‘Not Just Right Experience’ (NJRE) in Obsessive-Compulsive Disorder: Is NJRE a Manifestation of Autistic Traits?

Josselyn Hellriegel

D.Clin.Psy thesis (Volume 1)

2014

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: 

Name: Josselyn Hellriegel

Date: 25.09.2014

Overview

Part one, the literature review, aimed to describe clinical variables associated with the 'not just right experience' (NJRE) in obsessive-compulsive disorder (OCD). Twenty-two articles studying NJRE in OCD populations were reviewed. The findings suggested that NJRE is a prevalent phenomenon in OCD and is associated with more severe OCD symptomatology, earlier age of OCD onset, and a complex comorbid profile. NJRE was most likely to be associated with OCD symptoms of symmetry, ordering, and arranging. The review also highlighted existing ambiguity in how to define, conceptualize, and measure this phenomenon in OCD.

Part two, the empirical paper, explored whether NJRE was a marker of a neurodevelopmental pathway in OCD distinct from the motivational process harm avoidance (HA). The study examined the association of NJRE and HA with a range of variables including autistic traits, sensory abnormalities, set-shifting difficulties, earlier age of OCD onset, and responsibility beliefs. NJRE was not found to be related to autistic traits; however, it was associated with sensory processing difficulties and an earlier age of OCD onset possibly indicative of a developmental origin.

Part three, the critical appraisal, reflected on the challenges of testing theoretical ideas in an OCD population. Considerations are given to methodological limitations of the empirical paper including a small sample size. Lastly, the appraisal shares personal experiences and insights gained about the implementing the clinical study. It underscores the need for further research in order to adapt optimal treatment approaches in OCD.

This research project was a joint project with Trainee Clinical Psychologist, Caroline Barber.

Table of Contents

List of Tables and Figures

Part 1: Literature Review

Part 2: Empirical Paper

Appendices:

Acknowledgements

I would like to thank everybody who made this research process possible. In particular, I would like to thank my supervisor, Dr. William Mandy, for his enthusiasm and excellent support throughout the research process in helping me shape and organise my thoughts and ideas. I also would like to thank my mother and partner for their support and encouragement in the last months.

In addition, this research would have not been possible without my fellow Trainee Clinical Psychologist, Caroline Barber, my external supervisor, Prof. Naomi Fineberg, her clinical staff team, and the individuals who volunteered to take part in this research study.

I would also like to express my appreciation to the Cambridge Cognition team, who helpfully provided consultation in selecting outcome variables to address my research question.

I would also like to thank Dr. Laura Summerfeldt for providing me with the Obsessive-Compulsive Trait Core Dimensions Questionnaire which she developed.

Finally, I would like to thank my friends for their patience in the last year.

Part 1: Literature Review

Clinical Features Associated with the 'Not Just Right Experience' in Obsessive-Compulsive Disorder

Abstract

Background: The 'not just right experience' (NJRE) is thought to be a precipitating and maintaining factor in obsessive-compulsive disorder (OCD). However, researchers and clinicians interested in the aetiology of OCD have paid significantly less attention to this construct than to harm avoidance. In order to improve treatment outcome, in light of OCD being considered a heterogeneous condition, it would be valuable to continue to investigate NJRE's role in OCD.

Aim: This literature review aimed to provide a detailed and systematic clinical description of NJRE as an alternative and less understood underlying mechanism in OCD in order to learn more about its potential clinical usefulness.

Methods: The electronic databases PsyINFO and PubMed were searched to identify relevant articles that focused on clinical characteristics of NJRE in OCD.

Results: Twenty-two articles were identified. The results of the literature review suggested that NJRE is a prevalent phenomenon in OCD. It is associated with factors related to poorer treatment outcomes including increased severity of OCD symptoms, earlier age of OCD onset, and a complex comorbid profile. NJRE is frequently related to a specific subset of OCD symptoms including symmetry, arranging, and ordering.

Conclusion: Currently, it appears that NJRE warrants recognition in clinical assessments of OCD as it may impact upon treatment outcome. However, more research is needed to refine our understanding of this phenomenon and to assess the relevance of NJRE in routine clinical management of OCD. At the present time there exists conceptual ambiguity as to how to define and measure this construct.

Introduction

Obsessive-compulsive disorder (OCD) is a relatively common disorder affecting approximately 1% to 3 % of the population (Fontenelle, Mendlowicz, & Versiani, 2006). The definitive features of OCD are intrusive thoughts and images (obsessions) or urges (compulsions) characterized by pervading mental acts or repetitive behaviours. The obsessions and compulsions cause considerable distress and impairment in daily functioning (Knapp, Henderson, & Patel, 2000).

Despite apparent advances in overall treatment interventions, 40 % to 60 % of individuals with OCD do not respond favourably to treatment (Pallanti & Quercioli, 2006). Due to the heterogeneity of the OCD presentation and confounding clinical variables, identifying who will be responders to current OCD treatment modalities can be a challenge. A range of clinical variables are thought to contribute to overall poor outcome in the OCD population. These include the types of symptoms, in particular hoarding and sexual obsession (Black et al., 1998; Ferrão et al., 2006), and the severity of symptoms (Catapano et al., 2006; Ferrão et al., 2006; Franklin, Abramowitz, Kozak, Levitt, & Foa, 2000; Hollander et al., 2002; Keijsers, Hoogduin, & Schaap, 1994), as well as the presence of a comorbid presentation with a personality disorder (Baer, 1992; Catapano et al., 2006; Minichiello, Baer, & Jenike, 1987; Ravizza, Barzega, Bellino, Bogetto, & Maina, 1995), a tic syndrome (McDougle, 1994), or depression (Başoğlu, Lax, Kasvikis, & Marks, 1988; Buchanan, Meng, & Marks, 1996; Overbeek, Schruers, Vermetten, & Griez, 2002). In addition, early age of onset (do Rosario-Campos, 2001; Ferrão et al., 2012; Fontenelle, Mendlowicz, Marques, & Versiani, 2003; Ravizza et al., 1995) and impeding social factors including unemployment, low social economic status, and lack of a partner (Boschen, Drummond, Pillay, & Morton, 2010; Ferrão et al., 2006; Mishra & Sahoo,

2007), as well as the client's level of insight about his/her disorder (Neziroglu, Stevens, & Yaryura-Tobias, 1999) are thought to be important influences on treatment response in OCD.

As OCD is conceptualized to be a heterogeneous condition, it can be clinically useful, if not essential, to evaluate treatment outcomes within more homogenous entities (Robins & Guze, 1970). There have been numerous attempts to subgroup presentations of OCD according to symptom cluster (Calamari, Wiegartz, & Janeck, 1999; Ivarsson & Valderhaug, 2006), age of onset (Taylor, 2011), co-morbidity (Geller et al., 2003; Grados, Walkup, & Walford, 2003; Leckman et al., 2010), or response to pharmacotherapy or psychological treatment (Abramowitz, Franklin, Schwartz, & Furr, 2003; Mataix-Cols, Rauch, Manzo, Jenike, & Baer, 1999). In a continuous effort to delineate clinically meaningful subgroups, increasing attention is being paid to the underlying motivational processes of OCD (Chik, Calamari, Rector, & Riemann, 2010; Ecker & Gönner, 2008; Rasmussen & Eisen, 1992) as a useful dimension for classification. Research has, though, primarily focused on the role of harm avoidance (HA) as the core motivating force for engaging in compulsive behaviours, in this case, to reduce anxiety. The role of guilt (Shafran, Watkins, & Charman, 1996) and disgust (McKay, 2006) has interested a few researchers. More recently, it has been argued that a phenomenon labelled as "not just right experience" (NJRE) or "incompleteness" could be another core motivational dimension in OCD distinct from HA (Coles, Frost, Heimberg, & Rhéaume, 2003; Summerfeldt, 2004). In contrast to HA, obsessional precursors experienced in NJRE are vague and characterized by a sense of "wanting things to be a certain way". The compulsive behaviour is motivated to reduce the distress emanating from the sensation of things being not just quite right.

The NJRE construct was first described in the OCD literature in the turn of the 20th century by Pierre Janet (*les sentiments d'incompletude)* (Pitman, 1984). In an English translation of Janet's work, Pitman (1984) discusses Janet's speculations that obsessional ideas can be related to an underlying mental state of incompleteness. The feeling of incompleteness (INC) is driven by a lack of something or a sense that the action did not "produce the sought-for satisfaction" (Pitman, 1984; p.289). Despite early descriptions of what seemed to be a significant perceptual experience underlying obsessive compulsive behaviours, there have been proportionately few studies examining the clinical relevance of NJRE/INC in OCD as compared to HA. The limited research in this area may be related to the fact that this phenomenon is not easily conceptualised. NJRE has, hence, been inconsistently labelled, affecting in turn the ease of studying this phenomenon (Tolin, Brady, & Hannan, 2008). The most frequently used terms in the OCD literature are 'not just right experience' (NJRE) (Coles et al., 2003; Leckman, Walker, Goodman, Pauls, & Cohen, 1994), incompleteness (INC) (Rasmussen & Eisen, 1992; Summerfeldt, 2004) and sensory phenomena (SP) (Miguel et al., 2000); these are sometimes used interchangeably. NJRE has also been referred to as "premonitory urges" (Leckman, Walker, & Cohen, 1993), "sensory perfectionism" (Frost & DiBartolo, 2002) and the lack of "yedasentience" or a "feeling of knowing" (Szechtman & Woody, 2004). Theoretical differences have been proposed to explain nomenclature chosen. INC has been described as an internal experience (sensory affective experience) (Summerfeldt, 2004) driven by a sense of perfectionism (Ferrão et al., 2012; Lee et al., 2009). NJRE, on the other hand, was chosen to express more diffuse sensations of things feeling, looking, or sounding 'not just right'. The SP term has derived from tic disorder literature and includes the anatomically located physical sensations and mental (cognitive) sensations (including NJRE and INC)

preceding tics or compulsions. The tension reduction elicited by tics helps in equilibrating an internal state of discomfort as do compulsive behaviours in OCD.

In search of a consensus name for sensory experiences, a previous literature review surveyed data collected from 1980-2007 about sensory experiences in a clinical population of OCD and Tourette patients as well as in the general population, and attempted to identify overlaps (Prado & Rosário, 2008). It was concluded that the term sensory phenomenon (SP) best encompassed the physical and mental sensations seen in OCD and Tourette Syndrome (TS), but, in doing so, the perhaps unique cognitive aspects of the OCD sensory experience was not fully appreciated. For the purpose of this literature review "NJRE" has been chosen as the term best reflecting a cognitive component of wanting things to be just right or in aiming for a sense of completeness accompanying the sensory experiences. The choice of NJRE rather than SP, which historically has also included the physical sensations in tics, prioritizes a focus on cognitive components whilst still emphasizing the more sensation based experience as a model apart from traditional anxiety driven models of OCD.

Currently, more efforts are needed to synthesise the research findings of the 'not just right experience,' specifically in OCD. NJRE is a potentially important but under-researched construct which could enhance the understanding of the heterogeneity and complexity of OCD. In order to evaluate whether NJRE is a valid and clinically useful construct as proposed, the literature surveyed will be examined to initially summarize how NJRE has been conceptualized and measured. A prerequisite for engaging in clinical and research discussion is the establishment of an unambiguous clinical entity and is the first of several phases in identifying, and validating a homogenous clinical subgroup as outlined by Robins and Guze (1970). Therefore, the primary aim of this literature review

will be to identify clinical correlates associated with NJRE. Particular interest will be paid to the prevalence of NJRE in OCD and the relationship of NJRE to OCD symptoms, its developmental trajectory, and comorbidity. The literature review will further explore the following subsidiary questions: Does NJRE mark a subgroup of OCD individuals with distinct clinical features? Does NJRE underpin a specific profile of OCD symptoms? Does it aid in identifying different prognoses and treatment needs? Lastly, are NJREs specific to OCD or can they be associated with other psychopathologies?

Method

Search Strategy

The online databases "PubMed" and "PsychINFO" were searched for NJRE in OCD from the first publications until the end of August 2013. The search terms included all interchangeable or analogous concepts with NJRE describing a similar subjective experience. The following terms were used to search the databases:

> OCD **OR** obsessive compulsive **AND** NJRE **OR** "not just right experience*" **OR** "not-just-right-experience*" **OR** "just right" **OR** "sensory phenomena" **OR** "premonitory urge" **OR** yedasentience **OR** "feeling of knowing" **OR** "sensory tics" **OR** "sensory experience*"

In addition, the reference lists of retrieved studies were searched manually.

Selection Strategy

173 articles were identified on the basis of the search terms. Screening abstracts and keywords enabled a selection of peer reviewed articles written in English mentioning clinical variables associated with NJRE in OCD indiscriminate of gender and age. Articles were read and sorted according to inclusion and exclusion criteria.

Studies meeting the following inclusion criteria were reviewed:

- Study participants had to have a diagnosis of OCD based on a clinical assessment including but not exclusively based on the standardized classification system International Statistical Classification of Diseases and Related Health Problems (ICD) (World Health Organisation, 1992) or DSM (American Psychiatric Association, 2000).
- Studies had to measure the NJRE or one of its synonyms.
- Articles were included which focused on clinical characteristics of NJRE in OCD encompassing i.) prevalence of NJRE, ii.) relationship of NJRE to OCD symptoms, iii.) developmental trajectory, or iv.) comorbidity.

The following criteria were used to exclude studies:

- Studies which did not focus on the analysis of data such as articles focusing on theoretical models, reviews, and meta-analysis were excluded.
- Due to the narrow literature question, studies attempting to explore aetiology, outcome or underlying cognitive or biological mechanisms were excluded.
- Studies based on single case studies were excluded due to limited generalization of the findings.

Assessing methodological quality

Studies were assessed for methodological strengths and weaknesses and how these impacted on findings. Evaluations pinpointed reliability and the validity of measures, statistical testing selected, potential sample bias, confounding factors, and generalization of the results. No formalized scale for quantifying the methodological quality of the studies was used as not all of the questions of the appraisal tools were felt to be relevant

to the articles reviewed in this study (e.g. questions regarding follow-up of the participants).

Results

As is seen in the flowchart (Figure 1), initial searches yielded 173 articles referring to NJRE in OCD. After screening all abstracts, titles and keywords, 101 articles were excluded as their references to NJRE were of a transient nature and the NJRE phenomena itself was not of research interest. After assessing full-text articles, a further 25 studies were eliminated as they did not include participants with a diagnosis of OCD or had focused on healthy populations. Application of exclusion criteria meant excluding four further studies based on single case studies and five studies whose focus pertained to underlying cognitive or biological mechanisms underpinning the NJRE. An additional 11 studies were themselves reviews, meta-analyses, or theoretical papers and, thus, excluded. Five studies did not did not empirically assess NJRE. The remaining 22 articles met criteria established for this current literature review. The authors, their sample population including size and mean age, as well as study focus and methodology are summarized in Table 1.

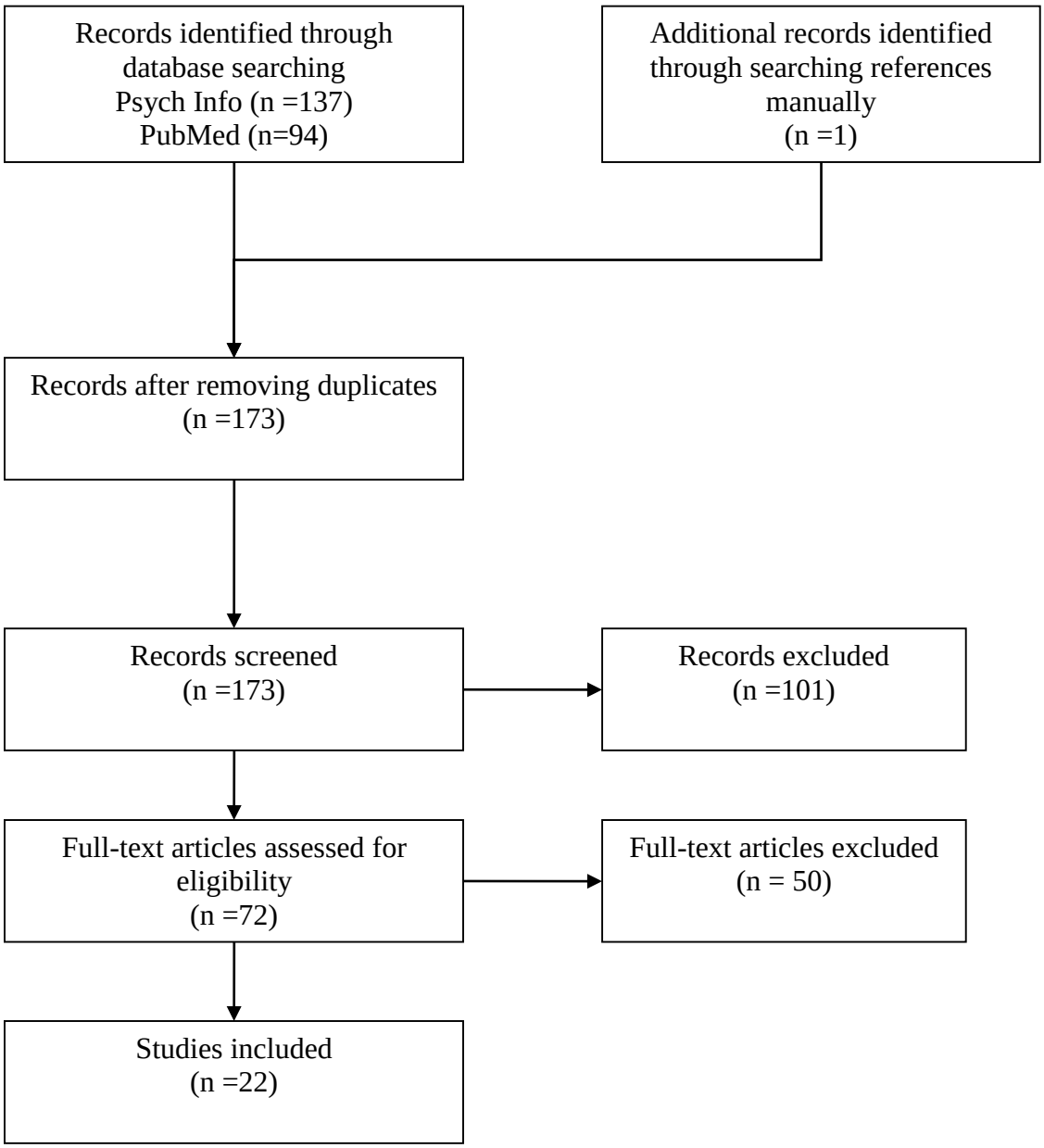

Figure 1. Flowchart of the literature search process.

