood, and possibly other emotions too. For example, having a rich mental image of winning a prestigious award may amplify feelings of excitement, interest and potential success, thus feeding into a heightened positive mood. Experimentally, the greater impact of mental imagery on emotions compared to verbal thoughts has been demonstrated in picture-word cue paradigms and verbal-versus-imagery processing of descriptions of unpleasant events with non-clinical groups (Holmes, Mathews, Mathews, Mackintosh & Dalgleish, 2008; Holmes & Mathews, 2005). In this model, and drawing on the literature around increased likelihood of performing an 'imagined' action (Carroll, 1978; Gregory, Cialdini, & Carpenter, 1982; Libby, Shaeffer, Eibach, & Slemmer, 2007), it is suggested that behaviour may be influenced as a result of the emotional response to imagery (e.g. Holmes et al, 2008; Holmes & Mathews, 2010), leading to

observable symptoms of bipolar disorder such as increased goal-directed behaviours in elevated mood (Figure 1). Holmes et al also make the assertion that individuals with bipolar disorder may be particularly 'imagery-prone' (Holmes et al, 2008).

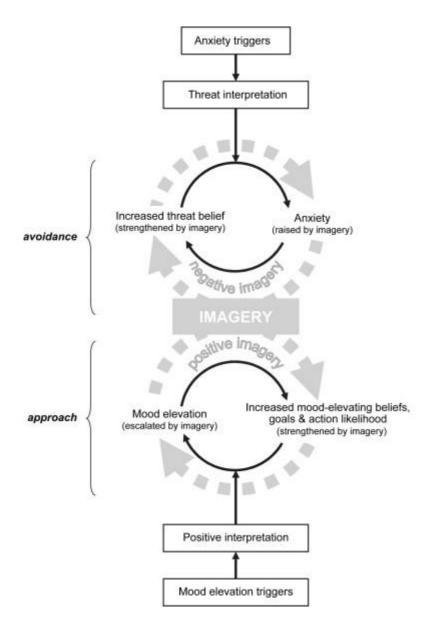


Figure 3. Model of mental imagery as an 'emotional amplifier' in bipolar disorder from Holmes et al (2008)

One potential limitation of much of the existing research on mental imagery in bipolar disorder is that it tends to rely on people's memories of their past experiences. As noted by Gregory et al (2010) and Ivins et al (2014), this approach is potentially problematic. For example, the accuracy of retrospective recall could be affected by current mood state, the amount of time that has passed since the experience, and events occurring during the intervening period that could alter or bias the memory. In

addition, cross-sectional studies are unable to contribute definitively to a discussion of causal pathways. This latter consideration is important because recent cognitive theories of bipolar disorder hypothesise some sort of causal association between intrusive mental images and symptoms associated with bipolar disorder. One solution is that individuals with bipolar disorder could be asked to report on these mental images as soon as possible after they occur.

In other studies involving clinical populations, a number of methodologies have been used to capture peoples' experiences as they occur, allowing for more ecologicallyvalid assessments of phenomena and exploration of causal pathways. One study utilised an ecological momentary approach to assess intrusive memories in trauma survivors, more than 40% of whom had a diagnosis of PTSD, building on existing evidence that had relied largely on retrospective recall (Kleim, Graham, Bryant & Ehlers, 2013). Participants were asked to record intrusions relating to their trauma experience on handheld computers over 7 days, at a maximum rate of once-per-hour. The findings provided support for previous studies by demonstrating that intrusions in PTSD are experienced with greater 'here-and-now' quality and stronger emotional responses, but also allowed for exploration of within-individual variance in experiences of intrusions and responses to triggers. In another study, Starr and Davila (2012) asked participants with a diagnosis of generalised anxiety disorder to complete a mood diary (either online or on paper) once-per-day over a 21-day period, both for the day overall and their mood at that moment. This allowed for the demonstration of temporal antecedence of anxiety over depression in daily symptoms. These studies also demonstrate that it is possible to conduct ecological momentary assessment of mood (Starr & Davila, 2012) and intrusive cognitions (Kleim et al, 2013) in clinical populations.

The present study required individuals with a diagnosis of bipolar I or II disorder and individuals with no current mental health conditions to report on their experiences of intrusive mental images and verbal thoughts twice-daily for 7 days. Based on the findings presented above, it was hypothesised that:

- Intrusive mental imagery would occur at a greater frequency and intensity in individuals with bipolar disorder compared to healthy controls;
- ii) Individuals with bipolar disorder would not experience more frequent or intense intrusive verbal thoughts compared controls.

The findings could have a number of important uses. First, they could begin to address the question of whether individuals are able to report on intrusive verbal thoughts and mental images as they occur. Second, they will allow for the frequency and intensity of intrusive thoughts and images in everyday life to be compared for individuals with and without bipolar disorder. These first two outcomes could lead to the development of more appropriate measures for assessing such phenomena. Third, the findings could set the scene for future studies to begin to routinely assess intrusive thoughts and images as they occur, in an individual's 'natural environment', and the associated appraisals and shifts in affect and behaviour that are posited to play a role in the development and maintenance of symptoms in bipolar disorder.

Method

Participants

The study initially aimed to recruit 30 participants in each group². Fifteen individuals with bipolar I or II³ disorder and 20 non-clinical controls were recruited. In the bipolar disorder group, around 30 individuals registered an initial interest in the study and received an information sheet and invitation to take part, giving an uptake rate of approximately 50%. Participants with bipolar disorder were recruited via service-user groups in the West of England, secondary mental health services in the South West of England, and advertisements displayed around the University of Bath and South West of England (in local shops and community centres). Recruitment from secondary mental health services included clinician-referrals, poster and leaflet advertisements in waiting rooms, and a trust-wide scheme in which letters were sent to all patients

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 $^{^2}$ Power analyses were conducted for the calculation of sample size based on the calculated effect-size achieved by Holmes et al (2011) for the difference between their groups (bipolar disorder and control) on levels of intrusive imagery of future events. The study included 23 individuals in each group, and achieved a medium effect size (d = 0.64) and an estimated power of 0.56 (1 – β), calculated from the means and standard deviations for each group reported in personal communication by the study's authors (20.05.14). Another study which utilised a week-long diary measure of intrusive cognitions included 20 participants who met criteria for a diagnosis of PTSD and 24 participants who did not in their investigation of the experience of intrusive memories in individuals who had experienced a traumatic event (Kleim et al, 2013). Based on these previous and relevant studies, it was anticipated that 30 participants in each group would be sufficient to provide adequate power to detect an effect of group membership on frequency and/ or intensity of goal related thoughts and imagery over one week. An alternative option for a priori sample size estimation would be the consideration of meaningful levels of difference between groups.

³ One participant met all criteria for depression and hypomania, consistent with a diagnosis of bipolar II disorder, with the exception that the duration of their hypomanic episodes was not reported to be as long as 4 days. However, since they lasted 2 days or more, and following a recent trial protocol (Mansell, Tai, Clark, Akgonul, Dunn, et al, 2014), the participant was included on the basis that they met criteria for a diagnosis of bipolar disorder not-otherwise-specified, and had received a diagnosis of bipolar II disorder from a psychiatrist.

registered as having a diagnosis of bipolar disorder. The healthy control group were recruited via advertisements displayed around the South West of England and University of Bath. All participants were offered a reimbursement of £20 upon completion of the study. The following exclusion criteria were applied: age under 18; English not spoken to a high standard; participation in any other research study within the last 2 weeks.

Participants in the bipolar disorder group were not excluded from the study if they were currently experiencing an episode of mania or depression, but care was taken to ensure that participants had capacity to consent to participation (i.e., able to retain, and weigh-up the information relevant to taking part, including possible risks and benefits, for long enough to make and communicate their decision) and that the participant was not at any increased risk of harm by taking part (i.e. encouraging communication with the care team about participation). If a participant's scores on the Beck Depression Inventory II or Internal State Scale indicated a current episode of mania or depression (a score of ≥ 29 for the Beck Depression inventory II, indicating current depression, or >/=200 on the Wellbeing subscale of the Internal State Scale, indicating hypomania; Lukasiewicz, Gerard, Besnard, Falissard, Perrin et al, 2013; Bauer, Vojta, Kinosian, Altshuler & Glick, 2000), participants were encouraged to take a week-long 'cooling-off' period in which to consider their participation further. The decision to include participants who were experiencing current (hypo)mania or depression was made on the basis that this would allow an exploration of experiences of intrusive thoughts and imagery in bipolar disorder across mood states. Holmes et al's (2008) model makes predictions that apply both to inter-episode mood instability and to 'bipolarity' (episodes of elevated mood in bipolar disorder in particular), and so should be applicable to individuals with bipolar disorder in different mood states.

In the non-clinical control group, individuals with a mental health diagnosis were not included in the study. This was checked using the SCID-I depression, mania, and PTSD modules, and also with a general probe in the initial interview ('do you have any current mental health conditions or concerns?"). In the bipolar disorder group, a diagnosis of bipolar I or II disorder on the SCID-I was required.

Design

The design was between-groups: comparisons were made between bipolar disorder and control groups on frequency and intensity of intrusive verbal thoughts and mental images reported over seven days. For the dependent variables of frequency and intensity of intrusive cognition there were two factors each, each with two levels: group (bipolar disorder, control) and cognition (verbal thought, mental imagery).

Measures

Demographic data

Demographic data were collected, including age, sex, marital status, ethnic background, years of education, and for participants in the clinical group only, age at diagnosis of bipolar disorder, number of inpatient admissions, current medications, first and most recent episodes of mania and depression.

Mood, anxiety and 'activity' ratings

Mood was assessed twice-daily throughout the study using a -10 to +10 scale, with 0 being 'completely neutral', -10 being the most 'low' I have ever felt, and +10 being the most 'high'. A measure of anxiety (0-10 scale) was included twice-daily, since anxiety is posited to be related to intrusive mental imagery within Holmes et al's (2008) model. Feelings of 'activity' or 'busyness' (akin to symptoms of hypomania) were assessed twice-daily using a 0-10 scale (Appendix J).

Sleep quality

Participants were asked to report on the quality of their sleep for the previous night, using a 0-10 scale, on a daily basis (Appendix J), since sleep quality is one factor known to impact upon bipolar disorder symptomatology (Plante & Winkelman, 2008; Harvey, Talbot & Gershon, 2009).

Intrusive cognitions

A diary-measure of intrusive thoughts and imagery was utilised (Appendix J). This was designed to be as simple and easy-to-use as possible in order to maximise participant compliance while eliciting all relevant information. Participants were asked, twice daily (as close as possible to 3pm and 10pm, as in a similar study conducted by Dodd et al, 2013), to think back on the period either since waking (3pm) or since the last record was made (10pm) and to record each intrusive verbal thought or mental image they had experienced. Participants were encouraged to complete the log online via a website (Bristol Online Surveys), although paper versions of the log were available to participants if they preferred. Participants were asked to record intrusive cognitions associated with visual or verbal experiences in a few words, stating whether it had been a mental image, verbal thought, or both. Participants were also asked to state, using a 0-10 scale, how 'vivid' the cognition had been, how intense, how important the cognition had felt, whether the cognition had relevance to their current goals, whether the cognition was completely novel or similar to a previously-experienced cognition and finally, using a -10 to +10 scale, whether the content of the cognition had been positive

or negative.

Life events

At the end of the seven days participants were asked to report the occurrence of any 'life events' during the week the diary was completed, and over the past month, from the list of significant life events provided by The Social Readjustment Rating Scale (Holmes & Rahe, 1967). Life events have been associated with bipolar disorder symptomatology (Johnson, Cueller, Ruggero et al, 2008; Reilly-Harrington et al, 1999). Representativeness

At the end of the seven days participants were also asked to complete a number of 'representativeness ratings' for the week as a whole, following D'Argembeau, Renaud, and Van der Linden (2009) in order to estimate i) the general representativeness of their experiences and therefore the likelihood that any departures from normal experience could have influenced the data, and ii) the degree to which priming, by drawing participants' attention to thoughts and images, could have had an impact on their experiences during the week. Participants were asked about representativeness for frequency, intensity and vividness of thoughts and images, mood, anxiety and sleep quality (Appendix K). These were probed using a scale from 'not at all representative' (0) to 'completely representative' (10).