Table 1
Summary descriptions of the studies included in this literature review

Authors	Sample Size (Population)	Mean Age (Standard Deviation)	Measurement of NJRE	Associated Variables

Chik et al., 2010	n=88 (OCD);
	n=43 (anxiety disorder);
	n=48 (students)
		36.41 (13.60)	Not Just Right Experiences-Questionnaire-Revised (NJRE-Q-R) (Coles, Heimberg, Frost, & Steketee, 2005)	1. Obsessive compulsive symptoms

Smith, Wetterneck, Hart, Short, & Björgvinsson, 2012	N=44 (OCD)	31.86 (10.08)	Perceived Threat from Emotions Questionnaire - Revised (PTEQ) (McCubbin & Sampson, 2006) + added questions about not just right feelings	1. Prevalence 2. Obsessive compulsive symptoms
Ferrão et al., 2012	N=1001 (OCD)	Not reported	University of São Paulo Sensory Phenomena Scale (USP-SPS) (Rosario et al., 2009)	1. Prevalence 2. Obsessive compulsive symptoms 3. Severity 4. Comorbidity—tic disorder 5. Age of onset
Lee et al., 2009	n=47 (OCD); n=41 (healthy controls)	37 (12)	USP-SPS (Rosario et al., 2009)	1. Prevalence 2. Specific relationship to OCD
Rosario et al., 2009	N=76 (OCD)	35.4 (12.4)	USP-SPS (Rosario et al., 2009)	1. Prevalence 2. Age of onset 3. Obsessive compulsive symptoms 4. Comorbidity- tic disorder

Authors	Sample Size (Population)	Mean Age (Standard Deviation)	Measurement of NJRE	Associated Variables
Diniz et al., 2006	N=168 (OCD)	30 (10)	University of São Paulo - Harvard Repetitive Behavior Interview (Miguel et al., 1995) (USP-Harvard Repetitive Behaviors Interview)	1. Comorbidity- tic disorder
Ecker & Gönner, 2008	N=202 (OCD)	37 (11)	Obsessive-Compulsive Trait Core Dimensions Questionnaire (OC-TCDQ) (Summerfeldt, Kloosterman, Parker, Antony, & Swinson, 2001)	1. Obsessive compulsive symptoms 2. Severity
Ecker, Kupfer, & Gönner, 2013	N=185 (OCD)	37.2 (10.6)	Obsessive-Compulsive Trait Core Dimensions Questionnaire- Revised- revised short form of OC-TCDQ (OC-TCDQ-R) (Ecker, Gönner, & Wilm, 2011)	1. Obsessive compulsive symptoms 2. Comorbidity-Obsessive Compulsive Personality Disorder
Starcevic et al., 2011	N=218 (OCD)	44 (1.1)	Functions of Compulsions Interview (Starcevic et al., 2011)	1. Prevalence 2. Obsessive compulsive symptoms
Coles, Pinto, Mancebo, Rasmussen, & Eisen, 2008	N=283 (OCD)	38.23 (12.24) OCD+OCPD; 40.16 (12.64) OCD-OCPD	Incompleteness Rating (Coles et al., 2008)	1. Comorbidity-Obsessive Compulsive Personality Disorder

Ghisi, Chiri, Marchetti, Sanavio, & Sica, 2010	n=30 (OCD);
	n= 12 (anxiety disorder);
	n=11 (depression);
	n=412 (university students)
		33.6 (12.6)	NJRE-Q-R (Coles et al., 2005)	1. Prevalence
				2. Specific relationship to OCD

Authors	Sample Size (Population)	Mean Age (Standard Deviation)	Measurement of NJRE	Associated Variables

Miguel et al., 2000	n=20 (OCD);
	n=20 (OCD +TS);
	n=21 (TS)
		36 (10.3)	USP-Harvard Repetitive Behaviors Interview (Miguel et al., 1995)	1. Prevalence
				2. Comorbidity- tic disorder

Leckman et al., 1994	n=31 (OCD +TS);
	n=61 (TS and obsessive symptoms);
	n=134 (tic disorder)
		32 (13)	"Just right" Interview (Leckman et al., 1994)	1. Prevalence
				2. Comorbidity- tic disorder
				3. Severity

Leckman et al., 1995	n=56 (tic-related OCD); n=121 (OCD)	39.2 (12.3) & 38.9 (10.2) different sites	"Just right" Interview (Leckman et al., 1994)	1. Prevalence 2. Comorbidity- tic disorders 3. Severity
Coles, Hart, & Schofield, 2011	N=18 OCD	33.22 (not reported)	Interview: course of OCD (Coles et al., 2011)	1. Course of OCD

Wahl, Salkovskis, & Cotter, 2008	n=38 (OCD-washers);
	n=41 (OCD other);
	n=43 (healthy controls)
		36.6 (11.8) OCD washer;
		35.8 (11.2) OCD
			Washing Interview and Inventory (Wahl et al., 2008)	1. Obsessive compulsive symptoms

Miguel et al., 2008	N=630 (OCD)	34.7 (.51)	USP-SPS (Rosario et al., 2009)	1. Prevalence
Rosario-Campos et al., 2001	n=42 (OCD)	31.4 (7.7) early onset; 32.9 (10.4) late onset	USP-Harvard Repetitive Behaviors Interview (Miguel et al., 1995)	1. Prevalence 2. Age of onset
Shavitt et al., 2006	N=41 (OCD)	30.5 (8.3)	USP-Harvard Repetitive Behaviors Interview (Miguel et al., 1995)	1. Prevalence

Authors	Sample Size (Population)	Mean Age (Standard Deviation)	Measurement of NJRE	Associated Variables
Gomes de Alvarenga et al., 2012	n=577 (OCD); n= 263 (OCD + tic disorder)	34.9 (0.54)	USP-SPS (Rosario et al., 2009)	1. Prevalence 2. Comorbidity- tic disorder
Miguel et al., 1995	n=15 (OCD); n=17 (TS)	37.4 (10.5)	USP-Harvard Repetitive Behaviors Interview (Miguel et al., 1995)	1. Prevalence
Tolin et al., 2008	N=99 (OCD)	39.00 (13.42)	Principal Component Analysis using Obsessive Beliefs Questionnaire-44 (Obsessive Compulsive Cognitions Working Group, 2005) and Obsessive Compulsive Inventory-Revised (OCI-R) (Foa et al., 2002)	1. Obsessive compulsive symptoms 2. Specific relationship to OCD

Note. OCD=obsessive-compulsive disorder; TS=Tourette Syndrome; OCPD= obsessive-compulsive personality disorder.

Measuring NJRE

Assessment methods. All assessments were based on self-report measures. The majority of the research reviewed (n=15) used semi-structured interviews to investigate NJRE. A questionnaire was used in only seven studies. Due to the challenge of operationalising this sensory-cognitive experience, researchers focused on more readily identifiable and measurable aspects of NJRE such as frequency and severity, immediate and delayed distress components, and the sensory modality most affected as is seen in Table 2.

Definition of NJRE. The literature reviewed exposed variations in terms of measuring and defining SP, NJRE or INC. Summarising the questionnaires and interviews, it appears that most authors agree that this experience refers to a mental/cognitive sensation in OCD leading individuals to perform compulsions until they feel just right or a sense of completion has been achieved. The only exception is that occasionally 'just right' experiences are described as having a physical and mental component (Leckman et al., 1994; Miguel, et al., 1995). The nomenclature (NJRE and INC) may be interchangeable (Coles et al., 2008; Ghisi et al., 2010; Summerfeldt et al., 2001) although attempts have been made to define NJRE and INC more succinctly, one description being that NJRE reflects a more externally triggered experience and INC an internal experience (Ferrão et al., 2012). In addition, INC has been associated with a sense of perfectionism (Summerfeldt et al., 2001); however, it is not clear whether wanting something to be 'perfect' is different than wanting something to be 'just right.' It has furthermore been proposed that the term SP encompasses both NJRE and INC (Rosario et al., 2009). However, the term SP also includes physical sensations that are primarily relevant to tic disorders.

Content of measures. Except for the Obsessive-Compulsive Trait Core Dimensions Questionnaire (OC-TCDQ), all the questionnaires assessed NJRE specifically (Coles et al., 2003; Leckman et al., 1994; Smith et al., 2012). The 'just right' interview also measured INC separately (Leckman et al., 1994). Unlike the other questionnaires, the OC-TCDQ uses the term INC in their questionnaire, but has defined INC as a sense of things being not-just right. The Not Just Right Experiences-Questionnaire-Revised (NJRE-Q) assesses a broader range of NJRE related clinical features than the OC-TCDQ including distress, rumination etc. Potential validity problems arise with closed-ended questions, as individuals may interpret the questions differently and cannot contextualise their responses.

Most interviews assessing 'not just right' experiences generally measured sensory perception in any sensory modality with the exception being the Functions of Compulsions interview (Starcevic et al., 2011) which focused on things "looking" not just right. The majority of the studies implementing semi-structured interviews used the University of São Paulo-Harvard Repetitive Behavior Interview (USP-SP) (Rosario et al., 2009) and University of São Paulo-Harvard Repetitive Behavior Interview (USP-Harvard) (Miguel et al., 1995) as measurements which collectively encompass both cognitive and physical sensory experiences. The remaining three studies using interviews focused on 'just right' perceptions (Coles et al., 2011; Starcevic et al., 2011; Wahl et al., 2008).

Psychometric properties. Generally it appeared that the questionnaires were more psychometrically sound than the semi-structured interviews. The two most widely implemented questionnaires, the NJRE-Q (Coles et al., 2003) and OC-TCDQ (Summerfeldt et al., 2001), were found to have good to excellent internal consistency for both non-clinical (Coles et al., 2003; Coles et al.,2005) and clinical populations (Ecker &

Gönner, 2008; Ghisi et al., 2010). The Perceived Threat from Emotions Questionnaire - Revised questionnaire (PTEQ-Revised), which has good internal consistency, was adapted to include additional questions about not-just-right feelings (Smith et al., 2012). The authors evaluated the internal consistency of this supplementary section and found it to be excellent. They also found it to have good convergent validity with measures of mood, responsibility, and thought (Smith et al., 2012). The "just right" perceptions questionnaire, which was developed specifically for the purpose of the study, revealed no information about its psychometric properties (Leckman et al., 1994).

Not all the semi-structured interviews assessed reliability and validity. In three such cases, the authors did seek preliminary control measures to ensure greater reliability by requiring consensus agreement between researchers, pre-interview training, or by conducting pilot tests (Coles et al., 2008; Coles et al., 2011; Starcevic et al., 2011). In addition, the interview schedules appeared to have face validity as questions seemed in line with the NJRE construct. However, the limited psychometric evaluation and, in particular, the lack of measures of inter-rater consistency necessitates interpreting results with caution. The flexibility and responsive nature of the interview as an assessment method, although potentially giving rise to difficulties with reliability, probes participants and allows for richer and less predetermined answers, and, ultimately, may provide for more valid data in exploratory research phases.

Summary. The review of the measures, as is seen in Table 2, highlights the complexity of assessing the 'not just right' construct. Currently there is no gold standard in assessing this phenomenon. All methodologies have their own specific strengths and weaknesses. Overall the questionnaires appear to be more psychometrically sound; however, they are not able to assess the construct in a more explorative manner. This is

particular important during a phase of research in which establishment of an unambiguous clinical entity is foremost, and researchers have not fully agreed on how to best define this construct.

Table 2
Summary of the measures used in the included studies

Measurement tool	NJRE/INC/SP Definition	Methodology	Psychometric properties	Studies using it
Semi-structured interviews				
USP-Harvard Repetitive Behaviours Interview (Miguel et al., 1995)	*Measures*: SP *Defined as*: "bodily sensations...or mental sensations (general, uncomfortable feelings or perceptions that includes urges to perform behaviour...an inner sense of incompleteness, imperfection or insufficiency, and the general perception of not being 'just right' that leads to the performance of behaviours until achieving that 'just right' feeling)" (Shavitt et al., 2006, p.278)	• Open ended questions and rating scale • Measures severity and frequency of SP	Inter-rater reliability =.98-.99 (Spearman's correlation) (Miguel et al., 2000).	(Diniz et al., 2006; Miguel et al., 1995; Miguel, 2000; Rosario-Campos et al., 2001; Shavitt et al., 2006)
Functions of Compulsions Interview (Starcevic et al., 2011)	*Measures:* visual 'just right' sensations *Defined as:* "to correct things, so that they look 'just right' or perfect" (Starcevic et al., 2011; p.451).	• Open-ended questions and rating scale • Measures level of distress and reason for performing compulsion	Not evaluated-interview designed for study.	(Starcevic et al., 2011)

Measurement tool	NJRE/INC/SP Definition	Methodology	Psychometric properties	Studies using it
Incompleteness Rating (Coles et al., 2008)	*Measures:* INC *Defined as:* need to "perform compulsion until it feels 'just right'" (Coles et al., 2008; p.291)	• Open-ended questions • Measures INC and consequences of not performing primary compulsion.	Not evaluated- consensus agreement in research team based on set criteria agreed to encompass INC	(Coles et al., 2008)
Interview- the course of OCD (Coles et al., 2011)	*Measures:* NJRE *Defined as:* "for things to feel 'just right'"(Coles et al., 2011; p.690)	• Open ended questions and rating scale • Measures OCD risk and transition factors based on list of symptoms	Not evaluated- training involved prior to administration	(Coles et al., 2011)
The Washing Interview and Inventory (Wahl et al., 2008)	*Measures:* just right *Defined as:* sensation of feeling right	• Open ended questions (interview) and rating scale (washing inventory) • Measures reasons for stopping washing and rating their importance	Inter-rater reliability= 0.87 (kappa) for OCD washers and 0.85 for non-compulsive washers (Wahl et al., 2008) Test-retest reliability for washing inventory= .63-.89 (Wahl et al., 2008)	(Wahl et al., 2008)

Measurement tool	NJRE/INC/SP Definition	Methodology	Psychometric properties	Studies using it
USP-SP (Rosario et al., 2009)	*Measures:* SP *Defined as:* physical sensations, externally triggered 'just right perceptions', internally triggered 'just right' perceptions of feeling of INC, and urge only	• Checklist with follow-up questions and rating scale • Measure past and current examples of SP and severity, frequency, amount of distress and interference	Inter-rater reliability=.92 (Kappa) (Rosario et al., 2009) Concordance between self-reports and 'expert USP-SPS ratings' =.84 (Kappa) (Rosario et al., 2009) Reported good convergent validity with gold standard clinical interview (Rosario et al., 2009)	(Ferrão et al., 2012; Gomes de Alvarenga et al., 2012; Lee et al., 2009; Miguel et al., 2008; Rosario & Prado, 2009)
<u>Questionnaires</u>				
"Just right" Perceptions Questionnaire (Leckman et al., 1994)	*Measures:* 'just right' and INC *Defined as: "*need for things to be just right" and psychasthenia ("an inner sense of 'incompleteness', 'imperfection' and 'insufficiency'") (Leckman et al., 1994, p.676)	• Measures onset, frequency, anatomical location, and characteristics of 'just right' perception including mental or physical and visual, auditory or tactile	Not evaluated- based on pilot tests	(Leckman et al., 1995; Leckman et al., 1994)

Measurement tool	NJRE/INC/SP Definition	Methodology	Psychometric properties	Studies using it
NJRE-Q-R (Coles et al., 2003)	*Measures*: NJRE *Defined as:*-"times when you have the subjective sense that something isn't just as it should be" (Coles et al., 2003; p.684).	• Measures: frequency, intensity, immediate distress, delayed distress, rumination, urge to respond, and responsibility • Items: 19 items rated on a binary scale and on 7 point Likert scale frequency, intensity, immediate distress, delayed distress, rumination, urge to respond, and responsibility,	Internal consistency for non-clinical sample= .67-.79 (Cronbach's alpha) (Coles et al., 2003) Internal consistency for clinical sample= .89 (Cronbach's alpha) (Ghisi et al., 2010)	(Chik et al., 2010; Ghisi et al., 2010)
OC-TCDQ (Summerfeldt et al., 2001)	*Measures:* INC *Defined as:* "the need to correct feelings of dissatisfaction regarding the need for experience to be flawless and perfect or feel 'just right' (Ecker & Gönner, 2008, p.897)	• Measures: harm avoidance and INC • Items: 20 items rated on 5 point Likert scale	Internal consistency for non-clinical sample HA (.91) and INC (.93) (Cronbach's alpha) (Coles et al.,2005) Internal consistency for clinical sample HA (.91) and for INC (.90) (Cronbach's alpha) (Ecker & Gönner, 2008)	(Ecker & Gönner, 2008)

Measurement tool	NJRE/INC/SP Definition	Methodology	Psychometric properties	Studies using it
OC-TCDQ-R (Ecker et al., 2011)	Short version of OC-TCDQ (Summerfeldt et al., 2001); see OC-TCDQ	• Measures: harm avoidance and INC • Items: 10 items rated on 5 point Likert scale.	Internal consistency for clinical sample HA (.77) and INC (.88) (Cronbach's alpha) (Ecker et al., 2011).	(Ecker et al., 2013)
PTEQ-Revised (McCubbin & Sampson, 2006) & questions about NJRF(Smith et al., 2012)	*Measures* "not just right feeling" *Defined as:* "needing to perform compulsions until they 'feel right'" (Smith et al., 2012, p.56)	• Measures: beliefs about emotions relevant including not just right feelings (NJRF) • Items: 5 specific NJRF rated on a 5 point Likert scale	Internal consistency PTEQ-Anxiety= .86 (Cronbach's alpha); PTEQ-NJRF =.94 (Cronbach's alpha) (Smith et al., 2012) Strong convergent validity with measures of mood, responsibility, and thought (Smith et al., 2012)	(Smith et al., 2012)

Note. USP-Harvard Repetitive Behaviours Interview= University of São Paulo -Harvard Repetitive Behavior Interview; USP-SP= University of São Paulo Sensory Phenomena Scale; NJRE-Q-R = Not Just Right Experiences-Questionnaire-Revised; OC-TCDQ= Obsessive-Compulsive Trait Core Dimensions Questionnaire; OC-TCDQ-R= Obsessive-Compulsive Trait Core Dimensions Questionnaire- Revised; PTEQ-Revised= Perceived Threat from Emotions Questionnaire –Revised; SP=sensory phenomena; NJRE= 'not just right experience'; INC=incompleteness.

Clinical presentation of NJRE in OCD

Review-selected research papers of NJRE in OCD have identified clinical variables addressing the questions of prevalence, NJRE relationship to obsessive compulsive symptoms, developmental trajectory, and comorbidity. A summary of these findings attempts to provide a clear clinical description of the NJRE phenomenon in OCD.

How frequent are NJREs?

Prevalence. Fourteen of 22 studies have reported prevalence rates of cognitive-sensory experiences in OCD patients. There was significant variation in whether studies reported the prevalence rates of SP, NJRE, and INC separately or collectively. It is, furthermore, important to note considerable variability in sample size and sample populations. Participants were drawn exclusively from OCD clinics, not community samples. Currently, there is no epidemiological data assessing NJRE rates in the wider community of OCD individuals.

Seven of these studies determined the prevalence rate of SP in OCD (Ferrão et al., 2012; Gomes de Alvarenga et al., 2012; Miguel et al., 2008; Rosario-Campos et al., 2001; Shavitt et al., 2006; Rosario et al., 2009; Miguel et al., 1995). SP is the terminology used in the OCD literature to most broadly describe sensory phenomena including mental sensory experiences (NJRE and INC) and physical sensory sensations. The reported prevalence rates of SP were high and varied from 57.5% to 72% (Ferrão et al., 2012; Gomes de Alvarenga et al., 2012; Miguel et al., 2008; Rosario-Campos et al., 2001; Shavitt et al., 2006; Rosario et al., 2009; Miguel et al., 1995). If separately considered, physical sensory sensations (27.6%) were less frequent than mental/cognitive sensory sensations (48.9%) (Rosario et al., 2009)

An inherent difficulty in determining SP prevalence relative to NJRE rates has been the inclusion of populations with tic disorders (TD) and the failure to differentiate cognitive and physical SPs. Up to a third of the OCD sample in several studies experienced tics, potentially inflating the prevalence rate of SP in OCD (Gomes de Alvarenga et al., 2012; Miguel et al., 2008; Shavitt et al., 2006; Rosario et al., 2009). Even though prevalence rates have been found to be higher with a comorbid TD (Miguel et al., 1995; Miguel, 2000), prevalence rates without tics are still found to be as high as 73% (Leckman et al., 1994).

Other studies have looked at prevalence rates for NJRE and INC, thus focusing more on mental constructs of sensory phenomena. Valid prevalence rates remained elusive as the cognitive phenomena were not well defined and it is unclear to what extent NJRE and INC are measuring the same or slightly different experiences. If independently rated, it appears that the prevalence rates are higher for NJRE (43.2% to 79.7%) (Ferrão et al., 2012; Lee et al., 2009; Rosario et al., 2009; Smith et al., 2012; Starcevic et al., 2011) as compared to INC (13.5% to 27%) (Ferrão et al., 2012; Lee et al., 2009). However, ambiguity remains as it has also been suggested that INC (81%) is more frequent than NJRE (73%) in individuals with OCD (Leckman et al., 1995).

An additional study compared prevalence of NJRE in OCD populations to a population of students. Ghisi et al. (2010) collected data for 30 OCD patients and 412 undergraduate students. All the OCD individuals reported to have experienced one NJRE. Furthermore, the majority of the undergraduate students (83%) reported experiencing a NJRE; however, their experiences of NJRE were less frequent and less severe than those experienced by individuals with OCD. Furthermore, they occurred in social situations: "when talking to people, I have had the sensation that my words did not sound just right."

This item may reflect self-consciousness in this younger population and in isolation may have little discriminating validity.

Of interest to some researchers was whether differences in prevalence could be found if NJRE were linked to a specific sensory modality. Visual and tactile 'just right' experiences were found to be most frequent (Leckman et al., 1995; Leckman et al., 1994). Lee et al. (2009) found that visual NJREs were the most commonly experienced.

Overall, it appears that NJREs are commonly experienced in OCD patients (Ferrão et al., 2012). Due to the limited isolated analysis of the different terms used to describe a similar phenomenon, data are ambiguous but point out trends. It remains unclear, due to lack of epidemiological community studies, as to what extent prevalence rates can be generalized. At present, the prevalence data is drawn from OCD specialist centres and may reflect the more severe end of the OCD spectrum. In addition, the presence of tics may confound prevalence ratings of NJRE in OCD.

NJRE relationship to OCD symptoms.

NJRE specific relationship to OCD. It appears that NJREs are common in OCD, but, it is, furthermore, important to evaluate whether NJREs enable discrimination of OCD patients from healthy controls or from other clinical populations. This is particularly important as NJREs occur in the general population. It appears that it is the severity and frequency of NJREs which distinguishes their appearance in healthy controls from their role as an underlying mechanism in OCD patients (Lee et al., 2009). In addition, studies could point out that NJREs are more helpful in identifying OCD than, for example, is perfectionism. Perfectionism is an OCD related phenomenon (Lee et al., 2009). Ghisi et al. (2010) similarly found that NJRE, but not perfectionist beliefs, differentiated between OCD patients and the clinically anxious or depressed patient in their small clinical sample.

These findings suggest that NJRE, even more than perfectionism, may be associated to OCD and may play a role in OCD pathology.

At this stage of research, however, it is not possible to draw general conclusions about the specificity of the NJRE concept as a clinical marker specific to OCD. Future research needs to extend the study by Ghisi et al. (2010) and explore the role of NJRE in sample populations across related clinical presentations in the DSM 5, such as trichitillomania, body dysmorphia, or even autism spectrum disorders.

NJRE relationship to OCD symptoms. There are nine studies reviewed which aim to assess whether specific OCD symptoms can be attributed to NJRE or other core motivational process. The majority of these studies have compiled symptom profiles using the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) (Goodman, 1989). Two studies have relied on the Obsessive-Compulsive Inventory (OCI) (Foa et al., 2002). Both measures are found to be comprehensive instruments, but differ slightly as to choices of obsessions and compulsions listed. A further study has used the Dimensional Obsessive Compulsive Scale. All measures rate the type and severity of symptoms. Tolin et al. (2008) used a factor analytic study to determine their results.

Research suggests that OCD symptoms can be underpinned by different motivational processes. Starcevic et al. (2011) presumes motivational heterogeneity in most individuals with OCD and found that most OCD patients perform compulsions for more than one reason (85.3%). This is clearly demonstrated in a study by Ecker and Gönner (2008) in which both INC and HA were associated with checking behaviours. Wahl et al. (2009) found that internal guiding processes including ‘just right’ experiences were not limited to a particular OCD symptom such as washing.

However, there are several studies suggesting OC symptoms can be associated with the core motivational processes. Ecker and Gönner (2008) directly compared symptom dimensions associated with INC and harm avoidance (HA) and could demonstrate that symptoms differed respective to the core motivational mechanism. They found that INC was related to OCD behaviours involving symmetry and ordering, and both INC and HA were related to checking behaviours. Other studies have subsequently supported these results and have consistently found that symmetry (Ferrão et al., 2012; Rosario et al., 2009; Smith et al., 2012; Starcevic et al., 2011) as measured by the Y-BOCS (the OCI-R does not include symmetry in its repertoire) and, similarly, ordering have been found to be associated to NJRE/INC/SP (Ecker et al., 2013; Ferrão et al., 2012; Rosario et al., 2009; Starcevic et al., 2011; Tolin et al., 2008). Other less frequently reported OCD symptoms associated with NJRE include the following: arranging (Ferrão et al., 2012; Rosario et al., 2009), checking (Ecker et al., 2013; Tolin et al., 2008), contamination/washing (Ferrão et al., 2012), mental neutralising (Tolin et al., 2008), hoarding (Tolin et al., 2008), and repeating compulsions (Starcevic et al., 2011).

It seems that the relationship between NJRE and obsessive compulsive (OC) symptoms is not linear. It has been proposed that NJRE and OC symptoms are modulated by the extent to which unhelpful beliefs are present. Chik et al. (2010) found that NJREs were prevalent in OCD patients with both high and low levels of 'unhelpful beliefs' but a relationship between NJRE and OC symptoms could only be established in the low level group. Perhaps NJRE accounts more strongly for OC symptoms in the absence of traditional cognitions associated with OCD symptoms. Unfortunately, this study failed to control for severity of OCD. There may be an array of motivational processes involved in

patients with chronic and severe OCD presentations making it more difficult to link NJRE to specific OC symptoms.

In conclusion, there appears to be motivational heterogeneity underlying symptom profiles of the OCD presentation. It appears that NJRE is more likely to be associated to OCD symptom profiles including symmetry and ordering symptoms. If further studies confirm Chik et al. (2010) findings that NJRE plays a more significant role in maintaining OC symptoms in the absence of strong unhelpful beliefs, than this could potentially suggest that some individuals with OCD and NJREs are less responsive to cognitive behavioural therapy (CBT). However, these findings and speculations are tentative.

Developmental trajectory of NJRE in OCD.

Age of onset. Age of onset has been found to be an important factor in understanding various clinical conditions (Moffitt, Caspi, Dickson, Silva, & Stanton, 1996) and may be accounted for by inheritable predispositions, for example, different genes are thought to contribute to an early versus late onset of Alzheimer's Disease (Bertram & Tanzi, 2008). These findings suggest that age of onset may be an important determinant suggestive of a distinct etiological subtype in a neurological disorder. Furthermore, an earlier age of clinical onset might be suggestive of a more developmental phenomenon mirroring early neurological differences in brain development. There are three studies interested in the relationship of NJRE to the age of OCD clinical onset. The first study by Rosario-Campos et al. (2001) compared early (<10 years) versus late (>17 years) onset OCD presentations. In this study (Rosario-Campos et al. 2001) and in a later study (Rosario et al., 2009) the early onset group had higher SP scores but, likewise, higher overall symptom severity and higher rates of tic-comorbidity. The predictive value of age was frequently limited in the reviewed studies due to the absence of statistical controls for

tics, as a potentially confounding variable presenting, too, at an early age. One study found that an earlier age of OCD onset was more frequently seen in OCD with SP; however, it was no longer an independent variable in a multivariate analysis (Ferrão et al., 2012). Hence, at this stage, research findings show that increased SP experiences in the OCD population may parallel an early age of onset, but findings need to be confirmed in studies controlling for confounding variables such as the effects of tics.

Course of NJRE in OCD. Age of onset could suggest a developmental origin; however, only one study has attempted to explore the trajectory of NJRE in OCD. In a retrospective study Coles et al. (2011) looked for the appearance of OCD behaviours in the transition from the manifestation of initial OCD symptoms to OCD diagnosis. Unfortunately, our understanding of the role of NJRE in this clinical trajectory is limited to the measurement tool employed in the study. Coles et al. (2011) used a relatively structured interview providing participants with a list of choices to identify risk and transition factors before development of full-blown OCD. NJRE was not a listed choice in the risk phase, yet NJREs, as were stress levels and time lost in consuming thoughts, could be identified as significant clinical factors in the transition phase before OCD diagnosis. Due to the limitations in the assessment method, we cannot conclude whether NJRE is an identifiable predisposing factor to OCD or not.

OCD symptom severity. There are four studies, which attempted to address the question as to whether the presence of NJRE predisposes to more severe obsessive compulsive symptoms or not. Results differed as to constructs measured. In an early study by Leckman et al. (1994), highest OCD scores, as measured by mean Yale Brown Obsessive Compulsive Scales (Y-BOCS), were related to most frequent 'just right' sensations. In this study all participants had a comorbid tic-disorder. However, since the

patients with or without NJRE did not differ in terms of tic severity, comorbidity may not have been a confounding variable. In a following study Leckman et al. (1995) confirmed these results in an OCD population, in which the majority of the subjects did not have a comorbid tic-disorder. Ferrão et al. (2012) found that overall symptom severity did not differ between OCD individuals with and without SP; however, specific symptoms such as symmetry/ordering/arranging, contamination/washing and hoarding were judged to be more severe in OCD within the SP group. Ecker and Gönner (2008) found, when comparing HA and INC in terms of their associations to OCD symptom dimensions, that INC and not HA was related to OCD symptom severity in two out of three analyses suggesting a preliminary link between INC and symptom severity.

It is of clinical interest that NJRE may to be related to symptom severity. Research into this phenomenon may provide a better understanding of the poor prognosis in some individuals with OCD.

Related disorders: comorbidity. Research literature interested in NJREs in OCD has looked for its appearance in comorbid tic presentations and personality disorders. Associations to other comorbid presentations have not yet been examined.

Tic-disorders. As patients with tic-disorders are known to experience sensory phenomenon (described as "physical urges"), it is not surprising that seven of the studies reviewed chose to look more carefully at tic-syndrome, OCD, and their comorbidity in hoping to better understand the sensory experiences in these perhaps "related" disorders. NJRE's are reported to be more frequent in OCD with TS as compared to OCD only (Miguel et al., 1995; Miguel, 2000). NJREs in comorbid OCD and TS have been reported to be as high as 81% to 90% (Leckman et al., 1994; Miguel, 2000). Comparing SP experiences in three groups of individuals (OCD, OCD-TS, and TS) it was found that

bodily sensations were only prominent in TS but that mental sensations were specific to a comorbid or OCD presentation (Miguel et al., 2000).

Diniz et al. (2006) additionally report in their study that SP in the OCD-TS group appears to be phenomenologically different and more frequent than in OCD patients without TS. It was argued that these findings were not explained by the global severity of the OCD presentation alone. However, results may be spurious as they fail to statistically correct for multiple comparisons. It has been, furthermore, suggested that OCD patients on the far end of the tic continuum (positive family history or Tourette syndrome) showed significantly more SP (Ferrão et al., 2012). Ferrão et al. (2012) found that a family history of tics and tic frequencies were approximately twice as frequent in the OCD-SP group as compared to the OCD group without SP.

Although authors have cited frequent experiences of SP/NJRE in tic-related OCD, it cannot be assumed that tics are an independent predictor for cognitive sensory phenomena. Leckman et al. (1995) did not find NJRE to be more frequent in a tic-related OCD group versus only OCD. Similarly, Rosario et al. (2009) did not find tics to be more frequent in a group of individuals with SP.

In summary, it appears that NJRE/SP experiences are frequently seen in individuals with a comorbid diagnosis of OCD and tic disorder. The contribution of the tic disorder to frequencies of cognitive sensory phenomena reflected in NJRE has not been clearly defined. Researched studies collecting data about NJRE in OCD-TS versus OCD disavow comparisons at this time as there were no controls for OCD symptom severity as a confounding variable. The contribution of other core motivational mechanisms such as HA beliefs to OCD symptoms were not taken into account.

Obsessive- Compulsive Personality Disorder (OCPD). High rates of comorbidity between OCPD and OCD are consistently reported (Garyfallos et al., 2010; Hummelen & Wilberg, 2008). This is perhaps unsurprising since several of the core diagnostic criteria of OCPD including preoccupation with details, hoarding, and perfectionism are particular pertinent to OCD (Eisen et al., 2006). This review highlighted that symptom dimensions in co-morbid groups (OCD-OCPD or OCD-OCPD traits) reflected those commonly described in OCD individuals experiencing sensory phenomena (Coles et al., 2008; Ecker et al., 2013). Studies by Coles et al. (2008) and Ecker et al. (2013) have explored whether NJRE is the underlying mechanism which accounts for overlaps in presentation. The study by Coles et al. (2008) yielded a statistical trend linking NJRE to OCD-OCPD. The findings by Ecker et al. (2013) were more conclusive in suggesting that NJRE could be identified as a common motivational factor underlying OCPD traits and OCD. Again, ambiguity in the conceptual formulation of NJRE may obscure definitive findings. Coles et al. (2008) acknowledged that there could have been limitations in their measurement method as some clients struggled to understand the concepts assessed in their semi-structured interview.