Procedure

Participants were recruited as described above. Initially, consent was obtained from participants and they were given the opportunity to ask questions. The mood disorder sections (depression, mania and hypomania) of the SCID-I v2 (First, Spitzer, Gibbon & Williams, 1996) were used to establish presence or absence of bipolar I or II disorder (according to grouping). The PTSD section of the SCID-I was also administered. Participants then completed the Internal States Scale, Beck Depression Inventory-II (BDI-II), and the Beck Anxiety Inventory (BAI). Participants were given the opportunity to practice identifying and distinguishing between intrusive verbal thoughts and mental images in a training phase based on the imagery interview utilised by Gregory et al (2010), and the questionnaire measures relating to verbal thoughts and mental imagery utilised by McCarthy et al (2012; see Appendix J), and were then asked to record all intrusive verbal thoughts and images twice-daily over the next seven days, along with measures of mood, anxiety, feelings of 'busyness/ activity' and sleep quality. At the end of the seven days participants were asked to report whether any life events had occurred, and asked about 'representativeness' (see Measures section). In addition, the final contact provided an opportunity for participants to ask questions about the study, comment on their experience of participation, and for debriefing to be completed

verbally in addition to the written information provided (Appendix L). This contact was an opportunity to obtain a verbal report from the participant on their compliance and estimate of the percentage of intrusive thoughts and images experienced that were reported in the diary. The study received ethical approval from the West of Scotland NHS Research Ethics Committee (ref: 15/WS/0158) on 06/10/2015.

Data analysis

Normality was assessed by visual inspection of the data and summary statistics, and the Shapiro-Wilk test of normal distribution. Homogeneity of variances was assessed using Levene's test. Data relating to the main hypothesis of greater frequency and intensity of intrusive mental imagery in individuals with bipolar disorder compared to controls, with no significant differences in frequency or intensity of intrusive verbal thoughts, were analysed using separate Mann-Whitney tests for frequency and intensity (mean of available observations, with a maximum of 14, i.e. 7 days). Mann Whitney tests were chosen largely because the sample size of the bipolar disorder group was small (n=12), and non-parametric tests are by convention considered more suitable in such cases (e.g. Williamsen, 1974). Specifically, *p*-values from parametric tests may be considered less credible where the sample size is small, in part because the interpretation of tests of normality are limited by smaller samples (since smaller samples give rise to the likelihood that the null hypothesis of non-normality will not be correctly rejected; that is, they lack power to identify deviation from normality).

Results

Descriptive statistics

Twelve individuals in the bipolar disorder group and 20 in the non-clinical control group completed the study. Groups were compared, using Mann-Whitney tests, on age, years of education, and on their scores on the BAI and BDI-II, Internal State Scale Activation score (Table 8), sleep quality, mood, anxiety and activity ratings, ratings of vividness, importance, relevance to current goals, valence and similarity of thoughts and images (Table 9), and representativeness ratings, number of life events and estimates of the percentage of spontaneous or intrusive thoughts and images recorded (Table 10). These analyses revealed significant group differences on age, depression score (BDI-II), anxiety symptom score (BAI), and vividness of mental images. There were no other significant between-group differences. Group comparisons revealed that a greater percentage of the control group participants were female (85%) compared to

the bipolar disorder group (58.3%) and a smaller percentage of controls identified their ethnic background as 'white British' (40%) compared to bipolar disorder group participants (93.3%). In the control group, 90% of participants described themselves as a 'full-time or part-time student' and 10% were 'employed full or part-time', whereas 41.7% of participants in the bipolar disorder group were in paid employment and 58.3% described themselves as in voluntary or unpaid employment, a carer, retired, or unemployed, and none were currently students. In the control group, 90% described their marital status as single and 10% 'other', whereas 58.3% of participants in the bipolar disorder group were single and 41.7% 'other'.

Table 8.

Group comparisons on background variables and measures at initial interview

Variable	Non-clinical control group Mean (SD)	Bipolar disorder group Mean (SD)	Non- clinical control group Median (range)	Bipolar disorder group Median (range)	U- statistic	Significance
Age	23 (5.99)	47.7 (9.37)	22 (26)	48 (30)	236.5	p < .001
Years of education	15.4 (1.82)	16.0 (2.41)	14 (5)	16 (10)	147.5	NS
BAI score	4.4 (2.7)	12.7 (9.6)	4 (9)	12.5 (34)	187	p = .008
BDI-II score	4.9 (3.01)	16.3 (9.6)	4.5 (11)	18 (29)	207	p = .001
Internal State Scale Activation score	104 (97.8)	148.3 (149.1)	65.0 (390)	115 (410)	130	NS

Table 9. *Group comparisons on diary measures*

Variable	Non-clinical control group Mean (SD)	Bipolar disorder group Mean (SD)	Non- clinical control group Median (range)	Bipolar disorder group Median (range)	U- statistic	Significance
Sleep quality	5.52 (1.16)	5.76 (1.6)	5.6 (4.6)	6.0 (4.8)	144	NS
Mood rating	1.97 (2.07)	1.89 (3.0	1.7 (7.6)	1.3 (11)	110.5	NS
Anxiety rating	1.75 (1.15)	2.85 (1.7)	1.8 (4.3)	2.9 (6.1)	170	p = .053
Activity rating	3.48 (1.45)	3.46 (1.9)	3.7 (5.4)	3.0 (6.4)	108	NS
Frequency of verbal thoughts	2.79 (1.9)	2.34 (1.64)	2.25 (6.6)	2.5 (5.3)	106	NS
Frequency of mental images	2.24 (1.46)	2.79 (1.62)	1.93 (5.8)	2.21 (4.4)	139	NS
Intensity of verbal thoughts	3.89 (1.67)	5.08 (2.04)	4.23 (5.8)	5.21 (6.9)	157	NS
Intensity of mental images	3.39 (1.52)	5.42 (1.21)	3.23 (5.6)	5.46 (4.1)	206	<i>p</i> <.001
Vividness of verbal thoughts	4.52 (2.19)	4.99 (2.3)	4.54 (8.6)	4.42 (7.0)	128	NS
Vividness of mental images	4.15 (1.89)	5.62 (1.2)	4.16 (7.4)	5.75 (4.1)	183	p =.013

Importance of verbal thoughts	4.73 (1.71)	5.14 (2.04)	4.78 (6.5)	5.40 (6.6)	133	NS
Importance of mental images	4.03 (1.92)	4.89 (1.1)	4.02 (5.8)	4.85 (3.8)	152	NS
Relevance of verbal thoughts to current goals	4.3 (1.54)	4.64 (1.8)	4.23 (6.1)	4.65 (6.1)	135	NS
Relevance of mental images to current goals	3.57 (1.66)	3.94 (1.1)	3.61 (5.5)	3.89 (3.4)	132	NS
Valence of verbal thoughts	1.74 (1.65)	1.34 (3.0)	1.35 (6.3)	1.36 (9.8)	105	NS
Valence of mental images	1.96 (1.47)	1.33 (3.0)	1.8 (4.8)	0.6 (10.1)	94	NS
Similarity of verbal thoughts	4.31 (1.85)	4.63 (2.1)	4.45 (6.7)	4.97 (6.7)	133	NS
Similarity of mental images	3.8 (1.67)	4.78 (1.8)	3.74 (5.4)	4.83 (6.0)	155	NS

Table 10. *Group comparisons on measures at final interview*

Variable	Non-clinical control group Mean (SD)	Bipolar disorder group Mean (SD)	Non- clinical control group Median (range)	Bipolar disorder group Median (range)	U- statistic	Significance
Sleep representativeness rating	7.3 (1.9)	8.08 (1.44)	8.0 (6)	8.5 (5)	151.5	NS
Mood representativeness rating	7.55 (1.7)	8.33 (2.01)	8.0 (6)	9.0 (7)	158.0	NS
Anxiety representativeness rating	7.8 (1.9)	7.17 (2.6)	8.0 (6)	8.0 (7)	105.0	NS
Activity representativeness rating	7.85 (1.6)	7.75 (2.01)	8.0 (6)	7.5 (5)	117.0	NS
Frequency of verbal thoughts representativeness rating	8.4 (1.6)	8.08 (2.02)	8.5 (6)	8.5 (7)	115.5	NS
Frequency of mental images representativeness rating	8.8 (1.2)	7.83 (2.29)	9.0 (3)	8.5 (7)	94.0	NS
Intensity of verbal thoughts representativeness rating	8.3 (1.6)	8.17 (2.29)	8.0 (6)	9.0 (8)	127.5	NS
Intensity of mental images representativeness rating	8.6 (1.6)	8.75 (2.01)	9.0 (5)	9.0 (7)	133.5	NS

Vividness of verbal thoughts representativeness rating	8.5 (1.3)	8.0 (2.73)	8.5 (4)	9.0 (8)	130.0	NS
Vividness of mental images representativeness rating	8.3 (1.3)	8.1 (2.3)	8.0 (4)	8.5 (8)	125.0	NS
Life events in past week	0.45 (0.6)	0.75 (0.97)	0 (2)	0.5 (3)	137.5	NS
Life events in past month	0.95 (1.3)	1.25 (1.7)	0 (4)	0.5 (5)	128.5	NS
Estimated percentage of all thoughts and images recorded	63.1 (24.3)*	59.58 (27.3)	60.0 (90)	65.0 (95)	110.0	NS
441 40 1				44.4		

^{*}N = 19, since one participant was unable to provide an estimate for this measure

Among the total recruited bipolar disorder group, twelve participants met criteria for a diagnosis of bipolar I disorder and three met criteria for bipolar II disorder³. Five met criteria for PTSD. Of the twelve completers, one met criteria for bipolar II disorder, and 11 for bipolar I disorder. Three participants met criteria for PTSD. Of the completers, two reported symptoms consistent with a current episode of depression, and one with a current episode of hypomania. Table 11 presents data on time since diagnosis (months), number of inpatient admissions, months since first, and last, episodes of depression and (hypo)mania, and mean BAI, BDI-II and Internal State Scale Activation scores. The data are presented separately for completers and non-completers. All participants with bipolar disorder reported that they were currently taking some form of psychoactive medication to manage their symptoms with the exception of one.

Table 11.

Diagnosis-related information for participants in the bipolar disorder group, with data for study completers and non-completers presented separately

	Completers	Non-completers
	(N=12)	(N=3)
Mean (SD) time since diagnosis (months)	195.0 (110.9)	268.0 (234.0)
Mean (SD) total episodes of depression	16.0(16.26) *	26.7 (22.5)
Mean (SD) total episodes of (hypo)mania	10.09 (7.77) †	20 (26)
Mean (SD) number of inpatient admissions	4.0 (3.3)	11.3 (8.5)
Mean (SD) time since last episode of depression	5.42 (5.9)	16 (15.1)
(months)		
Mean (SD) time since last episode of (hypo)mania	17.42 (23.7)	14.0 (13.9)
(months)		
Mean (SD) time since first episode of depression	333.6 (124.0) *	368.0 (123.2)

(months)		
Mean (SD) time since first episode of (hypo)mania	258.3 (127.9)	368.0 (123.2)
(months)		
Mean (SD) BAI score	12.67 (9.6)	16.7 (1.5)
Mean (SD) BDI score	16.3 (9.6)	11.3 (3.8)
Mean (SD) Internal State Scale Activation score	148.3 (149.1)	96.7 (89.6)

^{*} N = 10; † N = 11

Between-group comparisons of frequency and intensity of intrusive verbal thoughts and mental imagery

The main hypotheses were of significantly more frequent and intense experiences of intrusive mental imagery in the bipolar disorder group compared to controls, but no significant differences between groups on frequency or intensity of verbal thoughts. Tests of normality and visual inspection of the data indicated that data were relatively normally-distributed. Levene's test indicated homogeneity of variance in all cases (all p>.246). Mann-Whitney tests on frequency (mean number per half-day) and intensity (mean rating on a scale of 0-10) of verbal thoughts and mental images between groups indicated that individuals in the bipolar disorder group experienced mental images as significantly more intense (median=5.46, range=4.1) compared to controls (median=3.23, range=5.6), U=206, Z=3.348, p<.001. The effect size indicated a large effect (*r*=0.59). There were no significant differences in frequency of verbal thoughts for controls (median=2.25, range=6.6) versus the bipolar group (median=2.5, range=5.3), U=106, Z=-.545, p=.604, intensity of verbal thoughts (median controls=4.23, range=5.8; bipolar disorder group median=5.21, range=6.9), U=157, Z=1.44, p=.158, or for frequency of mental images (control group median=1.93, range=5.8; bipolar disorder group median=2.21, range=4.4), *U*=139, *Z*=.74, *p*=.477.4

Post-hoc analysis, using Wilcoxon signed-ranks tests of within-group differences revealed no significant differences for either group in frequency of verbal thoughts versus mental images, or intensity of verbal thoughts versus mental images (all *p*>.05).