In conclusion, follow-up research using psychometrically sound measures might better verify the clinical relevance of SP and symptom dimensions in a population of individuals with a comorbid OCD and OCPD diagnosis. Preliminary findings suggest that NJRE processes could explain similar behaviours seen in both OCD and OCPD.

Summary. In overview, the present literature review has identified several exploratory studies attempting to define the clinical presentation associated with NJRE in OCD. The conceptual difficulty exemplified in the studies in labelling and defining this experience has been a primary obstacle for this review, making it difficult to interpret

results to validate NJRE as a clinical construct und homogenous clinical subgroup in OCD. However, regardless of the term used (NJRE, INC or SP), studies reviewed allow an insightful exploration of a cognitive-sensory mechanism that seems to be highly prevalent in OCD and less clearly understood as a core motivational factor in OCD than HA. NJRE appears to be associated with a range of OC symptoms including, but not limited to, symmetry, arranging, and ordering. It can be ascertained that in OCD populations NJREs have been associated more frequently with early age of onset; however more research is needed to verify a developmental course. It is still unclear what role NJRE plays in the overall trajectory and prognosis of OCD. NJRE seems likely to occur at transition phases from latent to clinical manifestation of the disorder. It appears to be related to symptom severity at presentation affecting poorer treatment outcome. NJREs are more frequently seen in co-morbid conditions, in particular with associative tic-disorders, and perhaps OCPD.

Discussion

Key findings

This literature review aimed to provide a clinical description of NJRE in OCD as a means of establishing its utility in clinical practice. It attempted to summarize initial research findings which could help elucidate our understanding of the concept of NJRE and to address questions as to whether NJRE marks a subgroup of OCD individuals with distinct clinical features, underpins a specific profile of OCD symptoms, and whether it is associated with other psychopathologies. The current literature review identified 22 studies attending to the NJRE phenomenon in OCD. The majority focused on determining

prevalence of NJRE or its association to OCD symptoms and to co-morbid tic disorders in OCD populations.

Overview of NJRE in OCD. Ambiguity remained in how these sensory experiences and "feelings of not just right" were operationally conceptualized and, thus, measured. Hence it was challenging at times to compare findings and draw succinct conclusions. Terms (NJRE, INC, SP) were interchangeably applied, so that it remained unclear as to what extent these terms were referring to same or slightly different experiences. Variations in conceptualising NJRE could be meaningful in terms of discriminative and predictive potential in clinical practice.

Although studies did not lend clarity in establishing a clear-cut definition of the NJRE experience, they have, nevertheless, demonstrated that sensory-cognitive phenomena embodied in the construct NJRE are prevalent experiences in OCD populations. They suggest that to merely focus on harm avoidance in the understanding and treatment of OCD would be an oversimplification. Despite the inconsistencies in terminology used, the mere prevalence of this experience, suggested to be as high as 65 to 72% in larger studies focusing on SP (Ferrão et al., 2012; Gomes de Alvarenga et al., 2012; Lee et al., 2009; Miguel et al., 2008; Rosario et al., 2009; Shavitt et al., 2006) strengthens the argument for motivational heterogeneity in OCD.

Clinical characteristics. Clinical variables associated with NJRE in OCD could be identified in the literature review, which are potentially of significance to OCD clinical practice. NJREs were frequently associated with severe OCD symptomatology (Ecker & Gönner, 2008; Leckman et al., 1994; Leckman et al., 1995) and an earlier age of onset (do Rosario-Campos, 2001; Ferrão et al., 2012; Rosario et al., 2009), both of which have been associated with poorer treatment outcomes (Catapano et al., 2006; do Rosario-Campos,

2001; Ferrão et al., 2006; Ferrão et al., 2012; Fontenelle et al., 2003; Franklin et al., 2000; Hollander et al., 2002; Keijsers et al., 1994; Ravizza et al., 1995).

Furthermore, the literature review has established a high prevalence of NJREs in OCD patients with comorbid tic-disorders. Tentative findings also suggest that NJRE may also be related to OCPD. Treatment responses in comorbid conditions with OCD are also likely to be less successful (Baer, 1992; Catapano et al., 2006; McDougle, 1994; Minichiello et al., 1987; Ravizza et al., 1995).

NJRE does appear to underpin a specific profile of OCD symptoms. In the literature review symptoms of symmetry, ordering, and arranging were identified as most likely related to NJREs 'liking things to be a certain way'. However, this association is not exclusive, and a range of OCD symptoms including checking, hoarding, mental neutralising, repeating, and washing can be found together with NJREs. It is more than likely that most OCD symptoms are marked by multiple motivational processes (Starcevic et al., 2011).

It is not possible to conclude from the current literature that NJREs are specific to OCD, thus limiting appraisals of clinical usefulness. It would be essential to widen the literature search and explore this phenomenon in other related conditions. The association to comorbid tics and perhaps even OCPD suggests that NJRE may represent a shared bioneurological mechanism that overlaps with psychopathologies sharing comorbidity in OCD.

Theoretical Implications

It is theoretically possible that NJRE is an underlying motivational mechanism defining a subgroup of individuals with OCD. The literature review has identified NJRE as a prevalent experience in OCD populations and has, furthermore, highlighted a cluster

of features appearing to have clinical relevance to treatment outcome. At present, though, research findings are descriptive and not yet validating NJRE as a clear clinical entity or subgroup according to Robins and Guze (1970). In addition, the validity for clinical practice cannot be ascertained from this literature review which has not included adjunct scientific information about aetiology or family , laboratory, neuroimaging, or outcome studies (Kendell & Jablensky, 2003).

The literature review has, indeed, provided some evidence suggesting that NJRE is unlikely to be a clear marker of an OCD subgroup, but is rather a dimension coinciding with other motivational processes in OCD such as HA. The high prevalence of this experience in OCD and in the general population challenges the notion that NJRE is a specific marker of a subgroup. In addition, it appears that the severity and frequency rather than the mere presence of this phenomenon is indicative of clinical relevance in OCD (Lee et al., 2009). One may argue that the dimensional and categorical perspectives are not mutually exclusive. Perhaps those individuals on the severe end of the OCD spectrum experiencing NJREs differ as to underlying aetiologies and cognitive mechanisms from those OCD individuals in which HA can be identified as the primary motivational process.

Of interest are speculations that NJRE may be a marker for a more neurodevelopmental presentation of OCD. This hypothesis is based on the assumption that NJRE embodies a mechanism distinct from the socio-emotional basis of HA and anxiety driven OC symptoms. NJRE in OCD shares sensory features with neurological conditions such as tic disorders. The tendency for NJRE to be triggered by external stimuli in the environment has been noted. Leckman et al. (1995) portrayed patients with NJRE symptoms as experiencing "exquisite perceptual sensitivity to changes in their usual environment" (p.214). NJREs may be indicative of sensory processing differences as are

seen in Autism Spectrum Disorders (ASD). Repetitive behaviours are thought to ameliorate stress responses elicited by aversive sensory experiences in ASD (Gabriels et al., 2013). In speculation, sensory based experiences may arise from predisposing neurobiological differences so that a neurodevelopmental origin influences and /or explains the more unfavourable OCD course.

Clinical Implications

Regardless of unanswered questions and open speculations as to the neurodevelopmental influences predisposing sensory experiences in OCD, findings of studies reviewed suggest that the NJRE construct may warrant recognition in OCD clinical practice. It might be recommendable to assess motivational processes independently for clinical characteristics which can affect treatment outcome. Findings, even though tentative, suggest designing treatment protocols taking NJRE into consideration as a motivational dimension of OCD. Labelling NJRE may make it possible to deviate from traditional CBT approaches based on learned experiences of unhelpful beliefs to instead design a treatment protocol leading to better management of the sensory cognitive experiences leading to obsessive and compulsive behaviours. A case study demonstrated that a patient with INC benefited from exposure and ritual prevention (ERP). It was argued that the behavioural, rather than cognitive component of CBT are beneficial when working with OCD individuals with NJRE (Summerfeldt, 2004).

Methodological Issues

Measurement. A gold standard for measurements of NJRE in an OCD population does not currently exist. This is partly related to the novelty in researching this phenomenon, but also to the difficulties involved in conducting clinical research in OCD populations. Researchers have, as yet, primarily implemented self-report measures

compiled by semi-structured interviews and questionnaires. Self-report measures may be deemed useful at this point as an exploratory tool to better define clinical variations in NJRE. Validity and reliability have not yet been sufficiently evaluated. Reviewed studies have demonstrated a current interest in improving measuring devices for NJRE.

Sampling. The samples from research studies reviewed were derived from residential or outpatient mental health clinics, specialist OCD clinics, or private practice and likely reflect the more severe end of the OCD spectrum. Hence, it is not possible to generalize findings to less severe OCD presentations. However, generalization was slightly enhanced by the cross-cultural origins of data drawn from several different countries including the USA, Brazil, Germany, Italy and Australia.

Design. For the most part, studies reviewed were descriptive in nature. These studies were often hypothesis driven and represented early stages of research in this area. There were limited controls for potentially confounding variables such as symptom severity and tics in this exploratory stage of assessment. For example, before extrapolating recommendations for treatment, it would be important to control for severity and other core motivational mechanisms such as HA to ascertain whether NJRE per se is an important treatment variable. There were other statistical limitations in studies reviewed with the potential for inflating results, for example, failures to control for multiple statistical comparisons. To fully understand the clinical usefulness of NJRE, it is essential to focus on points of clinical interest and in a next research phase apply a more rigorous design and statistical analysis.

Future research

NJRE may be regarded as a 'red flag' that has heeded researchers to re-explore and reformulate the OCD clinical presentation. It appears that NJRE can be a helpful

construct to increase our understanding of the symptom profile und motivational heterogeneity of OCD. Currently, research has sought to establish indices for a broader understanding of this phenomenon, but has not yet been able to validate NJRE as homogenous subgroup. Future research should continue to attempt to better operationalise NJRE/INC/SP and improve reliability and validity of measurements. Due to the prevalence of NJRE in the general population as well as in the OCD population, meaningful clinical parameters for frequency and severity of sensory phenomena would need to be established. Adjunct research is needed to add to our knowledge and clarify the relevance of sensory experiences in OCD in clinical practice. It may be helpful to counteract self-report biases by assessing experimentally induced NJRE through behavioural experiments. Comparative research could then better systematically evaluate differential treatment options and outcomes for subgroups of OCD patients. Of interest and scarcely discussed in the clinical research literature are data about the neurodevelopmental trajectory of the occurrence of sensory cognitive phenomena relative to onset and frequency in the course of OCD.

Due to the focus on clinical aspects of NJRE in OCD in this review, neurocognitive or biological processes that might account for differing OCD presentations were not addressed, but are of important consideration. In summary, future research is essential to determine the full clinical utility of the NJRE experience in OCD.

References

Abramowitz, J. S., Franklin, M. E., Schwartz, S. A., & Furr, J. M. (2003). Symptom presentation and outcome of cognitive-behavioral therapy for obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology, 71,* 1049-1057.

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders (4th ed.).* Washington, DC: American Psychiatric Publishing.

Baer, L. (1992). Effect of Axis II Diagnoses on Treatment Outcome with Clomipramine in 55 Patients With Obsessive-Compulsive Disorder. *Archives of General Psychiatry, 49,* 862-866.

Başoğlu, M., Lax, T., Kasvikis, Y., & Marks, I. M. (1988). Predictors of improvement in obsessive-compulsive disorder. *Journal of Anxiety Disorders, 2,* 299–317.

Bertram, L., & Tanzi, R. E. (2008). Thirty years of Alzheimer's disease genetics: the implications of systematic meta-analyses. *Nature Reviews Neuroscience, 9,* 768-778.

Black, D. W., Monahan, P., Gable, J., Blum, N., Clancy, G., & Baker, P. (1998). Hoarding and treatment response in 38 nondepressed subjects with obsessive-compulsive disorder. *The Journal of Clinical Psychiatry, 59, 420–425.*

Boschen, M. J., Drummond, L. M., Pillay, A., & Morton, K. (2010). Predicting outcome of treatment for severe, treatment resistant OCD in inpatient and community settings. *Journal of Behavior Therapy and Experimental Psychiatry, 41,* 90–95.

Buchanan, A. W., Meng, K. S., & Marks, I. M. (1996). What predicts improvement and compliance during the behavioral treatment of obsessive compulsive disorder? *Anxiety, 2,* 22–27.

Calamari, J. E., Wiegartz, P. S., & Janeck, A. S. (1999). Obsessive–compulsive disorder subgroups: a symptom-based clustering approach. *Behaviour Research and Therapy, 37,* 113–125.

Catapano, F., Perris, F., Masella, M., Rossano, F., Cigliano, M., Magliano, L., & Maj, M. (2006). Obsessive-compulsive disorder: a 3-year prospective follow-up study of patients treated with serotonin reuptake inhibitors OCD follow-up study. *Journal of Psychiatric Research, 40,* 502–510.

Chik, H. M., Calamari, J. E., Rector, N. A., & Riemann, B. C. (2010). What do low-dysfunctional beliefs obsessive-compulsive disorder subgroups believe? *Journal of Anxiety Disorders, 24,* 837–846.

Coles, M. E., Frost, R. O., Heimberg, R. G., & Rhéaume, J. (2003). "Not just right experiences": perfectionism, obsessive–compulsive features and general psychopathology. *Behaviour Research and Therapy, 41,* 681–700.

Coles, M. E., Heimberg, R. G., Frost, R. O., & Steketee, G. (2005). Not just right experiences and obsessive-compulsive features: experimental and self-monitoring perspectives. *Behaviour Research and Therapy, 43,* 153–167.

Coles, M. E., Pinto, A., Mancebo, M. C., Rasmussen, S. A., & Eisen, J. L. (2008). OCD with comorbid OCPD: a subtype of OCD? *Journal of Psychiatric Research, 42,* 289–296.

Coles, M. E., Hart, A. S., & Schofield, C. (2011). Initial data characterizing the progression from obsessions and compulsions to full-blown obsessive compulsive disorder. *Cognitive Therapy and Research, 36,* 685–693.

Diniz, J. B., Rosario-Campos, M. C., Hounie, A. G., Curi, M., Shavitt, R. G., Lopes, A. C., & Miguel, E. C. (2006). Chronic tics and Tourette syndrome in patients with obsessive-compulsive disorder. *Journal of Psychiatric Research, 40,* 487– 493.

Do Rosario-Campos, M. C. (2001). Adults with early-onset obsessive-compulsive disorder. *American Journal of Psychiatry, 158,* 1899–1903.

Ecker, W., & Gönner, S. (2008). Incompleteness and harm avoidance in OCD symptom dimensions. *Behaviour Research and Therapy, 46,* 895–904.

Ecker, W., Gönner, S., & Wilm, K. (2011). [The measurement of motivational dimensions of OCD: incompleteness and harm avoidance]. *Psychotherapie, Psychosomatik, Medizinische Psychologie, 61,* 62–69.

Ecker, W., Kupfer, J., & Gönner, S. (2013). Incompleteness as a link between obsessive-compulsive personality traits and specific symptom dimensions of obsessive-compulsive disorder. *Clinical Psychology & Psychotherapy, 3*, 1-8.

Eisen, J. L., Coles, M. E., Shea, M. T., Pagano, M. E., Stout, R. L., Yen, S., … Rasmussen, S. A. (2006). Clarifying the convergence between obsessive compulsive personality disorder criteria and obsessive compulsive disorder. *Journal of Personality Disorders, 20,* 294–305.

Ferrão, Y. A., Shavitt, R. G., Bedin, N. R., de Mathis, M. E., Carlos Lopes, A., Fontenelle, L. F., … Miguel, E. C. (2006). Clinical features associated to refractory obsessive-compulsive disorder. *Journal of Affective Disorders, 94,* 199–209.

Ferrão, Y. A., Shavitt, R. G., Prado, H., Fontenelle, L. F., Malavazzi, D. M., de Mathis, M. A., … do Rosário, M. C. (2012). Sensory phenomena associated with

repetitive behaviors in obsessive-compulsive disorder: an exploratory study of 1001 patients. *Psychiatry Research, 197,* 253–258.

Foa, E., Huppert, J., Leiberg, S., Lanner, R., Kichic, R., Hajcak, G., & Salkovskis, P. (2002). The Obsessive-Compulsive Inventory: development and validation of a short version. *Psychological Assessment, 14*, 485-496.

Fontenelle, L. F., Mendlowicz, M. V., Marques, C., & Versiani, M. (2003). Early- and late-onset obsessive–compulsive disorder in adult patients: an exploratory clinical and therapeutic study. *Journal of Psychiatric Research, 37,* 127–133.

Fontenelle, L. F., Mendlowicz, M. V, & Versiani, M. (2006). The descriptive epidemiology of obsessive-compulsive disorder. *Progress in Neuro-Psychopharmacology & Biological Psychiatry, 30,* 327–337.

Franklin, M. E., Abramowitz, J. S., Kozak, M. J., Levitt, J. T., & Foa, E. B. (2000). Effectiveness of exposure and ritual prevention for obsessive-compulsive disorder: Randomized compared with nonrandomized samples. *Journal of Consulting and Clinical Psychology, 68,* 594-602

Frost, R. O., & DiBartolo, P. M. (2002). Perfectionism, anxiety, and obsessive-compulsive disorder. In G.L. Flett & P.L. Hewitt (Eds.), *Perfectionism: Theory, Research, and Treatment* (pp. 341-371). Washington: American Psychological Association.

Gabriels, R. L., Agnew, J. A, Pan, Z., Holt, K. D., Reynolds, A., & Laudenslager, M. L. (2013). Elevated repetitive behaviors are associated with lower diurnal salivary cortisol levels in autism spectrum disorder. *Biological Psychology, 93,* 262–268.

Garyfallos, G., Katsigiannopoulos, K., Adamopoulou, A., Papazisis, G., Karastergiou, A., & Bozikas, V. P. (2010). Comorbidity of obsessive-compulsive disorder

with obsessive-compulsive personality disorder: Does it imply a specific subtype of obsessive-compulsive disorder? *Psychiatry Research, 177,* 156–160.

Geller, D. A., Biederman, J., Stewart, S. E., Mullin, B., Farrell, C., Wagner, K. D., … Carpenter, D. (2003). Impact of comorbidity on treatment response to paroxetine in pediatric obsessive-compulsive disorder: is the use of exclusion criteria empirically supported in randomized clinical trials? *Journal of Child and Adolescent Psychopharmacology, 13,* 19–29.

Ghisi, M., Chiri, L. R., Marchetti, I., Sanavio, E., & Sica, C. (2010). In search of specificity: "not just right experiences" and obsessive-compulsive symptoms in non-clinical and clinical Italian individuals. *Journal of Anxiety Disorders, 24,* 879–886.

Gomes de Alvarenga, P., de Mathis, M. A., Dominguez Alves, A. C., do Rosário, M. C., Fossaluza, V., Hounie, A. G., … Rodrigues Torres, A. (2012). Clinical features of tic-related obsessive-compulsive disorder: results from a large multicenter study. *CNS Spectrums, 17,* 87–93.

Goodman, W. K. (1989). The Yale-Brown Obsessive Compulsive Scale. *Archives of General Psychiatry, 46,* 1006-1011.

Grados, M. A., Walkup, J., & Walford, S. (2003). Genetics of obsessive-compulsive disorders: new findings and challenges. *Brain and Development, 25,* 55–61.

Hollander, E., Bienstock, C. A., Koran, L. M., Pallanti, S., Marazziti, D., Rasmussen, S. A., … Zohar, J. (2002). Refractory obsessive-compulsive disorder: state-of-the-art treatment. *The Journal of Clinical Psychiatry, 63,* 20–29.

Hummelen, B., & Wilberg, T. (2008). The quality of the DSM-IV obsessive-compulsive personality disorder construct as a prototype category. *The Journal of Nervous and Mental Disease, 196,* 446-455.

Ivarsson, T., & Valderhaug, R. (2006). Symptom patterns in children and adolescents with obsessive-compulsive disorder (OCD). *Behaviour Research and Therapy, 44*, 1105–1116.

Keijsers, G. P., Hoogduin, C. A., & Schaap, C. P. (1994). Predictors of treatment outcome in the behavioural treatment of obsessive-compulsive disorder. *The British Journal of Psychiatry, 165,* 781–786.

Kendell, R., & Jablensky, A. (2003). Distinguishing between the validity and utility of psychiatric diagnoses. *American Journal of Psychiatry, 160,* 4-12.

Knapp, M., Henderson, J., & Patel, A. (2000). Costs of obsessive–compulsive disorder: A review. In M. Maj, N. Sartorius, A. Okasha, & J. Zohar (Eds.), *Obsessive–compulsive disorder* (pp. 253–299). New York: Wiley.

Leckman, J., Walker, D., & Cohen, D. (1993). Premonitory urges in Tourette's syndrome. *American Journal of Psychiatry, 150,* 98-102.

Leckman, J. F., Walker, D. E., Goodman, W. K., Pauls, D. L., & Cohen, D. J. (1994). "Just right" perceptions associated with compulsive behavior in Tourette's syndrome. *The American Journal of Psychiatry, 151,* 675–680.

Leckman, J. F., Grice, D. E., Barr, L. C., de Vries, A. L., Martin, C., Cohen, D. J., … Rasmussen, S. A. (1995). Tic-related vs. non-tic-related obsessive compulsive disorder. *Anxiety, 1,* 208–215.

Leckman, J. F., Denys, D., Simpson, H. B., Mataix-Cols, D., Hollander, E., Saxena, S., … Stein, D. J. (2010). Obsessive-compulsive disorder: a review of the diagnostic

criteria and possible subtypes and dimensional specifiers for DSM-V. *Depression and Anxiety, 27*, 507–527.

Lee, J. C., Prado, H. S., Diniz, J. B., Borcato, S., da Silva, C. B., Hounie, A. G., … do Rosário, M. C. (2009). Perfectionism and sensory phenomena: phenotypic components of obsessive-compulsive disorder. *Comprehensive Psychiatry, 50*, 431–436.

Mataix-Cols, D., Rauch, S. L., Manzo, P. A., Jenike, M. A., & Baer, L. (1999). Use of Factor- Analyzed Symptom Dimensions to Predict Outcome with Serotonin Reuptake Inhibitors and Placebo in the Treatment of Obsessive-Compulsive Disorder. *American Journal of Psychiatry*, *156,* 1409–1416.

McCubbin, R. A., & Sampson, M. J. (2006). The relationship between obsessive-compulsive symptoms and appraisals of emotional states. *Journal of Anxiety Disorders, 20*, 42–57.

McDougle, C. J. (1994). Haloperidol Addition in Fluvoxamine-Refractory Obsessive-Compulsive Disorder. *Archives of General Psychiatry, 51,* 302-308.

McKay, D. (2006). Treating disgust reactions in contamination-based obsessive-compulsive disorder. *Journal of Behavior Therapy and Experimental Psychiatry, 37*, 53–59.

Miguel, E. C., Coffey, B. J., Baer, L., Savage, C. R., Rauch, S. L., & Jenike, M. A. (1995). Phenomenology of intentional repetitive behaviors in obsessive-compulsive disorder and Tourette's disorder. *The Journal of Clinical Psychiatry, 56*, 246–255.

Miguel, E. C., do Rosario-Campos, M. C., da Silva Prado, H., do Valle, R., Rauch, S. L., Coffey, B. J., … Leckman, J. F. (2000). Sensory phenomena in obsessive-

compulsive disorder and Tourette's disorder. *Journal of Clinical Psychiatry, 61,* 150-156.

Miguel, E. C., Ferrão, Y. A., Conceição, M., Mathis, M. A. De, Torres, A. R., Fontenelle, L. F.,… Borges, M. C. (2008). The brazilian research consortium on obsessive- compulsive spectrum disorders : recruitment, assessment instruments, methods for the development of multicenter collaborative studies and preliminary results Consórcio Brasileiro de Pesquisa em Transtornos. *Revista Brasileira de Psiquiatria, 30,* 185–196.

Minichiello, W. E., Baer, L., & Jenike, M. A. (1987). Schizotypal personality disorder. *Journal of Anxiety Disorders, 1,* 273–276.

Mishra, B., & Sahoo, S. (2007). Management of treatment-resistant obsessive-compulsive disorder: An update on therapeutic strategies. *Annals of Indian Academy of Neurology,3,* 145-153.

Moffitt, T. E., Caspi, A., Dickson, N., Silva, P., & Stanton, W. (1996). Childhood-onset versus adolescent-onset antisocial conduct problems in males: Natural history from ages 3 to 18 years. *Development and psychopathology, 8,* 399-424.

Neziroglu, F. A., Stevens, K. P., & Yaryura-Tobias, J. A. (1999). Overvalued ideas and their impact on treatment outcome. *Revista Brasileira de Psiquiatria, 21,* 209–216.

Obsessive Compulsive Cognitions Working Group (2005). Psychometric validation of the obsessive beliefs questionnaire and the interpretation of intrusions inventory: Part 2, factor analyses and testing of a brief version. *Behaviour Research and Therapy, 43,* 1527–1542.

Overbeek, T., Schruers, K., Vermetten, E., & Griez, E. (2002). Comorbidity of obsessive-compulsive disorder and depression: prevalence, symptom severity, and treatment effect. *The Journal of Clinical Psychiatry, 63,* 1106–1112.

Pallanti, S., & Quercioli, L. (2006). Treatment-refractory obsessive-compulsive disorder: methodological issues, operational definitions and therapeutic lines. *Progress in Neuro-Psychopharmacology and Biological Psychiatry, 3,* 400-412.

Pitman, R. K. (1984). Janet's obsessions and psychasthenia: a synopsis. *The Psychiatric Quarterly, 56,* 291–314.

Prado, H., & Rosário, M. (2008). Sensory phenomena in obsessive-compulsive disorder and tic disorders: a review of the literature. *CNS Spectrums: The International Journal of Neuropsychiatric Medicine, 13,* 425-432.

Rasmussen, S. A., & Eisen, J. L. (1992). The epidemiology and differential diagnosis of obsessive compulsive disorder. *Journal of Clinical Psychiatry, 55,* 5–10.

Ravizza, L., Barzega, G., Bellino, S., Bogetto, F., & Maina, G. (1995). Predictors of drug treatment response in obsessive-compulsive disorder. *Journal of Clinical Psychiatry, 56,* 368-373.

Robins, E., & Guze, S. B. (1970). Establishment of diagnostic validity in psychiatric illness: Its application to schizophrenia. *American Journal of Psychiatry, 126,* 983–987.

Rosario-Campos, M. C., Leckman, J. F., Mercadante, M. T., Shavitt, R. G., Prado, H. S., Sada, P., … Miguel, E. C. (2001). Adults with early-onset obsessive-compulsive disorder. *The American Journal of Psychiatry, 158,* 1899–1903.

Rosario, M. C., Prado, H. S., Borcato, S., Diniz, J. B., Shavitt, R. G., Hounie, A. G., … Miguel, E. (2009). Validation of the University of São Paulo Sensory Phenomena Scale: initial psychometric properties. *CNS Spectrums, 14,* 315–23.

Shafran, R., Watkins, E., & Charman, T. (1996). Guilt in obsessive-compulsive disorder. *Journal of Anxiety Disorders, 10,* 509–516.

Shavitt, R. G., Belotto, C., Curi, M., Hounie, A. G., Rosário-Campos, M. C., Diniz, J. B., … Miguel, E. C. (2006). Clinical features associated with treatment response in obsessive-compulsive disorder. *Comprehensive Psychiatry, 47,* 276–281.

Smith, A. H., Wetterneck, C. T., Hart, J. M., Short, M. B., & Björgvinsson, T. (2012). Differences in obsessional beliefs and emotion appraisal in obsessive compulsive symptom presentation. *Journal of Obsessive-Compulsive and Related Disorders, 1,* 54–61.

Starcevic, V., Berle, D., Brakoulias, V., Sammut, P., Moses, K., Milicevic, D., & Hannan, A. (2011). Functions of compulsions in obsessive-compulsive disorder. *The Australian and New Zealand Journal of Psychiatry, 45*, 449–457.

Summerfeldt, L. J., Kloosterman, P. H., Parker, J. D. A., Antony, M. M., & Swinson, R. P. (2001). Assessing and validating the obsessive-compulsive-related construct of incompleteness. *In: Poster presented at the 62nd annual convention of the Canadian Psychological Association, Ste-Foy, Quebec.*

Summerfeldt, L. J. (2004). Understanding and treating incompleteness in obsessive-compulsive disorder. *Journal of Clinical Psychology, 60,* 1155–1168.

Szechtman, H., & Woody, E. (2004). Obsessive-compulsive disorder as a disturbance of security motivation. *Psychological Review, 111*, 111-127.

Taylor, S. (2011). Early versus late onset obsessive-compulsive disorder: evidence for distinct subtypes. *Clinical Psychology Review, 31,* 1083–1100.

Tolin, D. F., Brady, R. E., & Hannan, S. (2008). Obsessional Beliefs and Symptoms of Obsessive Compulsive Disorder in a Clinical Sample. *Journal of Psychopathology and Behavioral Assessment, 30,* 31–42.

Wahl, K., Salkovskis, P. M., & Cotter, I. (2008). "I wash until it feels right" the phenomenology of stopping criteria in obsessive-compulsive washing. *Journal of Anxiety Disorders, 22,* 43–61.

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines* (Vol. 1). World Health Organization.

Part 2: Empirical Paper

'Not Just Right Experience' (NJRE) in Obsessive-Compulsive Disorder:

Is NJRE a Manifestation of Autistic Traits?

Abstract

Aims: Harm avoidance (HA) and 'not just right experience' (NJRE) have been proposed to be two core motivational processes underlying obsessive-compulsive disorder (OCD). This study was interested in exploring the less well understood construct NJRE in OCD. The study hypothesized that NJRE demarcates a neurodevelopmental OCD subgroup distinct from HA related to autistic traits and/or to a broader phenotype of cognitive rigidity and sensory processing difficulties. In addition, it was hypothesized that NJRE would be associated with an earlier age of OCD onset. It was also predicted that HA, unlike NJRE, would be related to responsibility attitudes, which are characteristic of the traditional cognitive behavioural understanding of OCD.

Method: The constructs of NJRE and HA were assessed in an outpatient OCD sample (N=25). A correlational design investigated whether NJRE and HA are distinct entities in OCD and explored their relationships to a range of variables including ASD traits, sensory processing, set-shifting, age of OCD onset, and responsibility attitudes.

Results: NJRE was found to be only moderately (r=.34) correlated to HA. Significance was not established in this study. Consistent with predictions, NJRE was associated with sensory processing difficulties and an earlier age of OCD onset, but was not related to responsibility beliefs. No significant relationships were found between NRJE and ASD traits or set-shifting difficulties.

Conclusions: There was a lack of evidence demonstrating NJRE as a manifestation of autistic traits. However, NJRE was associated with sensory abnormalities and early onset of OCD, suggesting it may be a marker for difficulties of developmental origin. The role of NJRE as a developmental, and possibly neurodevelopmental, risk factor for OCD warrants further investigation.

Introduction

Obsessive-compulsive disorder (OCD) is a chronic and common psychiatric disorder with a prevalence of 1% to 3% (Fontenelle, Mendlowicz, & Versiani, 2006). It is characterized by intrusive thoughts and repetitive behaviours causing significant distress and impairment. Forty to sixty percent of persons with OCD, despite advances in treatment, are not responsive to therapy (Greist, 1995; Pallanti & Quercioli, 2006). Research seeking explanations for the differences in treatment outcomes has been confronted with the diversity in presentations of OCD (Fontenelle et al., 2006). To effectively develop meaningful treatment interventions and optimize treatment outcome, more research is needed to better understand the heterogeneity of clinical phenotypes. Subgroups have been defined based on obsessive compulsive symptom dimensions (Calamari, Wiegartz, & Janeck, 1999; Ivarsson & Valderhaug, 2006), on an earlier age of onset (Taylor, 2011) or on the presence of tics (Leonard et al., 1992) and streptoccocus-induced PANDAS (pediatric autoimmune neuropsychiatric disorder) (Swedo et al., 1998). The validity of these subgroups has not yet been verified (Leckman et al., 2010).

Improving the clinical utility and the predictive validity of diagnostic assessments may require re-evaluating the traditional nosology of OCD. OCD has historically been conceptualized as an anxiety disorder. However, evidence increasingly suggests that even though symptoms of anxiety are often present in OCD, their significance may be inconsistent (Nutt & Malizia, 2006). If compared to other anxiety disorders, OCD presents in a behaviourally and phenomenologically different way (Van Ameringen, Patterson, & Simpson, 2014). Hence, despite ongoing controversy (Bienvenu et al., 2012; Mataix-Cols, Pertusa, & Leckman, 2007; Starcevic & Janca, 2011), OCD has been removed from the classification of anxiety disorders in the Fifth Edition (DSM 5) of the Diagnostic and

Statistical Manual of Mental Disorders and placed in a discrete category labelled *"Obsessive-Compulsive and Related Disorders" (OCRDs)*. OCRDs encompass a range of conditions including "body dysmorphic disorder (BDD), trichotillomania (TTM; hair-pulling disorder), excoriation (skin-picking) disorder, hoarding disorder, substance/medication-induced OCRD, OCRD due to another medical condition, and other specified OCRDs" (Van Ameringen et al., 2014, p.1). These disorders are marked by a range of repetitive behaviours, some thought to be more cognitive in nature, as in OCD, and others more physically-focused (e.g., TTM). Even though the diagnostic criteria for OCD within this new classification reflects only minimal changes, the shift from classification as an anxiety disorder to a categorization based on repetitive behaviours will undoubtedly affect the way OCD is aetiologically understood and, therefore, treated. Indeed, the DSM 5 diagnostic reassignment of OCD to a discrete disorder focusing on repetitive behaviours is permissive to, if not demanding of, the development of a wider range of OCD treatments beyond those implemented to reduce anxiety.

Recent research has focused on understanding motivational processes underlying OCD as one possible way of understanding its complexity and variability. Repetitive behaviours seen in OCD are presently thought to be derived from two core motivational processes (Chik, Calamari, Rector, & Riemann, 2010; Ecker & Gönner, 2008; Rasmussen & Eisen, 1992). One is related to anxiety reduction and characterised by an exaggerated need to avoid harm, usually referred to as harm avoidance (HA). In the second, there may be less anxiety, and compulsive behaviours are driven by a need to reduce a sense of incompleteness (INC). This sense of incompleteness has been coined by Coles, Heimberg, Frost, and Steketee (2005) as a "not just right experience" (NJRE) and is thought to represent a form of sensory perfectionism (Frost & DiBartolo, 2002). Other motivational

processes such as guilt (Shafran, Watkins, & Charman, 1996) and disgust (McKay, 2006) are also acknowledged to be present in OCD, but INC/NJRE and HA are currently recognized as the two main motivational processes underlying repetitive behaviours (Ecker & Gönner, 2008).