Ability to report on experiences of intrusive verbal thoughts and mental images as they occurred

All 20 participants recruited into the non-clinical control group completed the study. However, three of the fifteen participants in the bipolar disorder group were unable to complete the study. Reasons given by non-completers included forgetting to complete the diary, finding the diary difficult to fit into a busy daily routine, and finding the

98

⁴ T-tests performed on the same data resulted in identical outcomes

requirements of the study too demanding. No participant mentioned feeling unable to identify intrusive thoughts or images or write about them. All participants were able to identify both verbal thoughts and mental images, suggesting that these were universally experienced and identified, and all participants were able to report on them using the diary measure. The maximum possible number of diary entries was 14 (i.e. entries twice daily, for 7 days). The mean number of complete entries per participant was 13.4, with a minimum of 11. Reasons for incomplete data included forgetting and not saving data on the website before logging-off.

Discussion

The study explored everyday experiences of intrusive mental imagery and verbal thoughts in individuals with bipolar disorder and non-clinical controls. It was anticipated that individuals with bipolar disorder would experience more frequent and more intense intrusive mental imagery compared to controls, but that groups would not differ significantly on frequency or intensity of intrusive verbal thoughts. The findings generally supported this hypothesis: intensity ratings for mental imagery were significantly higher in the bipolar disorder group, and there were no significant differences between groups in frequency or intensity of intrusive verbal thoughts.

The findings lend some support to Holmes et al's (2008) assertion that mental imagery is important in bipolar disorder (i.e., increased 'imagery susceptibility'; Holmes et al, 2008): it would appear at least that the subjective experience of intensity of mental imagery in bipolar disorder differs from that of non-clinical controls. Further support for Holmes et al's model comes from the finding that 'vividness' (a separate, but related measure) of mental imagery was rated higher in the bipolar disorder group compared to controls. The significant differences between groups in intensity and vividness of mental imagery held despite the majority of participants not meeting criteria for a current episode of (hypo)mania or depression. This would accord well with Holmes et al's (2008) assertion that mental imagery could impact upon shifts in mood in terms of both development of hypomania, for example, but also in more subtle mood instability during periods of euthymia. However, these findings should be treated with caution given the small sample-size of the clinical group in particular.

The findings were not entirely consistent with previous studies which have reported greater general use of imagery and more frequent intrusive imagery in individuals with bipolar disorder compared to those without (e.g., Holmes et al, 2011, Hales et al, 2011). One possible explanation is that the present study was not sufficiently powered to detect group-differences in frequency of mental imagery, due to the small sample-

size of the clinical group. Post-hoc power calculations suggested that group sizes would need to be much larger for detection of a medium-large effect, in contrast the large effect for group differences in intensity of mental imagery, which was present with just 12 participants in the bipolar disorder group.

Another possibility could be that previous studies have picked-up on experiences of more frequent mental imagery in episodes of (hypo)mania and/or depression. Retrospective studies may lack the sensitivity to distinguish between different mood states in bipolar disorder, especially where questionnaire measures such as the SUIS are used and participants are not instructed to consider their experiences for one particular mood state (e.g. euthymia). This idea would accord well with verbal feedback from participants in the bipolar disorder group at debrief, who generally commented that they experienced more frequent mental imagery in periods of (hypo)mania in particular, and may also be supported by the finding that there were no significant group differences in number of life events or sleep quality ratings, which may have been associated with relatively stable mood in the bipolar disorder group.

Finally, the present study did not explore aspects of intrusive mental images such as perspective (i.e., field-versus-observer), which is considered relevant to strength of emotional response to the image (e.g. Holmes & Matthews, 2008), or whether the image was past- or future-related: some studies demonstrated a higher frequency of future, goal-related imagery in individuals with bipolar disorder during depressed or (hypo)manic episodes (e.g. Gregory et al, 2010). Therefore, the possibility that the bipolar disorder group experienced a higher frequency of a particular type of intrusive mental image should not be discounted.

The outcomes of the post-hoc analyses for within-group differences in the frequency of verbal thoughts-versus-mental imagery, and intensity of verbal thoughts-versus-mental imagery, were perhaps surprising given previous findings suggesting a more 'imagery-based processing style' in individuals with bipolar disorder (Holmes et al, 2011) and experiencing mental images as 'more powerful' than verbal thoughts (Ivins et al, 2014). The same possibilities as outlined above may apply here.

The study also set-out to explore whether individuals with bipolar disorder are able to report on everyday experiences of intrusive verbal thoughts and mental images using a diary. The findings indicate that this is possible, given that the majority of participants were able to complete the study. The researcher (RO-C) who conducted interviews noted that all participants reported an intuitive understanding of intrusive verbal

thoughts and mental images, and generally required minimal additional instructions in order to complete the diary. However, two issues should be raised. First, estimates of the percentage of all thoughts and images participants had been able to record varied significantly, from 5-100% (although estimates did not differ significantly between groups). Therefore, it is possible that such a task is more difficult for some individuals than others. Second, it was the lead researcher's experience that participants in the bipolar disorder group struggled more than controls to consistently complete the diary, and many needed additional support and prompting. Therefore, researchers interested in exploring these phenomena in naturalistic settings in the future may wish to consider methods for supporting participants to complete the diary regularly (e.g., reminders, telephone support). The clinical implications of this finding are that it appears possible to support individuals with bipolar disorder to recognise and record intrusive mental imagery, and this could represent a feasible treatment target, although increased support to complete diaries may be required in the face of unpredictable schedules and, for some, low mood.

It should be noted that there were a number of limitations associated with the main findings that may reduce their generalizability. First, the sample-sizes were relatively small. As mentioned above, this could mean that the study was not sufficiently powered to detect a group-difference in frequency of mental imagery. However, the estimated size of each group needed to detect a medium-sized effect for this measure was 206 - a sample-size well beyond the scope of the present study. Second, the groups differed in a number of ways, including age, employment status, marital status and levels of depression and anxiety. Some of these differences would be expected. for example higher levels of depression and anxiety in individuals with a diagnosis of bipolar disorder, but others meant the groups were less comparable to begin with. These differences could have impacted on the outcomes of interest, and this possibility could have been averted if matched controls had been recruited. The use of an online screening questionnaire could have aided the recruitment of a matched control sample. Third, the study did not include a clinical control group. Some previous studies have included a sample with unipolar depression, which allowed for the demonstration of a more unique association between bipolar disorder and particular aspects of mental imagery. Fourth, a twice-daily diary measure was utilised to obtain data on participants' everyday experiences of intrusive thoughts and imagery. Other studies have utilised ecological momentary assessment (e.g. Kleim et al, 2013), where participants record their experiences as soon as they occur throughout the day, or an experience sampling approach (e.g. Gruber, Kogan, Mennin & Murray, 2013), where participants are prompted at random or quasi-random intervals to complete measures. Some benefits

of such alternative approaches could be the further minimisation of recall bias and elimination of problems with remembering to complete the diary at pre-specified intervals. For the purposes of the current study, twice-daily recording was utilised in an attempt to reduce demands on participants and therefore increase the likelihood of obtaining complete responses. However, future studies could consider utilising alternative approaches to data collection such as those mentioned above to gather data on everyday experiences of intrusive thoughts and imagery in this population. Fifth, participants in the bipolar disorder group were generally euthymic at the initial interview before completing the diary. However, one participant was experiencing hypomania and two participants met criteria for current depression. Since the SCID-I interview, Internal States Scale and BDI-II were completed only at the first interview, it was not possible to determine whether these participants experienced depression or hypomania throughout the course of the study, or indeed whether the mood status of any participant had changed over the course of the study. Mood status could have been assessed by repeated use of the Internal States Scale or BDI-II over the course of the study. In addition, further analyses could perhaps have assessed within-group differences in diary measures according to current mood state (i.e., ethymia, depression or mania). Finally, participants were not asked to provide data on whether the images or thoughts were present, past, or future-related. Previous theories have made explicit links between goal-attainment and mood elevation in bipolar disorder. The present study is unable to make any contributions to this aspect of the literature.

In summary, these findings provide some support for the idea that mental imagery could be important in bipolar disorder presentation, perhaps by acting as an 'emotional amplifier', as outlined in the cognitive model of Holmes et al (2008). Specifically, in a week-long diary in which participants recorded intrusive mental imagery and rated this on a number of dimensions, intensity of mental imagery was significantly greater in participants with bipolar disorder compared to controls. The study also demonstrated that individuals with bipolar disorder are able to report on everyday experiences of intrusive verbal thoughts and mental imagery in a diary.

Future studies could extend the present findings by exploring the temporal relationships between mood and intrusive imagery, by attempting to identify experiences of particular classes of intrusive mental image (e.g. field-versus-observer perspective; future-versus-past), by including a clinical control group (e.g. participants with unipolar depression) to explore the specificity of this effect to individuals with bipolar disorder and, finally, by including a larger sample of individuals with bipolar disorder and a matched non-clinical control group.

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Executive summary of research paper (525 words)

Bipolar disorder involves periods of intense low mood (depression) and elevated mood (mania), together with periods of relatively stable mood (euthymia).

Research has suggested that 'intrusive cognitions' ('mental events' that occur without intention or deliberation) might play a role in the development and maintenance of an episode of elevated or depressed mood in bipolar disorder.

Specifically, some studies have shown that people with bipolar disorder experience more frequent and intense intrusive 'mental imagery' compared to people with no mental health conditions, or people with a diagnosis of depression. This has led to the development of a theory by Emily Holmes and colleagues (2008) which suggests that intrusive imagery might have a role in the development and maintenance of episodes of mania and depression in bipolar disorder, and shifts in mood during periods of euthymia, by 'amplifying' existing emotions.

Researchers interested in these 'intrusive cognitions' have generally asked people to report on their past experiences (retrospective recall). This approach is potentially problematic because people's memories for past experiences of intrusive cognitions might be affected by how they are feeling when they are asked, how long ago the experience happened, and what has happened since.

Another problem with 'retrospective recall' is that it doesn't allow us to understand whether mental imagery leads to, or exacerbates, symptoms in bipolar disorder, or whether mental imagery happens as a result of bipolar disorder.

This study assessed the everyday occurrence of intrusive verbal thoughts and mental images in individuals with bipolar disorder, as well as 'controls' (people who did not have bipolar disorder). Participants were recruited from the general public and NHS sites in the South West of England by written advertisements and clinician-referrals. A diary method was used, with people recording their verbal thoughts and mental images twice-daily for one week on paper or via a website.

It was anticipated that people with bipolar disorder would experience more frequent and more intense mental imagery compared to controls, but that the groups would not differ on the frequency or intensity of their experiences of intrusive verbal thoughts. Twenty individuals with no mental health condition and twelve participants with a diagnosis of bipolar disorder completed the study. The results were partially consistent with the predictions: people with a diagnosis of bipolar rated their experiences of mental imagery as more 'intense', and also more 'vivid'. They did not report more frequent or intense experiences of intrusive verbal thoughts, or more frequent mental imagery.

The findings provided some support for the idea that mental imagery could act as an 'emotional amplifier' in bipolar disorder, being experienced as more intense and thus having a greater potential to impact on feelings and behaviour as a result.

This has implications for psychological interventions for bipolar disorder symptoms, which could include a greater focus on experiences of – and responses to – mental imagery, in order to attempt to reduce their impact on shifts in mood. In addition, the findings provided evidence that people are able to report on their everyday experiences of mental imagery. Future studies should follow-up these findings to further test the idea that mental imagery could lead to or escalate changes in mood in bipolar disorder.

Narrative overview

Word count: 2,073

I entered training with a very narrow research background, in 'eating behaviour', having completed my BSc and PhD research in this field. I remain passionate about this topic. However, I realised there would be limited chances to advance my knowledge in completely different research fields, and saw my DClinPsy training as a great opportunity for this. I hoped to develop additional research interests. I also imagined that I might gain alternative perspectives and approaches to bring to my research in the field of eating behaviour. Therefore, each project I undertook focused on a different clinical area – older adults (service improvement project), mental health in an adult population (major research project), and mental health in children and adolescents (literature review).

There were, I think, a number of benefits to pursuing three unrelated projects. First, I developed an understanding of some of the outstanding questions and current literature in three fields that were completely new to me. Although my knowledge in each remains limited, I am pleased that I have broadened my outlook in this way. Second, I have been able to appreciate the crossover and similarities across different fields. For example, in completing my service improvement project, I began to appreciate that a service's communications with its service users are very difficult to manage in a 'one-size-fits-all' way, which can be problematic where services are communicating largely via written information. I have more recently been able to think about how this could apply in another area, the specialist eating disorder service where I am currently on placement, where I have been helping the service to consider its written communications with service users. More broadly, I think that I am now more aware of the need to balance generous information provision with a tailored, personalized approach, particularly where this may involve sensitive or challenging topics for a service user. Similarly, completing a project exploring mental imagery in bipolar disorder opened my awareness to other areas in which imagery could represent a useful target for intervention – and perhaps deserves further research. Finally, I became more aware of differences between fields, such as a greater use of disordergeneric treatment approaches to anxiety presentations in children and adolescents, while disorder-specific approaches are more commonly utilised in adult populations.

In addition to the benefits I derived from undertaking three unrelated research projects within my training, there were also some challenges in taking this approach. First, the depth of my knowledge in each area feels very limited, due to the limited time I could

spend immersing myself in each literature. I have found this very uncomfortable at times, particularly when formulating my research questions, working toward ethical approval, and preparing the final written reports. This was a very different experience to my PhD research, where I felt much more immersed in the research literature throughout. Although I had always anticipated that having completed a PhD could only be a positive thing in terms of completing the research component of this training, it was in these aspects that I feel it may have been positively unhelpful. For example, the high standards I held around the depth of knowledge I needed to have for each project probably meant that I often felt unable to judge my work as 'good enough', and as a result spent more time than necessary putting together proposals and ethics panel applications. In the future, I would be inclined to lower my standards, having had the experience that when I had no choice but to submit something that I had not been able to prepare for as much as I'd have liked due to limited resources, the outcomes were often positive.

I will now discuss the development and implementation of the different projects reported in this portfolio in turn.

Literature review

Disorder-specific versus disorder-generic approaches to the treatment of anxiety disorders in children and adolescents

This project arose mainly out of a desire to gain some child and adolescent research experience. In the end, I found this one of the most enjoyable and rewarding projects. I was lucky to have an excellent, enthusiastic, and consistent supervisor in Maria Loades, who was extremely supportive of my clumsy attempts to determine a research question initially and helped me to develop skills in prioritization and breaking-down tasks into more manageable chunks. As a result, this was one of the first projects I completed. We quickly wrote the project up for submission to a journal, although we have not yet had the article accepted for publication. However, I am keen to continue to pursue publication of this review. I very much enjoyed the process of developing my research question and assimilating the information for the review, although I found conducting the literature search more challenging as it required a great deal of time and patience – and meticulous recording of searches. I would feel more confident to approach a critical review of the literature again in the future, however, and I now have a greater appreciation of the time and effort that goes into the process of conducting a systematic review.

Service improvement project

Provision of written information in a memory service

The service improvement project developed more 'organically' than the other research projects contained in this portfolio, and the subject had a great deal of personal meaning for me. The topic for the project arose from a memory service team meeting I attended while on my 'older adult' mental health placement in the first year of training. The team were debating the memory service's provision of written information, with some team members suggesting that service users felt overwhelmed by the quantity of information they received, and others arguing for the inclusion of additional information. I was fortunate to have a supervisor on this placement who was supportive of research, and she and another clinical psychologist in the team brought a great deal of time and enthusiasm to promoting and recruiting for the project. Alongside the development and implementation of this research, both of my grandfathers were diagnosed with dementia. I was aware of the stigma felt acutely by my grandmother in particular, after my paternal grandfather passed away. My grandmother was keen for me to provide reassurance that other people had not recognised my grandfather's rapid cognitive decline as 'dementia'. I also became aware of my mother's view that my maternal grandfather's dementia was considered a 'mental illness' (i.e., functional in nature, rather than 'organic'). I think these personal experiences particularly impacted on my consideration of these issues in the discussion section of my service improvement project, and gave me a greater insight into the different and complex ways that stigma and misunderstandings about dementia can impact on people with dementia and their loved ones. This project was the first opportunity I have had to employ qualitative data analysis. I enjoyed the greater freedom the method allowed me, to more fully represent different views and follow-up on unanticipated outcomes (e.g. the comments by some of the service users about their dislike of particular terms such as 'Alzheimer's' and 'Dementia').

Major research project

Everyday experiences of intrusive verbal thoughts and mental images in individuals with a diagnosis of bipolar disorder

On reflection, I think that a number of factors led me to undertake a main research project in this area. I had no direct experience of working with an individual with a diagnosis of bipolar disorder, and was keen to have the opportunity to improve my understanding in this area. In addition, my supervisor's views on the likely importance of mental imagery in bipolar disorder made intuitive sense to me. Finally, I noted that my supervisor had a great deal of enthusiasm for the subject, which I know can help me to maintain motivation in the face of adversity, such as when ethics or recruitment

hit snags. In hindsight, I am very glad that I made this choice, since there were a number of fairly large snags along the way! First, the process of applying for NHS ethical approval through IRAS was initially delayed by a change in the university's provice chancellor and then a long wait for a panel meeting. Although the remainder of the process was relatively smooth, we next hit a major snag in terms of recruitment, with a six-month delay between applying to recruit participants with bipolar locally, through an NHS trust's 'Everyone Included' scheme (which advertises research studies directly to patients who meet referral criteria) and commencement of recruitment due to commissioning issues, and then a request to make a substantial amendment to ethics in order to send the recruitment letter initially. We also came to a complete 'dead end' when attempting to recruit through the charity Bipolar UK's support groups. The project received some great support from an interested clinician in Birmingham. Despite visiting one support group in Birmingham and advertising at two others, attempts to recruit in this way were largely unsuccessful, and although I received a few more respondents from local CMHTs thanks to some really supportive local clinicians who raised the profile of the study among patients and colleagues and displayed posters in their waiting rooms, the numbers were still very low. Indeed, the most successful recruitment approach was through Everyone Included, which only began in late April 2016. Therefore, while I had a sample of 20 people in the 'non-clinical control' group by early February 2016, recruitment to the bipolar disorder group was much more of a challenge and required a huge amount of time and perseverance. I often wondered, in the worst moments, what I might have done differently if I had the opportunity. At these times I berated myself for choosing such an involved study with high demands on the participants, for conducting research with a difficult-to-reach group, and individuals with a relatively uncommon diagnosis, relative to rates of unipolar depression or some anxiety disorders, for example. However, I do feel very glad that I chose the project. Although it was extremely hard work, I learned a great deal about the process of obtaining NHS ethical approval for research, recruiting through the NHS, promoting research among clinicians and other NHS and charity staff, and - not least - skills in self-preservation! This last discovery came a bit later, but allowed me to keep going without burning out by becoming more selective about my methods of recruitment and subtly altering my rather apologetic and subtle approach to communication around recruitment where necessary. Although it was tough, I would jump at the chance to do it again, and particularly to be involved in data collection, which I thoroughly enjoyed. Finally, the project was supported by a number of individuals, some of whom I would like to mention specifically here. I was extremely lucky to benefit from the input of Dr Warren Mansell (University of Manchester), and to have the support with recruitment (as well as with many aspects of the research process and personal impact of research and training) of my fellow trainee, Rose Knight. In addition, I had the support of a brilliant and highly motivated undergraduate research assistant, Andrea Pintos, with the data inputting and website set-up for the project. In the initial phase of development, I received input from an individual with personal experience of bipolar disorder whose comments helped to shape the study design and research questions. I was also very lucky to have the support of two clinicians in particular, Dr Kian Vakili and Dr Chris Gillmore, whose efforts had a tremendous impact on the initial recruitment of participants with bipolar disorder. These sources of support, in addition to the unwavering support and enthusiasm of my main supervisor, James Gregory, were absolutely crucial to the project, and are addressed more thoroughly in the acknowledgements section of this portfolio.

Plans for future research

I had always intended to continue doing research once qualified. This remains my intention, despite the challenges involved in conducting research in the NHS. I have already begun to think about the forms this might take, the methods, and the questions. For now I have only vague plans, but I anticipate that future research endeavours will include many more service-related projects (e.g. audits, service development), dissemination of clinical work (e.g. case reports, case series, and reflective articles) and hopefully also some larger-scale research projects. I very much hope that research will always be a central element of my work in the future, and I hope that my passion for conducting research is clear to the reader of this portfolio.

Acknowledgements

I am so grateful to my wonderful friends and family, and Alex, for their love and support. I couldn't have done it without them. I feel very lucky to have been through training with an extremely supportive and cohesive group of fellow trainees. I am also fortunate to have had the guidance of some inspiring supervisors on each of my six placements. Through supervision in this context I have been able to improve my confidence and skill as a practitioner by facing challenges and testing things out in a safe and supportive environment as well as building my awareness of the things I tend to struggle with. The supervision I have received from members of the course team in relation to my projects has also been invaluable, and I am particularly grateful to Maria Loades and James Gregory for helping me to develop an insight into the ways of working that are most suited to me, and for helping me to notice the pitfalls of excessively high standards for achievement. There are a few other individuals whose contribution I would like to acknowledge here. For the past 9 months I have benefitted from the support of an excellent mentor, Will Devlin, whose words of wisdom and kindness have been invaluable to me. I am also very grateful for the support of Dr Warren Mansell with the development and realisation of my main research project. In addition, I would like to acknowledge Andrea Pintos, a committed and excellent undergraduate research 'apprentice' who contributed to the website development and data inputting for the project. Finally, I would like to extend a huge thank you to all the service users, staff, and individuals with personal experience who contributed in different ways to the various pieces of work contained within the three portfolios submitted.

Appendices

Appendix A. Search terms used, by database

Database	Inclusion terms	Exclusion terms
Science direct	Keyword: treat* OR therap*	Title: OCD OR PTSD OR
	OR psycholog*	depression OR ADHD
	Keyword: anx*	Title: adult*
	Child* OR adolecscen*	
	GAD OR social OR	
	separation OR phobia	
	Human	
	"School age (6 to 12 yrs)"	
	OR "Adolescence (13 to 17	
	yrs)"	
	Empirical study	
	Treatment outcome/ clinical	
	trial	
	Psychology	
	Peer reviewed journal	
APA Psychnet	Keyword: treat* OR therap*	Title: OCD OR PTSD OR
	OR psycholog*	depression OR ADHD
	Keywords: Anx*	Title: adult*
	Child OR adolescen*	
	GAD OR separation OR	
	social OR phobia	
	Peer reviewed journal	
	Population group: "Human"	
	Age group: "School age (6	
	to 12 yrs)" OR	
	"Adolescence (13 to 17	
	yrs)"	
	Methodology: "empirical	
	study"	
	Methodology: "treatment	
	outcome/ clinical trial"	



Staff information sheet: Written information provision in the North Somerset memory service

The North Somerset memory service would like to hear your opinions on the written information it provides.

You have been asked to take part because you are a member of staff working in the memory service.

In order to explore your opinions, you are invited to take part in a focus-group.

Whether or not you take part is your choice.

If you don't want to take part, you don't have to give a reason, and it won't affect any aspect of your work.

If you do want to take part now, but change your mind later, you can withdraw from the study at any time.

The main investigator is Rosie Oldham-Cooper, a trainee clinical psychologist at the University of Bath. Rosie was previously on placement in the North Somerset memory service. Rosie is supervised by a course tutor at the University of Bath, Dr Josie Millar, and also by Dr Laura Smart and Dr Kim Hartland who work as clinical psychologists in the North Somerset memory service.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. You do not have to decide today whether or not you will participate.