The focus in OCD research has primarily been on the role of HA in OCD (Rachman, 1997; Salkovskis, 1999; Salkovskis et al., 2000), but there is an increasing interest in understanding the clinical contribution of NJRE. NJRE has been associated with a specific symptom profile including symmetry, arranging, and ordering (Ferrão et al., 2012; Rosario et al., 2009; Smith, Wetterneck, Hart, Short & Björgvinsson, 2012; Starcevic et al., 2011; Ecker & Gönner, 2008) and with more severe OCD symptoms (Ecker & Gönner, 2008; Leckman et al., 1995; Leckman, Walker, Goodman, Pauls, & Cohen, 1994). In addition, NJRE has been associated with an earlier age of OCD onset (do Rosario-Campos, 2001; Ferrão et al., 2012; Rosario et al., 2009) and has been found to be less responsive to traditional cognitive behavioural therapies (CBT) (Summerfeldt, 2004). These last two properties could be indicative of NJRE representing an atypical developmental pathway in OCD. NJRE may target an aetiologically distinct construct contributing to the OCD presentation and outcome. Further research is still needed to enhance understanding of the construct of NJRE in OCD.

One approach to understanding NJRE in OCD, if hypothesized as having a developmental origin, is to review its presence and overlapping features within neurodevelopmental conditions displaying sensory phenomena (SP) and repetitive behaviours such as tic disorders (TD) and autism spectrum disorders (ASD). NJREs are frequently reported in co-morbid presentations of OCD-TD (Leckman et al., 1994). Similar to tics, NJREs are thought to be triggered by a sensory based discomfort. Whereas

tics appear to reduce a physically driven tension, repetitive behaviours in OCD may serve to reduce a discomfort related to a sensation of things being not just quite right (i.e. a sensory-cognitive experience). In particular due to the high rates of co-morbidity between OCD and ASD in both adults (Bejerot, Nylander, & Lindström, 2001) and in children (Ivarsson & Melin, 2008), there has been an increasing interest in exploring the association of OCD and ASD with the underlying repetitive behaviours seen in both conditions (Cath, Ran, Smit, van Balkom, & Comijs, 2008; Zandt, Prior, & Kyrios, 2007). The repetitive behaviours within ASD may appear as motor mannerisms, unusual preoccupations, sensory preferences or sensitivities, and insistence on sameness (South, Ozonoff, & McMahon, 2005). Interestingly, it is, in particular, insistence on sameness which may mirror an aetiological link between OCD and ASD. In a study by Abramson et al. (2005) findings showed that high scores on insistence on sameness in children with ASD were positively correlated with OCD behaviours in their parents. There has been only one past study which has specifically explored the relationship of NJRE, rather than OCD in general, to autism or autistic traits. It demonstrated that "resistance to change" and "repetitive sensory motor actions" were more likely to occur in autistic children if their parents specifically exhibited INC/NJREs (Kloosterman, Summerfeldt, Parker, & Holden, 2013, p.176). This relationship was stronger for families with two or more children with ASD.

Insistence on sameness and the sensory processing difficulties of ASD appear to share characteristics associated with NJRE in OCD. Rigid compulsive-like behaviours follow cognitive sensations of insisting on sameness (Bishop et al., 2013). This so called cognitive rigidity can be identified as set-shifting difficulties (Newman & McGaughy, 2011) and has been reported in autistic populations (Ozonoff et al., 2004; Pennington &

Ozonoff, 1996). Set-shifting difficulties have also been identified in OCD individuals (Purcell, Maruff, Kyrios, & Pantelis, 1998; Veale, Sahakian, Owen, & Marks, 2009) and particularly in those presenting with a symptom profile of symmetry/ordering (Lawrence et al., 2006), a profile which has been consistently linked to NJRE in OCD (Ecker, Kupfer, & Gönner, 2013; Ferrão et al., 2012; Rosario et al., 2009; Starcevic et al., 2011; Tolin, Brady, & Hannan, 2008; Smith et al., 2012).

Sensory processing abnormalities, including both hyper- and hyposensitivity are frequently seen in ASD and are now included in the diagnostic criteria for ASD in the DSM 5 (American Psychiatric Association, 2013). Individuals with ASD may react with utmost discomfort to environmental stimuli that would otherwise impact neutrally on others (Crane, Goddard, & Pring, 2009). Similarly, individuals with NJRE have been described to have a heightened perception of their environment (Leckman et al., 1994). It has been proposed that most NJREs are externally triggered (Ferrão et al., 2012) and moderated to a degree by varying sensory modalities (Leckman et al., 1995; Leckman et al., 1994; Lee et al., 2009).

In summary, symptom presentations of individuals with OCD experiencing NJRE and individuals with ASD show significant similarities in sensory experiences, cognitive rigidity, and repetitive behaviours. Analogues may be indicative of a shared neurobiological mechanism. More research is needed to determine whether NJRE can be a common link explaining repetitive behaviours in OCD and ASD beyond the effects of anxiety. It is possible that NJRE may be an important endophenotype for OCD and ASD.

Aim of study

There is evidence to suggest, that in addition to HA, NJRE may be an important mechanism in OCD. The NJRE dimension may reflect a broader phenotype of rigidity and

sensory processing differences overlapping with neurodevelopmental conditions such as ASD. Currently, there have been no empirical studies examining the association of NJRE and ASD in OCD. Understanding NJRE's association with ASD could increase our understanding of the complexity of OCD and its aetiology.

The aim of this study was to investigate whether NJRE is related to autistic traits in adults with OCD. NJRE may be a manifestation of autistic behaviour. A relationship could be indicative of a neurodevelopmental origin for repetitive behaviours in a subgroup of OCD clients experiencing NJREs and may improve our understanding of the relationship between ASD and OCD. In this study NJRE will also be examined for its usefulness as a broader marker for an atypical developmental origin in OCD distinguishing it from cognitive behavioural theories of HA origins. As a prerequisite to establishing the significance of NJRE in OCD, this study further intends to look at distributions of NJRE and HA in OCD. Of interest is to what extent these constructs reflect meaningful but discrete dimensions clinically useful in identifying a potential OCD subgroup.

Hypotheses

There is some evidence to suggest that NJRE may reflect an autistic phenotype in OCD. The present research study will test NJRE's association with ASD traits in OCD predicting that:

1. NJRE, but not HA, will be related to ASD traits as measured by the Autism Quotient (AQ).
2. NJRE will furthermore be related to specific problems associated with ASD including sensory processing and set-shifting difficulties.

In addition, it is predicted that:

3. NJRE, but not HA, will be associated with an earlier age of OCD onset.
4. Lastly, it is hypothesised that HA, but not NJRE, will be related to responsibility attitudes, which are characteristically linked to obsessional symptoms in a cognitive behavioural model of OCD.

Method

Design

This study was based on a cross-sectional correlational design aiming to examine the association between motivational processes (NJRE and HA) and a range of factors including: autistic traits, sensory processing, set-shifting difficulties, age of OCD onset, and responsibility beliefs.

Participants

There have been no previous studies looking at the association of NJRE to autistic traits in OCD on which to base a power calculation for the current study. To estimate the required number of participants, analyses were powered to detect moderate associations (.40) between variables. On this basis, holding alpha at 0.05 and demanding power of at least 0.8 for two-tailed tests, a sample size of 44 would be required (G-Power) (Faul, Erdfelder, Buchner, & Lang, 2009). Due to significant recruitment difficulties (see discussion section and critical appraisal), it was only possible to recruit N=25 participants, which provides 80% power to detect large (r >.50) associations between variables.

Twenty-five participants were included in the study. All participants attended the same OCD service. The inclusion criteria were: (i) participants had to have a primary diagnosis of OCD and (ii) be at least 18 years of age. The sample consisted of 16 (64%)

women and 9 (36%) men. The mean age was 46.84 (11.19) years, ranging from 25-65 years of age. The Yale Brown Obsessive Compulsive Scale (Y-BOCS) scores were collected for 24 participants. The mean total score was 24.33 (6.91), which is in the moderate range. The mean score for overall compulsions was 13.21 (3.02) and overall obsessions was 11.89 (3.4). The majority of the participants (n=17, 68% of sample) had a comorbid diagnosis and all participants were on prescription medication, see Table 1. Thirty-six percent were in employment. A fifth of the sample had AQ scores of 32 or more. AQ scores in this range are considered to reflect a probable diagnosis of ASD (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). Overall, more than half of the sample had an AQ scores higher than 25. An AQ score of ≥26 is considered to indicate elevated ASD traits possibly reflecting ASD (AQ=26), see Table 1 (Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005).

Table 1
Clinical and demographic variables

Variable	n (%)
Medication	
SSRI	23 (92%)
Tricyclic antidepressant	1 (4%)
Anxiolytics	4 (16%)
Antipsychotics	14 (56%)
Other	5 (20%)
Comorbid Diagnoses*	
Affective Disorder	11 (44%)
Psychotic Disorder	1 (4%)
Neurotic Disorder	1 (4%)
Personality Disorder	3 (12%)
Addictive Disorder	2 (8%)
Other	6 (24%)
AQ scores	
≥26**	13 (52%)
≥32***	5 (20%)
Employment	
Employed	9 (36%)
Unemployed	12 (48%)
Sick Leave	1 (4%)
Retired	2 (8%)

Note. SSRI= selective serotonin reuptake inhibitors; *Taxonomy was used in the clinical team; AQ= Autism Quotient; **=possible ASD, ***=probable ASD.

Measures

A range of self-report questionnaires, clinician-rated questionnaires, and a cognitive task assessing set-shifting were administered to address the research questions.

Self-report measures

I. *Obsessive-Compulsive Trait Core Dimensions Questionnaire (OC-TCDQ)* (Summerfeldt, Kloosterman, Parker, Antony, & Swinson, 2001) is a 20 item self-report measure of harm avoidance (10 items) and incompleteness (10 items). Example questions include "I feel driven to re-do or prolong activities or tasks until they feel "just right" for INC and "Even if harm is very unlikely, I feel the need to prevent it at any cost" for HA. Items are rated on a 5 point Likert scale from 1= "Never applies to me" and 5= "Always applies to me." It is found to have excellent internal consistency HA (.91) and INC (.93) (Coles et al., 2005). INC is also known as NJRE. The paper will use the term NJRE to refer to this experience.

II. *Adolescent /Adult Sensory Profile (AASP)* (Brown & Dunn, 2002) is a 60 item self-report measure to evaluate sensory processing abilities. There are four scores that produce a sensory profile (low registration, sensory sensitivity, sensation seeking, and sensation avoiding). Overall scores range between 60 and 300. Behaviours related to the everyday sensory experiences are rated on a 5 point Likert scale ranging from whether it applies 1= "almost never" to 5= "almost always". It is found to have acceptable reliability with coefficient alphas being around (0.64 and 0.78) (Brown & Dunn, 2002).

III. *Responsibility Attitudes Scale (RAS)* (Salkovskis et al., 2000) is a 26 item self-report aimed to measure general beliefs about responsibility characteristic of obsessive compulsive disorder. An example question includes "I often feel

responsible for things which go wrong." Items are rated on a 7 point Likert scale from 1= "totally agree" and 7= "totally disagree". Lower scores reflect higher responsibility beliefs. It has excellent reliability (.92) (Salkovskis et al., 2000).

IV. *State–Trait Anxiety Inventory (STAI)* (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983), is a self-report questionnaire measuring state and trait anxiety. There are 20 items measuring how the participant feels at the moment (state anxiety), for example, "I feel at ease" and 20 items measuring how the participant feels generally (trait anxiety), for example, "I am a steady person." Items are rated on a 4 point Likert scale ranging from 1= "not at all" to 4= "very much so" for the STAI State and 1= "almost never" to 4= "almost always" for the STAI trait form. It has been found to have excellent internal consistency (.89) (Barnes, Harp, & Jung, 2002).

V. *Autism Quotient (AQ)* (Baron-Cohen et al., 2001) is a 50 item self-report questionnaire measuring symptoms of ASD in adults. It can be subdivided into 5 domains: "social skill", "attention switching", "attention to detail", "communication", and "imagination". Items are scored to be either autistic like (score of 1) or non autistic like (score of 0). Respondents rate whether they agree or disagree on a 4 point Likert scale 1= "definitely agree" to 4= "definitely disagree" to questions such as "I find it hard to make new friends." A score of 32 is considered to be the cut-off score indicating a possible diagnosis of ASD (Baron-Cohen et al., 2001). A score of 26 is sometimes used when screening for autistic traits (Woodbury-Smith et al., 2005). The overall internal consistency has been found to be acceptable (.74) with the subtests ranging from .42 (imagination) to .76 (social skills) (Bishop & Seltzer, 2012). The internal consistency for the

subtests has been reported to be slightly higher in a previous study (.63-.77) (Baron-Cohen et al., 2001).

Clinician-rated measures

I. *Montgomery-Asperg Depression Rating Scale (MADRS)* (Montgomery & Asperg, 1979) is a 10 item clinician-rated questionnaire measuring the severity of depression. Items are rated on a 7 point Likert scale. The scale ranges from 0 to 6, which are added up to ascertain a total score. Overall scores range between 0 and 60. The internal consistency has been found to be excellent (.90-.92) (Carmody et al., 2006).

II. *Yale Brown Obsessive Compulsive Scale (Y-BOCS)* (Goodman, 1989) is a semi-structured interview consisting of a symptom checklist and measure of severity. The measure assesses the severity of the obsessions and compulsions separately. In addition it provides an overall measure of symptom severity ranging from 0-40. All severity items are measured using a 5 point Likert scale ranging from 0= no symptoms to 4= extreme symptoms. Scores between 10 and 20 indicate mild obsessive compulsive symptoms. Scores between 21 and 30 indicate moderate symptoms. Scores between 21 and 40 indicate severe obsessive compulsive symptoms (Boyette, Swets, Meijer, & Wouters, 2011). The internal consistency has been reported to be good (.78) (Deacon & Abramowitz, 2005).

Cognitive task

I. *Intra-extra dimensional shift (ID/ED) task* is a subtest from the Cambridge Automated Neuropsychological Test Battery (CANTAB) (Lowe & Rabbitt, 1998). The subtest is thought to require prefrontal function and is believed to specifically

assess set-shifting abilities (Ozonoff et al., 2004; Robbins & James, 1998). It is a computer administered task. The task requires participants to respond to visual (non-verbal) multidimensional shapes consisting of shapes and lines on a computer screen. Through trial and error participants learn to respond in a certain way to a specific shape. The contingencies eventually change and the respondent has to shift to another cognitive set/contingency. Performance requires conceptual flexibility. In total there are 9 stages including discrimination and learning phases, intradimensional tasks (shape remains salient, but lines are introduced) and extradimensional tasks (lines become relevant). The extradimensional tasks are the main trials measuring set-shifting. Three outcome variables associated with the extradimensional shift task (set-shifting measure) were identified in collaboration with the Cambridge Cognition team, who designed the CANTAB, which included i.) extradimensional shift (EDS) errors, ii.) intradimensional (IED) total errors adjusted, iii.) number of trials completed. EDS errors refer to errors made when a new dimensions is initially introduced. The IED total errors adjusted averages the total number of mistakes made in choosing a stimulus incompatible with the current rule and adjusts for discontinued trials. Number of trials allows looking at early discontinuation due to set-shifting errors.

Procedure

Ethical approval was obtained from the National Research Ethics Service London-Harrow committee (see Appendix B). Participants were recruited from a pool of individuals who had taken part in a preliminary study run by their clinical care team exploring autistic traits in an obsessive-compulsive disorder population. In total n=92

were approached in the preliminary study. As part of the initial exploratory study, participants had completed the AQ and the Y-BOCS. In addition, detailed information as to demographic and clinical variables including age, gender, employment status, age of OCD onset, treatment history, and comorbidity had been collected by their clinicians. Fifty-two participants in the preliminary study who had completed all measures and had indicated on a consent form that they would permit contact for future research projects were identified. The initial contact for this study was made by the clinical staff, and a participant information sheet (PIS) was given or sent to these 52 clinic attendees (see Appendix C). The research PIS explained the aim, time commitment, and tasks involved in two follow-up studies to be simultaneously administered exploring autistic traits in an obsessive-compulsive disorder. Potential participants had at least 48 hours to decide whether they were interested in study enrolment and were given an opportunity to discuss any questions over the telephone or in person with either researcher of these conjoint studies. The PIS and consent form were personally discussed in detail before commencing (see Appendix C and D). It was emphasized that the participants had a right to withdraw at any stage of data collection and that their participation/non-participation would not affect their continuous clinical care. If concerns about risk including harm to oneself or others should arise during evaluations, these would be discussed with the clinical care team. Otherwise, all information would be kept confidential. In total 25 people agreed to take part in the research.

Data for this project was collected in conjunction with another researcher looking specifically at neurocognitive profiles of participants with OCD and autistic traits (Barber, 2014). To minimize a participant's time commitment, data for both studies were collected by one researcher in one session. The list of additional neurocognitive tests administered

for the parallel project can be found in Appendix E. Testing lasted approximately 2-4 hours. A set order of task administration had been planned (see Appendix E); however, at times it was necessary to deviate from this order to minimize missing data.

Missing data

Due to time constraints and/or the inability of participants to complete testing measures due to clinical issues, including fear of contamination and high levels of anxiety, it was not possible to achieve full data sets for all participants. One MADRS, a measure of low mood, was missing. Only 21 out of 25 people completed the computerised neuropsychological test measuring set-shifting. One person had completed a different version of the Y-BOCS with their clinician, and, hence, it could not be included in the overall analysis of this project.