This document is 2.5 pages long. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

- The North Somerset memory service would like to find out about the views of its staff on the written information it provides
- We would like to improve the written information, to give people the best service possible

WHO CAN TAKE PART?

- You have been invited to take part because you are a member of staff
- You must be aged 18 or over to take part, but there is no upper age boundary
- You must understand what is being asked of you in order to give your consent to take part. If you have any doubts about this, please contact the investigator before making your decision to take part

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

- The first step in taking part would be to contact the investigator to express your interest
- When the investigator finds out that you are interested in taking part, she
 will give you an opportunity to ask questions, and you will be invited to a
 focus-group, held at Windmill House, Clevedon
- The focus-group will involve up to 5 other staff members, and will last no longer than 90 minutes. Tea, coffee and biscuits will be provided
- You will be asked to discuss your views on the written information the memory service provides for its service users with the other attendees
- We will ask some general questions to get conversations going
- The investigator and a member of the memory service staff will be in the room
- They will be listening to your ideas and feelings. We welcome both
 positive and negative comments your honest opinion is really
 important, so that we can make the service as helpful as possible for
 service users in the future
- The discussion will be recorded and later transcribed by the investigator
- The information you provide would be anonymised. This means that your responses could not be linked to your name or any other information that could identify you

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

- We feel that it is really important to get the views of staff members. However, some people might feel uncomfortable talking about their opinions in this sort of setting. Although the information you give would be anonymized, so that when the findings are written up there will be no information to link you with your comments, you may still prefer not to take part. We respect this position, and would encourage you to think carefully and contact the investigator if necessary before taking part.
- Some people might feel that a benefit of taking part would be the potential improvements to the written information provided as a result of the study
- Another possible benefit is having the opportunity to spend time reflecting on your own views and experiences with members of your team.

WHO PAYS FOR THE STUDY?

 The costs associated with the study will be covered by the University of Bath

WHAT ARE MY RIGHTS?

 Your participation would be voluntary, and you have the right to decline to participate, or withdraw from the study at any time, until the end of the

- study period. However, we could not remove you from the study after you had taken part in a focus-group, because the link between your name and the comments you made would have been removed.
- Choosing not to participate, or withdrawing from the study at any point would not affect your treatment as a member of staff in the service in any way
- You will be fully debriefed about the aims of the study immediately after the focus-group, both verbally and in writing
- You will also receive a copy of a full report on the findings after the study has ended

WHAT HAPPENS AFTER THE STUDY?

- The discussions you have in the focus-group will be recorded and transcribed. The audio recording would be destroyed, and the written transcription would be stored securely at the University of Bath for up to 3 years, with Dr Josie Millar (University of Bath). This written record would not contain participants' names or any identifying information about you. After this time the written record would also be destroyed
- The findings will be written up in a report for the memory service, and also for Rosie Oldham-Cooper's doctoral thesis. Eventually, it is hoped that the findings would be published in an academic journal. No information that identifies you as a participant would be included in any of these written reports.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact the lead investigator:

Dr Rosie Oldham-Cooper, Clinical Psychologist in training

Address: Department of Clinical Psychology, Claverton Down Road, Bath, North East Somerset BA2 7AY

Email: r.oldham-cooper@bath.ac.uk

Or you could contact Dr Laura Smart or Dr Kim Hartland, N Som memory service



Service user information sheet: Written information provided by the North Somerset memory service

The North Somerset memory service would like to hear **your** opinions on the **written information** it provides.

This includes people who have recently been diagnosed with a dementia, their family members, their carers, or their friends.

Whether or not you take part is **your choice**.

If you don't want to take part, you don't have to give a reason, and it won't affect your treatment.

If you do want to take part now, but change your mind later, you can withdraw from the study at any time.

The main investigator is Rosie Oldham-Cooper, a trainee clinical psychologist at the University of Bath. Rosie was previously on placement in the North Somerset memory service. Rosie is supervised by a course tutor at the University of Bath, Dr Josie Millar, and also by Dr Laura Smart and Dr Kim Hartland who work as clinical psychologists in the North Somerset memory service.

This Participant Information Sheet will help you decide if you'd like to take part. It says why we are doing the study, what taking part would involve, what the benefits and risks might be, and what would happen next.

You do not have to decide today whether or not you will participate. Before you decide you may want to talk about the study with other people, such as family, friends, or healthcare providers.

This document is 3 pages long. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

- The North Somerset memory service would like to find out about the views of its service users on the written information it provides
- We would like to improve the written information, to give people the best service possible

WHO CAN TAKE PART?

You have been invited to take part because you are a service user

- The term 'service user' means anyone who uses the North Somerset Memory Service
- This includes people with memory problems (patients of the service) and also their family members, friends and carers, provided they attended the appointments too
- You must be aged 18 or over to take part, but there is no upper age boundary
- You must understand what is being asked of you in order to give your consent to take part. If you have any doubts about this, please contact the investigator before making a decision

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

- When the investigator finds out that you are interested in taking part, she
 will give you an opportunity to ask questions, and you will be invited to a
 focus-group, held at Windmill House, Clevedon
- The focus-group will involve up to 5 other service users, and will last no longer than 90 minutes. Tea, coffee and biscuits will be provided.
- We believe it is really important to get the views of all types of service user – patients, carers, family members and friends. This will mean that your focus-group is likely to include different sorts of service users.
- You will be asked to discuss your experiences of receiving written information from the memory service with the other attendees
- We will ask some general questions to get conversations going
- The investigator and a member of the memory service staff will be in the room
- They will be listening to your ideas and feelings. We welcome both positive and negative comments – your honest opinion is really important, so we can make the service as helpful as possible in the future
- The discussion will be recorded and later transcribed by the investigator
- The information you provide would be anonymised. This means that your responses could not be linked to your name or any other information that could identify you

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

- Some people might find it difficult to share their experiences in a focusgroup.
- Some patients may choose to attend with a family member, friend, or carer. This is fine, as long as both people have attended the appointments. However, some people may find it difficult to talk about some things in front of their loved ones.
- Some people might also feel that the diagnosis of dementia occurred too recently for them to feel able to talk about their experiences just yet.
- If you have concerns about any of the above, you might want to spend some time thinking about whether you would like to take part, or contact the investigators to discuss this further.

- Some people might feel that a benefit of taking part would be the potential improvements to the written information provided by the memory service in future.
- Another possible benefit is having the opportunity to talk about your experiences with other people who had similar experiences.

WHO PAYS FOR THE STUDY?

- The costs associated with the project will be covered by the University of Bath
- You will be reimbursed for your travel expenses

WHAT ARE MY RIGHTS?

- Your participation is voluntary, and you have the right to decline the invitation to take part, or withdraw from the project at any time, until the end of the study period. However, we could not remove you from the study after you had taken part in a focus-group, because the link between your name and the comments you made would have been removed.
- Choosing not to participate, or withdrawing from the study at any point would not affect the service you receive in any way.
- You will be fully debriefed about the aims of the study immediately after the focus-group, both verbally and in writing
- You may also opt-in to receive a short written summary of the outcomes of this project after the study has ended

WHAT HAPPENS AFTER THE STUDY?

- The discussions you have in the focus-group will be recorded and transcribed. The audio recording would be destroyed, and the written transcription would be stored securely at the University of Bath for up to 3 years, with Dr Josie Millar (University of Bath). This written record would not contain participants' names or any identifying information about you. After this time the written record would also be destroyed
- The findings will be written up in a report for the memory service, and also for Rosie Oldham-Cooper's doctoral thesis. Eventually, it is hoped that the findings would be published in an academic journal. No information that identifies you as a participant would be included in any of these written reports.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact the lead investigator:

Dr Rosie Oldham-Cooper, Clinical Psychologist in training

Address: Department of Clinical Psychology, Claverton Down Road, Bath, North East Somerset, BA2 7AY

Email: r.oldham-cooper@bath.ac.uk

Or you could contact Dr Laura Smart or Dr Kim Hartland, North Somerset memory service

You might also find it helpful to contact the Patient Advice and Liaison Service (PALS)

Telephone: 01249 468261 Freephone: 0800 073 1778 Email: <u>awp.pals@nhs.net</u>

Address: PALS Office, Avon and Wiltshire Mental Health Partnership

NHS Trust,

Jenner House, Langley Park, Chippenham, Wiltshire, SN15 1GG

Appendix D. Table summarizing the written information pack provided by the memory service and comparing against NICE (2006) guidance on topics to be covered within written information that is provided by clinicians alongside verbal communication of a diagnosis of dementia

Topics recommended for inclusion Written information included in packs in written information by NICE provided by the service (2006) Signs and symptoms The dementia guide (A5, 128 pages) Course and prognosis The dementia guide
(2006) Signs and symptoms The dementia guide (A5, 128 pages)
Signs and symptoms The dementia guide (A5, 128 pages)
Course and prognosis The dementia guide
1 3
Treatments The dementia guide
Local care and support services Memory matters group information sessions
advertisement (single A4 sheet)
Age UK Somerset information leaflet (A5)
Dementia services and support booklet
Reconnect booklet from ReThink
Community transport information (pamphlet)
Adult social services and housing information
sheet, carer's assessment (2 A4 sheets)
Timetable of local events (single A5 sheet)
Carers information booklet (A5, 4 pages)
Care connect booklet (support service;
pamphlet)
Positive step supporting carers pamphlet
Dementia services and support booklet (A5,
16 pages)
North Somerset care directory (A4 15 pages)
Support groups Memory matters group information
Timetable of local events
Positive step supporting carers pamphlet
Sources of financial and legal Memory matters group information sessions
advice and advocacy advertisement
Age UK Somerset information leaflet
The dementia guide
Adult social services and housing information
sheet, carer's assessment
Medico-legal issues, including
driving
Local information sources including Memory matters information sessions

libraries and voluntary	advertisement
organisations	Dementia services and support booklet
	North Somerset care directory

Appendix E. Advertisements for participants in the Bipolar disorder group and the nonclinical control group





Research participants needed: Bipolar Disorder diary study

RECRUITING NOW!

ARE YOU AGED 18 OR OVER WITH A DIAGNOSIS OF BIPOLAR DISORDER?

IF SO, THIS STUDY MAY INTEREST YOU

YOUR PARTICIPATION WOULD INVOLVE AN INITIAL INTRODUCTORY SESSION (APPROX. 2 HOURS) AND YOU WOULD BE ASKED TO KEEP A DIARY FOR ONE WEEK

WE WILL REIMBURSE YOU £20 FOR YOUR PARTICIPATION

If you would like more information, please email Rosie at bpdiarystudy@bath.ac.uk with subject 'diary study' or leave a message on 07973 979489

Study approved by West of Scotland NHS research ethics committee 06.10.15 (ref: 15/WS/0158)

BATH



Research study: getting a better understanding of Bipolar Disorder Recruiting non-clinical control group!

RECRUITING NOW!

ARE YOU AGED 18-65 WITH NO CURRENT MENTAL HEALTH DIFFICULTIES AND NO HISTORY OF BIPOLAR DISORDER?

IF SO, THIS STUDY MAY INTEREST YOU

YOUR PARTICIPATION WOULD INVOLVE AN INITIAL INTRODUCTORY SESSION (APPROX. 2 HOURS) AND YOU WOULD BE ASKED TO KEEP A DIARY FOR ONE WEEK WE ARE ABLE TO REIMBURSE YOU £20 FOR YOUR TIME

If you would like more information, please email Rosie on bpdiarystudy@bath.ac.uk with subject 'diary study' or leave a message on 07973 979489

Study approved by West of Scotland NHS research ethics committee 06.10.15 (ref: 15/WS/0158)



Participant information sheet: Bipolar disorder diary study

Your researcher, Rosie Oldham-Cooper, is a Trainee Clinical Psychologist. She is based in the NHS and also registered with the University of Bath, undertaking a Doctorate in Clinical Psychology. Her work in this study is being conducted under the supervision of Dr James Gregory (University of Bath) and Dr Warren Mansell (University of Manchester).

This research is being carried out to find out more about some of the processes that happen in bipolar I and bipolar II disorder.

We are asking 30 individuals with a diagnosis of bipolar I and II disorder, and 30 people with no diagnosis of any mental health difficulty to take part.

We will ask all participants to take part in an approximately 2-hour long initial interview, and then in a second approximately 1-hour long interview around 7 days later.