Statistical Analysis

All variables were tested for normality using the Kolmogorov-Smirnoff test. None deviated from normality, so parametric statistics were used throughout. One research aim was to explore whether HA and NJRE, two core motivational processes in OCD, reflect meaningfully distinct dimensions, and to then determine their distributions in the OCD sample. This was achieved by looking at histograms and conducting a bivariate Pearson's correlation between NJRE and HA. The mean scores of NJRE and HA in this sample were compared to a non-clinical sample using independent t-tests. To address whether NJRE could be indicative of an autistic phenotype in OCD, the dominant research objective, Pearson's correlations were used to measure the association between, on the one hand, NJRE and HA, and on the other hand, factors associated with ASD including the AQ, sensory processing difficulties, and set-shifting difficulties. In addition, it was of interest to reveal whether NJRE, unlike HA, was correlated with an earlier age of OCD onset and

whether in this OCD population an overinflated sense of responsibility could be correlated with HA, but not NJRE. When both NJRE and HA were significantly correlated to one of these variables of interest, a Steiger Z test was administered to determine if one relationship was stronger than another.

Secondary analyses were conducted to explore the specific relationship to subdomains of the Autism Quotient (AQ) and Adolescent /Adult Sensory Profile (AASP) using bivariate Pearson's correlations.

Furthermore, the relationship of the core motivational processes to anxiety, depression and OCD severity were explored using Pearson's correlations to assess whether these factors could be possible confounding variables. If, for example, anxiety was related to both the predictor and outcome variables, than a partial correlation was calculated to statistically control for this potentially confounding variable.

The numerous comparisons increase the risk of a Type I error. The corrected Bonferroni alpha level based on the primary hypotheses indicated a stringent alpha level (0.05/14=0.004). Due to limited power in terms of the small sample size, reporting findings based on the corrected alpha level could inflate the risk of a Type II error. Hence, comparisons described below were hypothesis driven and the exact p values were reported.

Results

Primary Analyses

Exploring HA and NJRE as constructs in OCD. The distribution of these motivational processes (HA and NJRE) was assessed using the Kolmogorov-Smirnov test. Both HA (p=.20) and NJRE (p=.17) did not violate the assumption of normality. In addition the skewness and kurtosis were calculated to be < 1.96 for both NJRE and HA.

The sample values for HA were *M*=38.00, *SD*=1.54 and values for NJRE were *M*=37.48, *SD*=1.66. These values were significantly higher (HA: t (24) =8.795, p<0.001 and NJRE: t (24) = 5.415, p<0.001) than the means derived from a non-clinical sample, in which values for HA were *M*= 24.48, *SD*=7.78, and for NJRE were *M*=28.51, *SD*=7.52 (Summerfeldt, personal communication). NJRE and HA were not found to be significantly associated. The relationship between NJRE and HA was modest to low and not statistically significant, r=.34, p=.092.

Potential confounding variables. Correlational analyses were used to examine the association between OCD symptom severity, low mood, and anxiety (state and trait) and NJRE, HA, AQ, sensory processing, age of onset, and set-shifting, in order to explore for potential confounding effects. As is seen in Table 2, AQ was associated with overall OCD symptom severity (Y-BOCS total), low mood (MADRS), and trait anxiety. In addition age of OCD onset was associated with OCD symptom severity (Y-BOCS total) and trait anxiety. Lastly, sensory processing difficulties (AASP) were associated with overall OCD symptom severity (Y-BOCS total), low mood (MADRS), as well as trait and state anxiety, see Table 2.

Table 2

Exploring possible confounding variables including OCD symptom severity (Y-BOCS), low mood (MADRS), and anxiety (STAI)

		Y-BOCS total	MADRS	STAI state	STAI trait
NJRE	Pearson r	.42*	.34	.29	.57**
	95% CI	[.02, .71]	[-.08, .65]	[-.12, .62]	[.23, .79]
	Sig. (2-tailed)	.040	.110	.158	.003
	N	24	24	25	25
HA	Pearson r	.33	.26	.49*	.58**
	95% CI	[-.09, .65]	[-.17, .59]	[.11, .74]	[.23, .79]
	Sig. (2-tailed)	.121	.226	.014	.003
	N	24	24	25	25
AQ total	Pearson r	.52**	.54**	.38	.54**
	95% CI	[.15, .76]	[.17, .77]	[-.02, .67]	[.19, .77]
	Sig. (2-tailed)	.009	.007	.062	.005
	N	24	24	25	25
Age of onset	Pearson r	-.49*	-.23	-.17	-.48*
	95% CI	[-.74, -.10]	[-.58, .19]	[-.53, .24]	[-.74, -.11]
	Sig. (2-tailed)	.016	.284	.413	.014
	N	24	24	25	25
ASSP total	Pearson r	.53*	.54*	.50*	.43*
	95% CI	[.16, .77]	[.18, .78]	[.13, .75]	[.04, .70]
	Sig. (2-tailed)	.008	.006	.011	.033
	N	24	24	25	25
EDS errors	Pearson r	.06	.19	-.07	-.001
	95% CI	[-.39, .49]	[-.27, .57]	[-.48, .38]	[-.43, .43]
	Sig. (2-tailed)	.793	.423	.779	.996
	N	20	21	21	21
IED total errors adjusted	Pearson r	.08	.25	.03	.06
	95% CI	[-.38, .51]	[-.21, .61]	[-.41, .45]	[-.38, .48]
	Sig. (2-tailed)	.733	.281	.906	.790
	N	20	21	21	21
RAS total	Pearson r	-.25	-.05	-.27	-.17
	95% CI	[-.59, .18]	[-.45, .36]	[-.59, .15]	[-.53, .24]
	Sig. (2-tailed)	.249	.806	.200	.423
	N	24	24	25	25
Y-BOCS	Pearson r	1	.61**	.37	.58**
	95% CI		[.26, .82]	[-.04, .67]	[.22, .79]
	Sig. (2-tailed)		.002	.075	.003
	N		23	24	24

		Y-BOCS total	MADRS	STAI state	STAI trait
MADRS	Pearson r		1	.52**	.48*
	95% CI			[.14, .76]	[.09, .74]
	Sig. (2-tailed)			.010	.018
	N			24	24
STAI state	Pearson r			1	.52**
	95% C)				[.16, .76]
	Sig. (2-tailed)				.007
	N				25
STAI trait	Pearson r				1
	95% CI				
	Sig. (2-tailed)				
	N				

Note. NJRE= not-just-right-experience; HA=harm avoidance; AQ= Autism Quotient; ASSP= Adolescent /Adult Sensory Profile; EDS=extradimensional shift; IED=intradimensional; RAS=Responsibility Attitude Scale; Y-BOCS= Yale Brown Obsessive Compulsive Scale; MADRS=Montgomery-Asperg Depression Rating Scale; STAI=State Trait Anxiety Inventory.
* Correlation is significant at the 0.05 level (2-tailed); ** Correlation is significant at the 0.01 level (2-tailed).

Relationship to an autistic phenotype. The main aim of the study was to identify whether NJRE, but not HA, was related to ASD traits (AQ) and to a broader phenotype of ASD including cognitive rigidity and sensory processing difficulties.

AQ. Contrary to predictions, AQ total score was not significantly correlated with NJRE in this sample. AQ was similarly not correlated with HA, see Table 3.

Sensory processing. NJRE was positively correlated with sensory processing difficulties. The relationship to sensory processing was significant even at the rigorous Bonferroni corrected level (p=.004). In addition, HA was also associated to sensory processing difficulties, see Table 3. In order to evaluate whether these correlations differed significantly, a Steiger Z analysis was administered. The correlations did not significantly differ Z=0.82, p= 0.205.

OCD symptom severity and trait anxiety correlated with both NJRE and sensory processing and so may be confounding variables. In order to statistically control for this, correlations were recalculated using partial correlations. The sensory processing difficulties were still significantly associated to NJRE even after controlling for total OCD severity (r=.56, p=.005), and trait anxiety (r=.53, p=.008) using partial correlations.

Both state and trait anxiety were correlated with HA and sensory processing. Hence to control for the possibility of state and trait anxiety confounding the associations' partial correlations were calculated. Partial correlations showed that the relationship between HA and sensory processing was no longer significant after controlling for state anxiety (r=.32, p=.132) and trait anxiety (r=.32, p=.128).

Set-shifting. Set-shifting difficulties were measured based on the error rate in the extradimensional shift task of the ID-ED. There are three important variables associated to extradimensional (set-shifting) performance i.) EDS errors, ii.) IED total errors

adjusted, iii.) number of trials completed. Contrary to the study hypothesis, NJRE was not associated with set-shifting difficulties measured by EDS errors and IED total adjusted errors in this sample, as is seen in Table 3. In addition, it was predicted that NJRE would be associated to more set-shifting errors and hence earlier trial discontinuation. However, NJRE did not predict early continuation of trials. The majority of participants completed all trials n=13 (61.9%), whereas n=8 (38.1%) completed only 7 trials. A logistic regression was conducted to evaluate whether HA or NJRE could independently predict the likelihood of completion of this task, but, neither HA or NJRE could predict early discontinuation, $X^2(2) = .15$, p= .933.

Relationship to age of OCD onset. As predicted, NJRE was negatively correlated with age of onset of OCD, and this remained significant after Bonferroni correction (p=.004). Higher scores on NJRE were associated with an earlier age of onset. The correlation between age of onset and HA was not significant in this sample, as is seen in Table 3.

OCD symptom severity and trait anxiety were related to both age of onset and NJRE and could hence be confounding variables. However, the relationship between NJRE and age of OCD onset remained significant after controlling for OCD symptom severity (r=-.48, p=.022) and trait anxiety (r=-.44, p=.032) using partial correlations.

Relationship to responsibility attitudes. NJRE was, furthermore, as predicted, not significantly correlated with responsibility beliefs in this sample, as is seen in Table 3. HA was, though, as predicted, negatively correlated with responsibility attitude scale (RAS) scores and was significant at the corrected Bonferroni level (p=.004). Consequently, high HA was associated with low RAS, indicative of high responsibility attitudes.

Table 3

NJRE and HA relationship to AQ, age of onset, sensory processing (ASSP), set-shifting (EDS errors and IED total errors adjusted), and responsibility beliefs (RAS)

		NJRE	HA	AQ total	Age of onset	ASSP total	EDS errors	IED total errors adjusted	RAS total
NJRE	Pearson r	1	.34	.14	-.59**	.64**	-.05	-.09	-.35
	95% CI		[-.06, 0.65]	[-.27, .51]	[-.26, -.80]	[.32, .82]	[.39, -.47]	[.36, -.50]	[.10, -.68]
	Sig. (2-tailed)		.092	.500	.002	.001	.848	.699	.091
	N		25	25	25	25	21	21	25
HA	Pearson r		1	.32	-.37	.48*	-.003	.05	-.64**
	95% CI			[-.08, .64]	[.03, -.67]	[.11, .74]	[.43, -.43]	[-.39, .47]	[-.28, -.84]
	Sig. (2-tailed)			.114	.069	.015	.989	.831	.001
	N			25	25	25	21	21	25
AQ total	Pearson r			1	-.09	.520**	.22	.24	-.13
	95% CI				[.31, -.48]	[.16, .76]	[-.24, .59]	[-.21, .61]	[.28, -.50]
	Sig. (2-tailed)				.637	.008	.341	.295	.547
	N				25	25	21	21	25
Age of onset	Pearson r				1	-.39	.10	.10	.32
	95% CI					[-.68, .01]	[-.35, .51]	[-.35, .52]	[.09, .63]
	Sig. (2-tailed)					.056	.662	.674	.121
	N					25	21	21	25
ASSP total	Pearson r					1	.09	.11	-.53**
	95% CI						[-.36, .50]	[-.34, .52]	[-.77, -.18]
	Sig. (2-tailed)						.706	.635	.006
	N						21	21	25

		NJRE	HA	AQ total	Age of onset	ASSP total	EDS errors	IED total errors adjusted	RAS total
EDS errors	Pearson r						1	.96**	.17
	95% CI							[.89, .98]	[-.28, .56]
	Sig. (2-tailed)							.000	.458
	N							21	21
IED total errors adjusted	Pearson r							1	.19
	95% CI								[-.26, .58]
	Sig. (2-tailed)								.406
	N								21
RAS total	Pearson r								1
	95% CI								
	Sig. (2-tailed)								
	N								

Note. NJRE= not-just-right-experience; HA=harm avoidance; AQ= Autism Quotient; ASSP= Adolescent /Adult Sensory Profile; EDS=extradimensional shift; IED=intradimensional; RAS=Responsibility Attitude Scale.
* Correlation is significant at the 0.05 level (2-tailed); ** Correlation is significant at the 0.01 level (2-tailed).

Secondary analysis

Following the evaluation of the initial hypotheses, further bivariate correlations were conducted to explore the specific relationship to the subdomains of the AQ and AASP.

AQ subdomains. The AQ can be subdivided into five subdomains including attention switching, attention to detail, social skills, communication and imagination.

Potential confounding variables. To explore for potential confounding variables, bivariate correlations of AQ subdomains were calculated. These highlighted that 'attention switching' was associated with OCD symptom severity and low mood. 'Social skills' was associated with low mood as well as state and trait anxiety. Lastly, communication was associated with OCD symptom severity, low mood and state and trait anxiety, see Table 4.

Table 4

Confounding variables related to the AQ's 5 subdomains including OCD symptom severity (Y-BOCS), low mood (MADRS), and anxiety (STAI)

		Attention switching	Attention to detail	Social skills	Communication	Imagination
Y-BOCS total	Pearson r	.52**	.14	.31	.53**	.29
	95% CI	[.15, .77]	[-.28, .52]	[-.05, .67]	[.16, .77]	[-.13, .62]
	Sig. (2-tailed)	.009	.505	.146	.007	.176
	N	24	24	24	24	24
MADRS	Pearson r	.49*	.04	.49*	.50*	.25
	95% CI	[.10, .74]	[-.37, .44]	[.10, .74]	[.12, .75]	[-.17, .59]
	Sig. (2-tailed)	.016	.859	.016	.012	.242
	N	24	24	24	24	24
State Anxiety	Pearson r	.30	.15	.51**	.41*	-.11
	95% CI	[-.11, .62]	[-.26, .51]	[.14, .75]	[.02, .69]	[-.48, .30]
	Sig. (2-tailed)	.147	.480	.010	.041	.618
	N	25	25	25	25	25
Trait Anxiety	Pearson r	.39	.21	.42*	.45*	.29
	95% CI	[-.01, .68]	[-.20, .56)	[.02, .67]	[.06, .72]	[-.12, .62]
	Sig. (2-tailed)	.053	.309	.039	.025	.156
	N	25	25	25	25	25

Note. Y-BOCS= Yale Brown Obsessive Compulsive Scale; MADRS=Montgomery-Asperg Depression Rating Scale; STAI=State Trait Anxiety Inventory.

* Correlation is significant at the 0.05 level (2-tailed); ** Correlation is significant at the 0.01 level (2-tailed).

Relationship to AQ subdomains. Table 5 illustrates correlations between HA and NJRE and these 5 subdomains of the AQ. None of the correlations were significant; however, there was a trend indicating that attention switching may be positively associated with NJRE (p=.052).

Table 5

Correlations between the core motivational processes and the 5 subdomains of the Autism Quotient (AQ)

		NJRE	HA	Attention switching	Attention to detail	Social skills	Communication	Imagination
NJRE	Pearson r	1	.34	.39	.29	-.02	.02	-.14
	95% CI		[-.06, 0.65]	[-.002, .68]	[-.12, .62]	[-.41, .38]	[-.38, .41]	[.29, -.51]
	Sig. (2-tailed)		.092	.052	.157	.918	.919	.499
	N		25	25	25	25	25	25
HA	Pearson r		1	.16	.32	.25	.29	.01
	95% CI			[-.25, .52]	[-.09, .64]	[-.16, .59]	[-.12, .61]	[-.38, .40]
	Sig. (2-tailed)			.444	.119	.228	.166	.974
	N			25	25	25	25	25
Attention switching	Pearson r			1	.25	.40*	.50*	.15
	95% CI				[-.16, .59]	[.01, .67]	[.13, .75]	[-.26, .52]
	Sig. (2-tailed)				.232	.048	.012	.473
	N				25	25	25	25
Attention to detail	Pearson r				1	-.06	.02	-.28
	95% CI					[-.45, .34]	[-.38, .41]	[-.60, .14]
	Sig. (2-tailed)					.759	.945	.184
	N					25	25	25
Social skills	Pearson r					1	.74**	.49*
	95% CI						[.49, .89]	[.11, .74]
	Sig. (2-tailed)						.000	.014
	N						25	25
Communication	Pearson r						1	.59**
	95% CI							[.25, .79]
	Sig. (2-tailed)							.002
	N							25

		NJRE	HA	Attention switching	Attention to detail	Social skills	Communication	Imagination
Imagination	Pearson r							1
	95% CI							
	Sig. (2-tailed)							
	N							

Note. NJRE=not-just-right-experience; HA=harm avoidance.

* Correlation is significant at the 0.05 level (2-tailed); ** Correlation is significant at the 0.01 level (2-tailed).

Sensory processing profile. Further bivariate correlations were conducted to investigate the relationship between core motivational processes and detailed sensory processing profiles.

Potential confounding variables. Low registration and sensory sensitivity were found to correlate with OCD symptom severity, low mood, and state and trait anxiety. In addition, sensation avoiding was associated with OCD symptom severity, low mood and trait anxiety as is seen in Table 6.