You would also be asked to keep a diary for a week. This would involve making entries twice a day for 7 days. We'd ask for information about thoughts and 'mental pictures/ images' that pop into your head. We'd also ask about how you'd slept the previous night, about your mood, energy levels, and other simple information on how you were feeling that day.

You would be reimbursed £20 at the second interview. This would be the end of your participation, but you would be able to request to hear about the outcomes of the whole study at a later date if you were interested.

Whether or not you take part is your choice.

If you don't want to take part, you don't have to give a reason, and it won't affect your treatment.

If you do want to take part now but change your mind later, you can withdraw from the study at any time. Upon your withdrawal, all information you provided would be destroyed.

This Participant Information Sheet will help you decide if you'd like to take part. It says why we are doing the study, what taking part would involve, what the benefits and risks might be, and what would happen next.

You do not have to decide today whether or not you will participate. Before you decide you may want to talk about the study with other people, such as family, friends, or healthcare providers.

This document is 3 pages long. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

- The study is designed to look at thoughts and mental pictures/ images that people experience 'popping into their head' day-to-day
- These might be particularly relevant to bipolar disorder
- We would like to find out more about these thoughts and images as they occur in everyday life in people with and without bipolar disorder
- To do this, we are asking 30 people with a diagnosis of bipolar I or bipolar II disorder, and 30 people with no mental health condition to fill-out a diary for a week to tell us about these experiences
- We hope that the findings will give researchers and clinicians more ideas about possible psychological treatments to ease the symptoms of bipolar disorder

WHO CAN TAKE PART?

- You must either have a diagnosis of Bipolar I or II disorder or no diagnosable mental health conditions to take part in this study
- You must be aged 18 or over to take part, but there is no upper age boundary
- You must understand what is being asked of you in order to give your consent to take part. If you have any doubts about this, or any of the other criteria listed, please contact the investigator before making a decision

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

- When the investigator (Rosie Oldham-Cooper) finds out that you are interested in taking
 part, she will give you an opportunity to ask questions, and you will be invited to arrange
 an initial assessment with her at a time and date to suit you
- The initial assessment can be held over the telephone or at the university of Bath
- The initial assessment will last around 2 hours, and will involve hearing more information about the diary section of the study and answering questions about your mental health, current mood, and information such as your age and years of education
- The diary section of the study can begin immediately after the initial assessment interview, if you choose to participate in the study. This will involve you completing a ready-made diary twice-daily for seven consecutive days about thoughts and mental images that pop into your head, and also answering some other questions about your mood, sleep, etc.
- You can choose to complete a paper version of this or a website version.
- At the end of the seven days, you would again speak with Rosie for around one hour about your experience of participating in this study, and Rosie would ask a few more questions about the recent week. You would be fully debriefed at this point about the aims and purpose of the study.
- You would be reimbursed £20 on completion of the study. This reimbursement does not represent a fee as such: your participation is voluntary. However, we hope that this is sufficient to reimburse you for the time you committed to the study, and is a token of our appreciation for your involvement.
- The information you provide would be **anonymised**. This means that your responses could not be linked to your name or any other information that could identify you

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

- Some people might find it difficult to share their experiences in this way, or be uncomfortable with talking with a stranger.
- You might also feel that now is not a good time to take part, or be concerned about committing time to completing the measures.
- If you have concerns about any of the above, you might want to spend some time thinking about whether you would like to take part, or contact the investigators to discuss this further.
- Some people might feel that a benefit of taking part would be the potential improvements to the psychological treatment of bipolar disorder in the future.
- Another possible benefit is having the opportunity to talk and think more about your experiences.

WHO PAYS FOR THE STUDY?

The costs associated with the project will be covered by the University of Bath

WHAT ARE MY RIGHTS?

- Your participation is voluntary, and you have the right to decline the invitation to take
 part, or withdraw from the project at any time, until the end of the study period.
 However, we could not remove you from the study after you had taken part, because
 the link between your name and the information you provided would have been
 removed (anonymisation)
- Choosing not to participate, or withdrawing from the study at any point would not affect the service you receive in any way.
- You will be fully debriefed about the aims of the study immediately after you have taken part, both verbally and in writing
- You may also opt-in to receive a short written summary of the outcomes of this project after the study has ended

WHAT HAPPENS AFTER THE STUDY?

- The information you provide would be made anonymous (i.e. there would be no way of linking your name or any other personal identifying information with the information you provided for the study) and stored securely at the University of Bath for up to 10 years, with Dr James Gregory (University of Bath). After this time the written record would also be destroyed
- The findings will be written up in a report for Rosie Oldham-Cooper's doctoral thesis.
 Eventually, it is hoped that the findings would be published in an academic journal. No information that identifies you as a participant would be included in any of these written reports.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact the lead investigator:

Dr Rosie Oldham-Cooper, Clinical Psychologist in training

Telephone: 07973 979489

Email: bpdiarystudy@bath.ac.uk

Or you could contact her supervisor, Dr James Gregory, Clinical Psychologist:

Address: Department of Clinical Psychology, Claverton Down, University of Bath

Telephone: 01225 386120

Email: j.d.gregory@bath.ac.uk



University of Bath, Department of Clinical Psychology

Study reference: BPdiarystudy number:	Centre/site reference:	Participant reference	
Consent form – Bipolar disorder	diary study		
Your researcher is a Trainee Clinical registered with the University of Bath Her work in this study is being condu (University of Bath) and Dr Warren Market the only other people who will have a Participants will not be able to be ide. The researcher should have explained. The nature and purpose of the Why you have been asked to What will be required of you are the information that you confidential, except in the circumary place you or others at right.	n, undertaking a Doctorate in acted under the supervision Mansell (University of Manchaccess to the information product the following to you: e study; participate in the study; as part of the study; provide will be made anony cumstances where information	n Clinical Psychology. of Dr James Gregory nester). These will be oduced by this study	
 may place you or others at ris That you have the right to wit request for any information the study and destroyed; Participation or not in the study and some information collector responsible individuals from the monitoring or auditing, to ensappropriately. 	hdraw from the study at any lat you have provided to be drived by will not affect your accested during the study may be he sponsor (University of B.	withdrawn from the s to treatment looked at by ath) for the purpose of	
		Please tick]
I have had the above explained to m in the study.	e and I agree to participate		
I agree for Rosie Oldham-Cooper an access to the information produced f purposes of this study.			
Name of participant (Print)	Signature of participar	Date	
Name of researcher (Print)	Signature of researche	er Date	



University of Bath, Department of Clinical Psychology

Study reference: BPdiarystudy number:	Centre/site reference:	Participant reference
Information-sharing consent for	orm – Bipolar disorder diary s	tudy
screening questionnaires of on to for this study; That this will mean you do That this information will not the information would responsible individuals from the study and destroyed; That you have the right to can request for any inform each study and destroyed; That some information collaresponsible individuals from	o request for your responses on completed during Rose Knight's not need to complete these que of be passed-on without your co d not be passed-on if you choos cudy; ou provide will remain anonymon; withdraw from either study at ar ation that you have provided to	estionnaires again; onsent; e not to take part in ous – your name will ouy point and that you be withdrawn from to treatment; looked at by th) for the purpose of
		Please tick
I have had the above explained to Knight passing the relevant quest during her study to Rosie Oldham	onnaire information I provided	
Name of participant (Print)	Signature of participant	Date
Name of researcher (Print)	Signature of researcher	Date

Appendix I. Guide to sources of support for participants

Please use the following information on sources of support if you notice any changes in how you are feeling (i.e., your mood and general mental wellbeing) that are larger than you might normally experience

1. Contact your GP or mental health professional

Here is a web link to the NHS guide to seeking support via NHS services: http://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/services-explained.aspx

2. Web links and telephone numbers for potentially useful alternative sources of support

Rethink Mental Illness Support and advice for people living with mental illness.

Phone: 0300 5000 927 (Mon-Fri, 10am-2pm)

Website: www.rethink.org

CALM CALM is the Campaign Against Living Miserably, for men aged 15-35.

Website: www.thecalmzone.net

Bipolar UK A charity helping people living with manic depression or bipolar disorder.

Website: www.bipolaruk.org.uk

Samaritans Confidential support for people experiencing feelings of distress or despair.

Phone: 08457 90 90 90 (24-hour helpline)

Website: www.samaritans.org.uk

Sane Charity offering support and carrying out research into mental illness.

Phone: 0845 767 8000 (daily, 6pm-11pm)

SANEmail email: sanemail@org.uk

Website: www.sane.org.uk

Mind Promotes the views and needs of people with mental health problems.

Phone: 0300 123 3393 (Mon-Fri, 9am-6pm)

Website: www.mind.org.uk

The Mental Health Foundation Provides information and support for anyone with mental health problems or learning disabilities.

Website: www.mentalhealth.org.uk

A guide to filling in the measures for the bipolar disorder diary study

First of all, thank you very much for agreeing to take part in this study. We hope that you find it an interesting and positive experience.

Please read the following guide carefully and take a moment to look through the questionnaire measures, too. You'll have the opportunity to talk this information through with Rosie before you start filling the questionnaires out.

Each day, we ask that that you record the following information.

At 3pm, or as close to this time as possible, please complete:

- 1) The sleep quality measure to tell us about the previous night's sleep
- 2) The 'how am I feeling' measures to record how things have been since you woke up
- 3) The diary of thoughts and mental images to record the 'cognitions' you've experienced since waking

At 10pm, or as close as possible to going to bed, please complete:

- 1) The 'how am I feeling' measures to record how things have been since you woke up
- 2) The diary of thoughts and mental images to record the 'cognitions' you've experienced since waking

Below is a guide to completing each measure. Please read the information carefully and ask Rosie to explain anything you are still unsure about.

1) The sleep quality measure

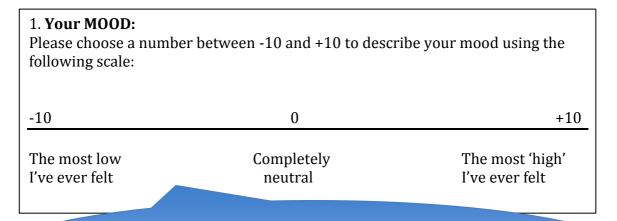
your sleep at 10/10

Use this scale to rate your sleep quality the previous night. For example, you might rate your sleep at 5/10 if it was of average quality, or 6/10 if it was a bit better than average. Remember to rate the quality of your sleep only in comparison to yourself. For example, if you'd never slept more than 2 hours at a time and got more than 2 hours during the study, you might rate

2) The 'how are you today?' measures

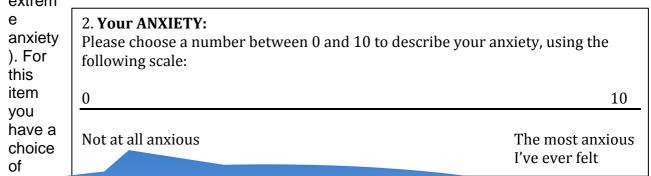
This questionnaire contains 3 items

The first is about your mood (e.g. from low, down, depressed, to 'high', elated, or extremely happy). You have a choice of numbers between -10 and +10



Use this scale to rate how your mood has been since you last made the rating. Please consider the whole scale and rate your mood relative to your own experiences only.

The second is about how anxious you feel (from totally relaxed and calm, to extrem



Use this scale to rate how anxious you have telt since you last made the rating. Please consider the whole scale and rate your own experiences only.

numbers between 0 and 10

The third is about your activity levels or 'busyness'. Your answer on this measure might not actually be related to how active you are being, but you might be simply be *feeling* more active some days compared to others.

3. Your levels of ACTIVITY/ 'BUSYNESS'

Please choose a number between 0 and 10 to describe your levels of activity/ busyness, using the following scale:

0 10

The least active/busy I've ever felt

The most active/ busy I've ever felt

ofher people.

Use this scale to rate your activity levels or busyness since you last made the rating. Again, consider the whole scale and think about what is normal for you, rather than comparing yourself to

3) The thought and mental image diary measure

The final measure to be completed on a twice-daily basis is the diary of thoughts and mental images.

This one might feel quite difficult at first. You will have a chance to practice this with Rosie, but please read the following information and try to get an idea of what you will be asked to do.

We are interested in 'verbal thoughts' and 'mental images/ pictures' that 'pop into' your head spontaneously— you didn't deliberately think about them before they occurred.

A 'verbal thought' refers to a thought that you experience in words in your mind. An example of a verbal intrusive thought might be, "I could cook pasta for dinner tonight", whereas a related mental image might be of you eating a bowl of pasta. Similarly, you might have a verbal thought like, "I'm going to have a great time on my holiday", while a related mental image might be of yourself relaxing on holiday, with all the associated sights and smells. A mental image,

therefore, can be like a picture or a film, and it might be fleeting and vague or very detailed and involving lots of your senses. Similarly, verbal thoughts might be vague or detailed.

Importantly, we are only interested in those thoughts that pop into your mind without intention, or are unwanted.

We would like you to record the general theme or content of your thought or image (e.g. 'argument with partner', or 'winning award'). Please don't spend too long on this bit – we'd just like a rough idea of what you experienced.

We'd also like you to say whether you had a thought or an image, or if it was both, which one came first (e.g. 'thought, then image')

Next, we'd like to know how real or vivid the experience was. Just like the anxiety and sleep ratings above, we'd like you to rate the 'realness' on a scale of 0-10, where 0 is 'not at all real/ vivid' and 10 is 'like it was actually happening/ I was there'.

We'd also like to hear about how intense the thought or image was. For example, did you have really strong emotions in reaction to the thought or image? A score of 10 would be 'the most intense experience I can imagine' and 0 would be 'not at all intense'.

Please then say how important the thought or image felt on a scale of 0-10, with 0 being 'not at all important'.

Your thought or image might have been relevant to a current goal you hold (e.g., passing an exam, going shopping) – a score of 0 would mean that the thought or image was totally irrelevant to any of your current goals, whereas a score of 10 means it was 'completely relevant'.

The image might have been positive, negative, or completely neutral. For example, a thought about death might be very negative, whereas a thought or image about an upcoming holiday could be negative. As with the mood ratings, please use a minus number to describe something negative (where -10 is the most negative it could have been) and a plus number to describe something positive (where +10 is the most positive it could be).

Finally, we'd like you to say whether the thought or image was the same as or similar to a thought or image you've had previously – or whether it was completely novel. A new thought or image would get a score of 0 (not similar to a previous thought or image) whereas a thought or image that was identical to a previous one would get a score of 10.

Please don't worry if this feels confusing at first – it should become much easier with practice. Remember, you'll have a chance to talk about this with Rosie before you try it so do ask about anything that isn't clear.

Please make a rating of how representative of, or similar-to, a typical week your experiences in the following areas have been, using the following 0-10 scales:

1. Your SLEEP, on average, this week compared to a typical week	k:
0	10
Not at all	Completely
representative	representative
1	1
2. Your MOOD, on average, this week compared to a typical week	k:
0	10
Not at all	Completely
representative	representative
1	1
3. Your ANXIETY, on average, this week compared to a typical w	eek:
0	10
Not at all	Completely
representative	representative
4. Your BUSYNESS/ ACTIVITY LEVELS, on average, this week coweek:	mpared to a typical
	10
Not at all	
Not at all	Completely
representative	representative
5. HOW OFTEN you have experienced VERBAL THOUGHTS that your head:	just popped into
0	10
Not at all	Completely
representative	representative
r	- F

6. HOW VIVID your experience of these verbal thoughts has been?

0	10
Not at all	Completely
representative	representative
7. HOW INTENSE your experience of these verbal thoughts ha	as been?
0	10
Not at all	Completely
representative	representative
8. HOW OFTEN you have experienced MENTAL PICTURES/ IN popped into your head:	MAGES that just
0	10
Not at all	Completely
representative	representative
9. HOW VIVID your experience of these mental pictures/ image	ges has been?
0	10
Not at all	Completely
representative	representative
10. HOW INTENSE your experience of these mental pictures/	images has been?
0	10
Not at all	Completely
representative	representative

Appendix L. Debrief sheet

Debrief sheet: Bipolar disorder diary study

Thank you very much for participating in this study. We hope that you found it a positive experience.

Below is some further information on the aims of the study. Please take time to read it and contact Rosie Oldham-Cooper if there is anything you don't understand or if you'd like more information.

- Bipolar disorder involves periods of intense low mood (depression) and high mood (mania), together with periods of relatively stable mood (euthymia).
- Research has suggested that 'intrusive cognitions' (verbal thoughts and 'mental images/ pictures' that occur without intention or deliberation, or 'pop into' one's head) might play a role in the development and maintenance of an episode of elevated or depressed mood in bipolar disorder.
- Researchers interested in these 'intrusive cognitions' have generally asked people to report on their past experiences (retrospective recall).
- This approach is potentially problematic because people's memories for past experiences of these intrusive cognitions might be affected by how they are feeling when they are asked, how long ago the experience happened, and what has happened since.
- Another problem with 'retrospective recall' is that it doesn't allow us to understand
 whether 'intrusive cognitions' lead to the difficulties associated with bipolar disorder,
 or whether they happen as a result of bipolar disorder. This is important because many
 recent theories suggest that intrusive images may cause symptoms associated with
 bipolar disorder.
- This study looked at the everyday occurrence of intrusive verbal thoughts and mental images in individuals with bipolar disorder, as well as in people who do not have bipolar disorder.
- This was achieved by asking participants to keep a diary of their experiences of intrusive verbal thoughts and mental images over a seven-day period
- The study is important because we do not yet understand whether people can report
 'in the moment' on intrusive thoughts and images. We also hope we can begin to
 understand how often these occur in day-to-day life, and whether people with bipolar
 disorder have them more often or have more intense experiences of them compared
 to healthy controls.
- Understanding more about this could eventually lead to the development of improved psychological treatments for the symptoms of bipolar disorder.
- The findings will be written up as part of Rosie's doctoral thesis, and we hope that they
 will also be published in an academic journal for the benefit of other researchers in
 this field.

Thanks again for being a part of this research. Please find contact details for your researcher, Rosie Oldham-Cooper, below.

Rosie Oldham-Cooper: bpdiarystudy@bath.ac.uk

Appendix M. Research ethics committee favourable opinion letter

WoSRES West of Scotland Research Ethics Service



Dr Rose Oldham-Cooper Trainee Clinical Psychologist Taunton and Somerset NHS Foundation Trust University of Bath Claverton Down Bath BA27AY West of Scotland REC 5
Ground Floor - Tennent Building
Western Infirmary
38 Church Street

Glasgow G11 6NT

Date 06 October 2015

Direct line 0141 211 2102

E-mail WoSREC5@ggc.scot.nhs.uk

Dear Dr Oldham-Cooper

REC reference:

Study title: Everyday experiences of verbal thoughts and mental

images in individuals with a diagnosis of bipolar

disorder 15/WS/0158

Protocol number: N/A IRAS project ID: 161058

Thank you for your letter of 17 September, which was received on 23 September, responding to the Committee's request for further information on the above research and submitting revised documentation. I apologise for the delay of my reply.

The further information has been considered on behalf of the Committee by the Chair and one of the Committee members.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Sharon Macgregor, WoSREC5@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below. The additional changes stated in point 4 and 5 of your covering letter were also considered and given a favourable opinion.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the

study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (<u>catherineblewett@nhs.net</u>), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

The final list of documents reviewed and approved by the Com		
Document	Version	Date
Copies of advertisement materials for research participants [Advert BPD group]	1	17 July 2015
Copies of advertisement materials for research participants [Advert control group]	1	17 July 2015
Covering letter on headed paper [Covering letter]		17 September 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Liability certificate]		
Interview schedules or topic guides for participants [Instructions]		
Letter from sponsor [Letter from sponsor]		
Non-validated questionnaire [DIARY SHEET]	1	09 April 2015
Non-validated questionnaire [Sleep quality questionnaire]	1	09 April 2015
Non-validated questionnaire [Mood questionnaire]	1	09 April 2015
Non-validated questionnaire [Representativeness ratings]	1	09 April 2015
Other [Flowchart protocol]	1	09 April 2015
Other [Guide to completing measures]	1	17 July 2015
Participant consent form [Participant consent form]	2	17 September 2015
Participant consent form [Information sharing consent form]	1	09 April 2015
Participant information sheet (PIS) [Participant information sheet]	1	10 April 2015
REC Application Form [REC_Form_16072015]		16 July 2015
Research protocol or project proposal [Research protocol]	1	17 July 2015
Summary CV for Chief Investigator (CI) [CV Rose Oldham-Cooper]		
Summary CV for supervisor (student research) [CV JG]		
Validated questionnaire [SCID I]		
Validated questionnaire [Life events]		
Validated questionnaire [Internal States Scale]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

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 R&D staff at our training days - see details at http://www.hra.nhs.uk/hra-training/

15/WS/0158

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

for Dr Stewart Campbell

5 Macgregor

Enclosures: "After ethical review - guidance for researchers"

Copy to:

Professor Jane Millar, University of Bath Ms Marie Norton, Avon & Wiltshire Mental Health Partnership NHS Trust

Appendix N. Recruitment approval letter from Avon and Wiltshire Mental Health Partnership NHS Trust



Our Reference: AWP 921

Dr Rosie Oldham-Cooper University of Bath Claverton Down Bath BA2 7AY

9th December 2015

Hannah Antoniades Research and Development Avon & Wiltshire Mental Health Partnership NHS Trust Fromeside Blackberry Hill Hospital Manor Road Fishponds Bristol BS16 1EG 0117 378 4267

hannah.antoniades@nhs.net

Dear Dr Oldham-Cooper,

Title of study: Characteristics and processes in bipolar disorder presentation

Approval date: 09 December 2015

End date: 15 May 2016

Thank you very much for applying to undertake your research in AWP.

We are pleased to advise that we are able to grant your study R&D permission at Avon and Wiltshire Mental Health Partnership NHS Trust. Under the conditions of approval, you are required to:

- 1. Document any study activity on RiO for the relevant patient records. *Please refer to the attached RiO guidance document.*
- 2. Update recruitment figures regularly via EDGE (a Clinical Management System). This enables us to keep a clear track of all Trust-wide study activity, which we need to report to our research funders. Failure to comply with this will result in your research being suspended, so please make sure you complete this on a monthly basis. We will set up an account for you, and your login instructions will be emailed to you. Please refer to the attached EDGE guidance document.
- Notify us if you plan to recruit participants from any clinical team not originally outlined in your New Study Checklist. This ensures we can keep track of the research activities undertaken by all clinical teams across the Trust.

The R&D Permission in the Trust is valid until 15 May 2016. If you require any extension to this in the future please contact us to arrange.

The documentation listed below has been received and all the relevant governance checks have now been completed

I am therefore happy to provide R&D Permission for the above study across all locations within the Trust parameters.

Document	Version	Date
Copies of advertisement materials for research participants [Advert BPD group]	1	17 July 2015
Copies of advertisement materials for research participants	1	17 July 2015

Continued... Chair Anthony Gallagher

Headquarters
Jenner House, Langley Park, Chippenham. SN15 1GG

Chief Executive lain Tulley

[Advert control group]		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors		
only) [Liability certificate]		
Letter from sponsor [Letter from sponsor]		
Non-validated questionnaire [DIARY SHEET]	1	09 April 2015
Non-validated questionnaire [Sleep quality questionnaire]	1	09 April 2015
Non-validated questionnaire [Mood questionnaire]	1	09 April 2015
Non-validated questionnaire [Representativeness ratings]	1	09 April 2015
Other [Flowchart protocol]	1	09 April 2015
Other [Guide to completing measures]	1	17 July 2015
Participant consent form [Participant consent form]	2	17 September 2015
Participant consent form [Information sharing consent form]	1	09 April 2015
Participant information sheet (PIS) [Participant information sheet]	1	10 April 2015
Research protocol or project proposal [Research protocol]	1	17 July 2015
Summary CV for Chief Investigator (CI) [CV Rose Oldham-		
Cooper]		
Summary CV for supervisor (student research) [CV JG]		
Validated questionnaire [SCID I]		
Validated questionnaire [Life events]		
Validated questionnaire [Internal States Scale]		

Please be aware that if there are any amendments to the above documents they must be sent to Hannah Antoniades, Research and Development Operations Manager for permission prior to use within the Trust.

You are reminded that you must report any adverse event or incident whether or not you feel it is serious, quoting the study reference number. This requirement is in addition to informing the Chairman of the relevant Research Ethics Committee. You are also required to submit to the Research and Development Operations Manager (Hannah Antoniades) a final outcome report on completion of your study, and if necessary to provide interim annual reports on progress. Should publications arise, please also send copies to Hannah Antoniades for inclusion in the study's site file.

You must also abide by the research and information governance requirements for any research conducted within the NHS:

- Work must be carried out in line with the Research Governance Framework which details the responsibilities of everyone involved in research.
- You must comply with the Data Protection Act 1998 and where required, have up to date Data
 Protection Registration with the Information Commissioners Office. Where staff are employed,
 this includes having robust contracts of employment in place and ensuring that staff are made
 aware of their obligations through training and similar initiatives.
- You must ensure that you understand and comply with the requirements of the NHS
 Confidentiality Code of Practice:
 (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH 4069253)
- You must have appropriate policies and procedures in place covering the security, storage, transfer and disposal of information both personal and sensitive, or corporate sensitive information. Any information security breach must be reported immediately to the Trust.
- Where access is granted to sensitive corporate information, this must not be further disclosed without the explicit consent of the Trust unless there is an override required by law. Where disclosure is required under the Freedom of Information Act 2000, the Trust will assist you in processing the request.

Please note that, as a public authority, the Trust is obligated to comply with the provisions of the Freedom of Information Act 2000, including the potential disclosure of information held by the Trust in connection with this study. Where a request for potential disclosure of personal, corporate sensitive, or contract information is made under the Freedom of Information Act 2000, due regard shall be made to any duty of confidentiality or commercial interest.

Yours sincerely

Distributed

Hannah Antoniades Research & Development Operations Manager Avon and Wiltshire Mental Health Partnership NHS Trust

CC: Kian Vakili Dr James Gregory

Appendix O. Recruitment approval letter from Birmingham and Solihull Mental Health NHS Foundation Trust



National Centre for Mental Health The Barberry, Research and Innovation Department 25 Vincent Drive Edgbaston Birmingham B15 2FG

> Tel: 0121 301 2002/2207 Fax: 0121 301 4321 Research.innovation@bsmhft.nhs.uk

7 January 2016

Dr Rosie Oldham-Cooper Trainee Clinical Psychologist Taunton and Somerset NHS Foundation Trust University of Bath Claverton Down Bath BA2 7AY

Dear Rosie

Everyday experiences of verbal thoughts and mental images in individuals with a diagnosis of bipolar disorder

R&I Project ID: NRR1393

Thank you for providing us with the documentation to support your application for R&I approval. We have received notification of a favourable ethical opinion and following a review of all the documentation I am pleased to inform you that your project has been given full NHS permission and you may begin your research at Birmingham and Solihull Mental Health NHS Foundation Trust.

Please note that the Trust's approval of this research is given on the understanding that you are aware of and will fulfil your responsibilities under the Department of Health's Research Governance Framework for Health and Social Care, including complying with any monitoring/auditing of research undertaken by the Research & Innovation Department. In particular, whilst conducting your study you should respect the confidentiality of data obtained from participants.

Any researcher(s) whose substantive employer is not Birmingham and Solihull Mental Health NHS Foundation Trust must have a Letter of Access (LOA) or an Honorary Research Contract before accessing the relevant site(s) to conduct their research. If a Letter of Access/Honorary Research Contract has not been issued please contact us immediately.

Chair: Sue Davis, CBE Chief Executive: John Short

PALS Patient Advice and Liaison Service Customer Relations Mon – Fri, 8am – 8pm
Tel: 0800 953 0045 Text: 07985 883 509 Email: pals@bsmhft.nhs.uk Website: www.bsmhft.nhs.uk





Improving mental health wellbeing

We wish you all the best in completing your research and would appreciate you keeping the department up to date of any changes throughout the course of the project. We must also insist that you include us in the dissemination of results for you research and where applicable, ask that you submit a copy of your final report. If you require any advice or support on any aspect of your study please do not hesitate in contacting the department quoting the reference ID cited in the subject header.

Yours sincerely

L.M. EVerud.

Linda Everard

Research and Innovation Implementation and Performance Manager





Email: awp.researchforall@nhs.net

Everyone Included Research & Development Department Avon & Wiltshire Mental Health Partnership NHS Trust Fromeside, Bristol BS16 1EG Tel: 0117 378 4535

29/02/2016

Dear Rosie,

We are pleased to inform you that your study has been accepted to use Everyone Included by the **Everyone Included Virtual Review Panel.**

The study was 'accepted with changes', which relate to improving the content and readability of the Research Opportunity Letter. We have attached a copy of this letter for your information.

What next?

Before we can start processing any letters, we require copies of the following approvals:

- Ethics (REC) Approval Approval must list Everyone Included as an additional recruitment method and include a proof copy of the Research Opportunity Letter (please update with final version). If you have already received REC without Everyone Included, this should be added via a substantial amendment.
- AWP R&D Approval Please also ensure you have followed the R&D Governance process.
- Funding There will be a cost attached to using Everyone Included in order to cover the expense of consumables (such as paper, envelopes and postage) and the administration work for processing the letters. The total cost will depend on how many letters you wish to process and your availability to assist with processing. The cost options are attached for your consideration.

We are excited to assist you with recruitment and thank you for your patience with the application process.

ayley Richards

Yours Sincerely,

Tim Williams Acting Medical Director **Hayley Richards**

Acting Chief Executive

Julian Walker

Director of Research & Development

"AWP is a learning, teaching and research trust; we aim to inform you about relevant research opportunities, unless you tell us otherwise.'

Appendix Q. Recruitment letter for Everyone Included





Everyone Included Research & Development Department Avon and Wiltshire Mental Health Partnership NHS Trust Blackberry Hill Hospital Bristol, BS16 2EW

> Tel: 0117 378 4535 Email: awp.researchforall@nhs.net

Hello.

Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) is your local NHS mental health service provider. We are an Everyone Included 'Research for All' Trust which means we aim to let everyone know about relevant opportunities to take part in research, unless they tell us otherwise. We do this to give everyone the chance to decide for themselves whether to take part in research.

The following information is about a research study you might be interested in:

Do our thoughts affect our mood?

This study is looking at people's experiences of intrusive thoughts (vivid, distressing or unwanted thoughts that pop into our head without explanation) and mental images (visual thoughts). In particular how these thoughts affect the way we feel.

Taking part involves answering some questions and completing a short diary (twice a day for 7 days) about any intrusive thoughts or images and how you are feeling.

If you are interested in taking part, the researcher, Rosie, will arrange an initial telephone call to tell you more about the study and check if you can participate. If you decide to, at the end of the 7 days there will be a final meeting (up to 1 hour) to answer some more questions. You can also ask the researcher questions. This will either be by telephone or at the University of Bath, whichever is preferable.

You will receive £20 as a thank you for your time once you have completed the study.

Any answers given will be anonymous and strictly confidential. It will not be possible to identify anyone taking part when looking at the study findings. You are not obliged to take part. Your care will not be affected in any way.

To find out more please contact the Everyone Included team by:

88Waller

We look forward to hearing from you soon.

Best wishes.

Julian Walker

Director of Research & Development

Rosie Oldham-Cooper Clinical Psychologist in Training

[&]quot;AWP is a learning, teaching and research trust; we aim to inform you about relevant research opportunities, unless you tell us otherwise."

Appendix R. Confirmation of approval from Avon and Wiltshire Mental Health Partnership Trust for Service Evaluation (service improvement project)



Avon and Wiltshire Mental Health Partnership AWP Trust

AWP Quality Academy Blackberry Centre Manor Road Fishponds BS16 2EW

0117 378 4238/ 07825 725296

Rosie Oldham Cooper

Date: 6th January 2015

Dear Rosie

Provision of written information in a memory service in the South West of England: exploring staff and service user perspectives on the content and timing of written information about dementia and available services.

AWP Reference: 2014.E022

This letter is to confirm that your evaluation is now <u>approved</u> and also provides you with our reference number.

If you do need any further support or information, please contact us using the contact details above, quoting our reference number for your study.

The importance of disseminating all evaluation work cannot be over emphasised. It is only by sharing our learning that we can improve services across AWP. For this reason, the findings of all evaluation work should be reported to the Evaluation team via email. The team will champion the results of service evaluations, and work with evaluators to ensure those results are disseminated and acted upon, and that the results of evaluations are reflected in future service delivery. The team will also work with evaluators to produce publications for the public domain.

I very much look forward to receiving the results of your evaluation in due course.

Yours sincerely,

Janet Brandling

Appendix S. Author Guidelines for the Journal of Anxiety Disorders (where the literature review is under review)



JOURNAL OF ANXIETY DISORDERS

AUTHOR INFORMATION PACK

TABLE OF CONTENTS

•	Description	p.1
•	Audience	p.1
•	Impact Factor	p.1
•	Abstracting and Indexing	p.2
•	Editorial Board	p.2
•	Guide for Authors	p.4



ISSN: 0887-6185

DESCRIPTION

Journal of Anxiety Disorders is an interdisciplinary journal that publishes research papers dealing with all aspects of anxiety disorders for all age groups (child, adolescent, adult and geriatric). Manuscripts that focus on disorders formerly categorized as anxiety disorders (obsessive-compulsive disorder, posttraumatic stress disorder) and the new category of illness anxiety disorder are also within the scope of the journal. Research areas of focus include: traditional, behavioral, cognitive and biological assessment; diagnosis and classification; psychosocial and psychopharmacological treatment; genetics; epidemiology; and prevention. Theoretical and review articles that contribute substantially to current knowledge in the field are appropriate for submission.

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AUDIENCE

Psychiatrists, Psychologists, Behavior Therapists

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BEFORE YOU BEGIN

Ethics in publishing

Please see our information pages on Ethics in publishing and Ethical guidelines for journal publication.

Declaration of interest

All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. More information.

Submission declaration and verification

Submission of an article implies that the work described has not been published previously (except in the form of an abstract or as part of a published lecture or academic thesis or as an electronic preprint, see 'Multiple, redundant or concurrent publication' section of our ethics policy for more information), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder. To verify originality, your article may be checked by the originality detection service CrossCheck.

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Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop.

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Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.

Additional Information

Editorial guidance

The Journal of Anxiety Disorders publishes articles of relevance to the epidemiology, psychopathology, etiology, assessment, treatment, and prevention of anxiety and related disorders in both child and adult populations. The format of the articles includes randomized controlled trials, single case clinical outcome studies, theoretical expositions, epidemiological studies, investigations of early mechanisms of risk, genetic and biomarker studies, neuroimaging studies, critical literature reviews, meta-analyses, and dissemination and implementation studies. We are also interested in evaluations of novel treatment delivery strategies, including the use of information technologies. Authors are encouraged to use methodologically rigorous sampling, structured or semistructured diagnostic interviews, randomization, therapist fidelity, and inter-rater reliability procedures where appropriate. Given limited journal space, we can accept only a limited number of studies, and we prefer to publish studies of clinical or community samples. However, we recognize that studies using other samples (e.g., undergraduate analogues) can provide meaningful increments to knowledge. Therefore, while emphasizing our preference for clinical or community samples that are most appropriate for the question under study, we will consider studies using other samples in so far as we judge them to make a significant incremental contribution to the understanding of anxiety and related disorders or anxiety psychopathology more broadly.

PREPARATION

NEW SUBMISSIONS

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process.

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References

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

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Formatting requirements

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.

If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.

Divide the article into clearly defined sections.

Figures and tables embedded in text

Please ensure the figures and the tables included in the single file are placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file.

Use of word processing software

Regardless of the file format of the original submission, at revision you must provide us with an editable file of the entire article. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier). See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Subdivision - numbered sections

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

Results

Results should be clear and concise.

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

• The title page must be the first page of the manuscript file.

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Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself. The abstract should not exceed 150 words in length and should be submitted on a separate page following the title page.

Graphical abstract

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TABLE OF CONTENTS

•	Description	p.1
•	Audience	p.1
•	Impact Factor	p.1
•	Abstracting and Indexing	p.2
•	Editorial Board	p.2
•	Guide for Authors	p.5



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An International Multi-Disciplinary Journal

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