Table 6
Confounding variables related to the sensory sensitivity profile including OCD symptom severity (Y-BOCS), low mood (MADRS), and anxiety (STAI)

		Low registration	Sensation seeking	Sensory sensitivity	Sensation Avoiding
Y-BOCS total	Pearson r	.51*	.19	.44*	.45*
	95% CI	[.13, .76]	[-.23, .55]	[.04, .71]	[.06, .72]
	Sig. (2-tailed)	.012	.379	.033	.026
	N	24	24	24	24
MADRS	Pearson r	.57**	-.02	.59**	.42*
	95% CI	[.23, .79]	[-.42, .38]	[.25, .81]	[.02, .70]
	Sig. (2-tailed)	.004	.915	.002	.042
	N	24	24	24	24
State Anxiety	Pearson r	.44*	.23	.50*	.32
	95% CI	[.06, .71]	[-.18, .57]	[.13, .75]	[-.08, .64]
	Sig. (2-tailed)	.027	.267	.011	.117
	N	25	25	25	25
Trait Anxiety	Pearson r	.48*	-.17	.46*	.41*
	95% CI	[.10, .73]	[-.53, .24]	[.08, .73]	[.02, .69]
	Sig. (2-tailed)	.016	.414	.020	.040
	N	25	25	25	25

Note. Y-BOCS= Yale Brown Obsessive Compulsive Scale; MADRS=Montgomery-Asperg Depression Rating Scale; STAI=State Trait Anxiety Inventory.
* Correlation is significant at the 0.05 level (2-tailed); ** Correlation is significant at the 0.01 level (2-tailed).

Relationship to sensory processing profile. Table 7 shows that NJRE was positively correlated with a sensory processing profile of low registration, sensory sensitivity, and sensory avoiding. The relationship between NJRE and low registration and sensation avoiding was still significant after applying a more rigorous alpha level. HA was associated with sensory sensitivity at a corrected Bonferroni level and with sensation avoiding.

As both HA and NJRE were significantly related to sensory sensitivity and sensation avoiding ($p<0.05$) the correlation coefficients were statistically compared. The correlations between the motivational processes and sensory sensitivities were very similar and a Steiger's Z analysis showed that the difference between these correlations was not significant ($z=-0.21$; $p= 0.582$). The correlation with sensation avoiding was similarly not significant ($z= 0.61$; $p= 0.272$).

OCD symptom severity and trait anxiety were related to both NJRE and low registration. To control for a potentially confounding effect, correlations were recalculated using partial correlations. The relationship between NJRE and low registration was still significant after applying a partial correlation to control for OCD symptom severity ($r=.49$, $p=.016$) and trait anxiety ($r=.46$, $p=.024$).

Similarly, OCD symptom severity and trait anxiety were related both to NJRE and sensory sensitivity, which could suggest symptom severity and trait anxiety being confounding variables. The relationship between NJRE and sensory sensitivity was still significant after controlling for OCD symptom severity ($r=.49$, p-.018) using partial correlations. The relationship was no longer significant when factoring in trait anxiety ($r=.34$, $p=.103$).

State and trait anxiety were related to both HA and sensory sensitivities. The relationship between HA and sensory sensitivity remained significant after controlling for state anxiety (r=.41, p=.047). It was no longer significant after controlling for trait anxiety (r=.40, p=.056).

OCD symptom severity and trait anxiety were again related to both NJRE and sensation avoiding and could be potential confounding variables. However, the relationship between NJRE and sensation avoiding remained significant even after controlling for OCD symptom severity (r=.50, p=.014) and trait anxiety (r=.47, p=.021).

The last potential confounding variable was trait anxiety, which was related to both HA and sensation avoiding. The relationship between HA and sensation avoiding did not withstand analyses with partial correlations to control for trait anxiety (r=.26, p=.224).

Table 7

Correlations between core motivational processes (NJRE and HA) and 4 categories of the sensory profile

		NJRE	HA	Low Registration	Sensation seeking	Sensory sensitivity	Sensation avoiding
NJRE	Pearson r	1	.34	.61**	.18	.51**	.59**
	95% CI		[-.06, 0.65]	[.28, .81]	[-.24, .53]	[.15, .75]	[.25, .80]
	Sig. (2-tailed)		.092	.001	.403	.009	.002
	N	25	25	25	25	25	25
HA	Pearson r		1	.31	.07	.55**	.43*
	95% CI			[-.09, .63]	[-.03, .45]	[.20, .78]	[.04, .71]
	Sig. (2-tailed)			.126	.734	.004	.032
	N			25	25	25	25
Low registration	Pearson r			1	.21	.67**	.66**
	95% CI				[-.19, .56]	[.37, .84]	[.36, .84]
	Sig. (2-tailed)				.306	.000	.000
	N				25	25	25
Sensation seeking	Pearson r				1	-.03	.12
	95% CI					[-.42, .37]	[-.24, .49]
	Sig. (2-tailed)					.897	.574
	N					25	25
Sensory sensitivity	Pearson r					1	.79**
	95% CI						[.57, .90]
	Sig. (2-tailed)						.000
	N						25

Note. NJRE= not-just-right-experience; HA=harm avoidance.

* Correlation is significant at the 0.05 level (2-tailed); ** Correlation is significant at the 0.01 level (2-tailed).

Discussion

This study aimed to explore the "not just right experience" (NJRE) in OCD. It was of interest to investigate whether NJRE could be defined as a distinct construct and a possible marker for a subgroup of individuals with OCD. It was hypothesised that NJRE may point to an autistic phenotype and, hence, it was predicted that NJRE, unlike HA, would be associated to higher AQ scores, sensory abnormalities, and set-shifting difficulties. In addition, it was predicted that NJRE would be related to earlier signs of an atypical development in OCD disorders as compared to HA. Lastly, it was hypothesised that HA, but not NJRE, would be correlated to learned assumptions such as responsibility beliefs.

NJRE was found to be a continuous dimension in OCD that was not significantly associated with HA in this small sample of individuals with OCD. This finding suggests that it is unlikely that HA and NJRE are strongly related to each other, although it is not possible to exclude the possibility that in a larger study a small or moderate relationship may be detected. Even though NJRE appeared to define a separate construct from HA in this sample, it did not pinpoint a distinct OCD subgroup nor mark the presence of ASD traits. The presence of NJRE was, however, related to sensory abnormalities, and there was a trend towards an association with repetitive behaviours (attention switching) as measured by the AQ. Contrary to the hypothesis, NJRE was not related to set-shifting difficulties as measured by the CANTAB. As predicted, there was evidence that NJRE and not HA was associated to an earlier age of OCD onset. Lastly, HA, but not NJRE, was significantly associated with responsibility beliefs.

NJRE as a dimension in OCD

There are ongoing debates as to whether the heterogeneity of OCD is best understood in terms of subtypes or corresponding to a set of dimensions (Taylor, 2010). It was purported that NJRE could potentially define a subgroup of OCD. However, the continuous distributions of NJRE and HA does not support this hypothesis. The current study found no evidence for a natural cut-off point between those with high and low levels of NJRE. Furthermore, the presence of NJRE in non-clinical populations (Ghisi, Chiri, Marchetti, Sanavio, & Sica, 2010; Pietrefesa & Coles, 2009), strengthens the understanding of NJRE as a dimension rather than a marker of a discrete subgroup. It may be that, similar to autistic traits, (Constantino et al., 2003; Skuse, Mandy, & Scourfield, 2005), NJRE is widely distributed in the general population and that only the extreme end of its distribution is of clinical significance. Indeed, NJRE scores were significantly higher in this sample as compared to a healthy student population. It would be important to continue to study the clinical relevance of NJRE and determine a clinical cut-off.

In addition to illustrating a continuous distribution of NJREs in OCD, the data suggest that HA and NJRE are likely measuring different constructs in OCD. The correlation between NJRE and HA was modest to low at 0.34 and, in analyses powered to detect moderate to large effects (r >.5), was not statistically significant. Nevertheless, this correlation is relatively small when considering that the phenotypic overlap between ASD and attention deficit hyperactivity disorder (ADHD), which are widely recognised as two distinct disorders, is between .51-.54 (Ronald, Simonoff, Kuntsi, Asherson, & Plomin, 2008). It can be argued that like ASD and ADHD, NJRE and HA have shared but also unique pathophysiologies or even aetiologies. One hypothesis is that NJRE has a neurodevelopmental basis. In an attempt to better

understand the dimensional aspects of NJRE, this study explored NJRE relationships to neurodevelopmental features.

NJRE relationship to ASD

One important aim of the study was to look at the relationship of NJRE to ASD traits. The findings of this study suggested that NJRE was not related to autistic traits as measured by the AQ. It is however, difficult to fully rule out a relationship between NRJE and ASD, due to limitations of the study. Firstly, the study was underpowered and may have missed small to medium effect sizes. Secondly, there have been questions raised about the sensitivity of the AQ, (Bishop & Seltzer, 2012; Ketelaars et al., 2008) currently a widely used adult ASD screening tool (Bishop & Seltzer, 2012). For example, in a sample of individuals with a confirmed diagnosis of ASD only 27% scored in the clinical cut-off range of the AQ (Bishop & Seltzer, 2012). Hence, the AQ may not have reliably detected ASD in the research sample. Verification of autistic traits with a standardised clinician rated diagnostic measure would seem essential and could include the Autism Diagnostic Interview, Revised (ADI-R) (Couteur, Lord, & Rutter, 2003), Developmental, Dimensional and Diagnostic Interview (3di) (Skuse et al., 2004) or the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000).

The relationship of NJREs to ASD traits may, furthermore, have been falsely negated due to the use of the AQ total score. NJREs may not be related to autism in its entirety. ASD is considered to be a 'fractionable' condition with a present understanding that the social (social interaction and communication) and non-social (repetitive and restrictive behaviours and interests) domains are likely related to distinct aetiologies and cognitive mechanisms (Happé & Ronald, 2008). The non-social domain of ASD has been independently reported in the absence of social communication difficulties in other types of psychopathology, such as eating disorders

(Pooni, Ninteman, Bryant-Waugh, Nicholls, & Mandy, 2012). The association of NJRE with the non-social domain of ASD has been cited in past research. Parental levels of INC (NJRE) were found to be related to their autistic children's repetitive behaviour (i.e. non-social domain of ASD) (Kloosterman et al., 2013).

Of the five subdomains in the AQ, poor "attention switching" is likely related to adherence of routines associated to theoretical underpinnings of repetitive behaviour reflecting the non-social domain of autism (Hoekstra et al., 2011). In the present study there was only a statistical trend (p=.052) to suggest that NJRE was associated to 'attention switching.' However, the AQ subscales are found to have only moderately robust psychometric properties. The coefficient alpha for attention switching is .67 (Baron-Cohen et al., 2001). It would be essential to replicate these findings in a larger sample size with a more comprehensive measure of restricted repetitive behaviours (RRB) using the ADI-R (Couteur et al., 2003), 3di (Skuse et al., 2004) or Repetitive Behavior Scale-Revised (RBS-R) (Bodfish, Symons, Parker, & Lewis, 2000). It is also important to note that these measures have been designed for measuring autism in childhood. More research is needed to develop and validate equivalent measures for adult populations.

The non-social domain of ASD is furthermore characterised by sensory abnormalities (Mandy, Charman, & Skuse, 2012) whose relevance to autism has been recognized by inclusion in the DSM 5 as a core diagnostic criterion for ASD (American Psychiatric Association, 2013). Sensory abnormalities including hypo- and hyper-sensitivity are associated to RRB rather than to social and communication difficulties of ASD (Mandy et al., 2012). The positive correlation between NJRE and sensory abnormalities reported in the present study strengthens the argument that NJRE may, indeed, be related to the non-social domain of ASD. In addition to general

sensory processing difficulties, OCD individuals with NJRE were more likely to demonstrate specific hypo-sensitivity (low registration), hyper-sensitivity, and sensation avoiding.

Anxiety and low mood have been found to be related to sensory processing difficulties in past research. For example, anxiety levels have been associated with overall sensory processing (Rodgers, Glod, Connolly, & McConachie, 2012). Sensation avoiding has been thought to be related to low mood (Brown & Dunn, 2002). This study identified anxiety, low mood, and OCD symptom severity as potential confounding variables, by their association with NJRE and HA as well as with sensory processing and its subcomponents (sensory sensitivity, low registration, sensation avoiding, and sensation seeking) as measured by the AASP. Partial correlations were calculated to control for the effects of anxiety, low mood, or OCD symptom severity. Unlike HA, NJRE's relationship to sensory processing was not confounded by mood, anxiety, or OCD severity. Surprisingly, sensory sensitivity, one component of sensory processing, was consistently associated with HA even after controlling for state anxiety and OCD severity, but was no longer significant after controlling for trait anxiety. The relationship of NJRE to sensory sensitivity was similarly insignificant when controlling for trait anxiety. These findings suggest that sensory sensitivities may be linked to a general tendency of perceiving threat rather than reflecting current levels of anxiety (Spielberger et al., 1983). Fearful individuals may be highly aware of their environment and 'sensitive' to any changes in their surroundings. However, it is less clear whether this awareness is due to neurological differences or to learned experiences. In order to better understand sensory processing mechanisms in HA and NJRE, it would be helpful to follow-up correlational findings as determined by the AASP with neuroimaging to observe whether individuals with higher expressed

NJREs as compared to HA use comparable neurological mechanisms to process sensory information.

In general, measures of sensory processing difficulties in this study need to be interpreted with caution due to methodological limitations and the inability to control for the effect of medications. The findings are based on a self-report questionnaire. There have been no previous studies which have evaluated whether the AASP (sensory processing questionnaire) is able to distinguish between sensory abnormalities and symptoms of OCD. Individuals with OCD may have found the sensory process questions in the AASP confusing. Their answers could have been erroneously inflated due to symptoms of OCD rather than the experience of sensory environments as aversive per se.

All OCD participants in this study were on medication. In particular, antidepressants are known to affect the somatosensory cortex and can lead to changes in neurological thresholds for sensory processing (Quednow et al., 2004). It is possible that the presence and attributes of NJREs in this study are due to additive medication effects or that medications are inflating the rate of sensory processing difficulties irrespective of NJREs.

Cognitive explanations for non-social domains of ASD have focused on difficulties with preservation, planning, and set-shifting (Hill, 2004). This study explored NJRE's relationship to set-shifting difficulties. NJRE was not related to set-shifting difficulties, contrary to prediction. There are several reasons which could explain this finding. Firstly, set-shifting difficulties may not be related to NJRE, but, then again, findings may also be related to methodological limitations. Set-shifting was measured using the IDED subtests of the CANTAB. The CANTAB has been found to be able to discriminate between cognitive performances in clinical as

compared to healthy populations (De Luca et al., 2003). However, there is limited information as to whether it is sensitive enough to detect differences within clinical populations (Smith, Need, Cirulli, Chiba-Falek, & Attix, 2013). It has been found to only weakly correlate with traditional neuropsychological tests (Smith et al., 2013). Perhaps the CANTAB was unable to detect subtle set-shifting differences between OCD populations experiencing HA or NJRE. It would be interesting to replicate this study using the Wisconsin Card Sorting task, which was successfully used to detect a negative association between set-shifting difficulties and the symmetry/ordering dimension in OCD (Lawrence et al., 2006). Lastly, it can be challenging to establish convergent validity between questionnaires and computerized neuropsychological tests (Vasconcelos, Sergeant, Corrêa, Mattos, & Malloy-Diniz, 2014). Even if NJRE was related to cognitive rigidity, it may not necessarily correlate well with neuropsychological measures. Nevertheless, at this stage it appears that set-shifting difficulties as measured by the IDED are not differentially related to HA and NJRE.

In summary, there is some limited evidence to speculate that NJRE may be a manifestation of the non-social domain of ASD in particular in regards to sensory abnormalities; however, findings are tentative due to methodological limitations. Further investigations are warranted to explore this idea.

NJRE as a broader marker of atypical development

Supplementary to the hypothesis of NJRE being a marker of ASD was the suggestion that NJRE in OCD could be more broadly conceptualised as an atypical developmental pathway distinct from HA. Hence, it was predicted that in addition to more sensory processing difficulties, NJRE would be related to an earlier age of OCD onset and not to learned assumptions of, for example, an over inflated sense of responsibility. Gillberg (2010) discusses the 'ESSENCE' in child psychiatry, which

refers to "early symptomatic syndromes eliciting neurodevelopmental clinical examinations" (p.1543). He refers to a range of symptoms including "motor abnormality, general developmental delay, speech and language delay, social interaction/communication problems, behaviour problems, hyperactivity/inattention, hypoactivity, inattention/does not listen, sleep problems, and feeding difficulties" (Gillberg, 2010, p. 1545). It may be that NJRE, marked by sensory abnormalities and perhaps cognitive rigidity, is an additional symptom of a broad syndrome of atypical neurodevelopment starting in childhood.

Current results, which can only be interpreted with caution, suggest that an earlier age of OCD onset is related to NJRE, corresponding to results found in previous research (do Rosario-Campos, 2001; Ferrão et al., 2012). However, it is important to consider that the study may have been underpowered and so not able to detect an association between age of OCD onset and HA. Findings, if substantiated, may imply earlier key differences in the developmental trajectory of OCD and could support the notion that OCD plus NJRE is better understood as a developmental disorder. These findings concur with a previous review suggesting that juvenile OCD onset reflects a developmental subgroup (Geller, Biederman, & Jones, 1998). The review by Geller et al. (1998) highlighted that early onset OCD (juvenile OCD) was characterised by familial loading, male predominance, lack of insight, comorbidity with developmental disorders and lower non-verbal reasoning abilities. The prevalence of NJREs was not explored.

It has been difficult to verify OCD as a developmental subgroup based on age of onset (Leckman et al., 2010). This may be partly related to the inconsistencies in definitions of "onset." For example, onset may refer to the initial presentation of subclinical symptoms or to the point in time when the clinical diagnosis of OCD was

made (Leckman et al., 2010). Perhaps NJRE can be identified as a link between the early onset and developmental presentation of OCD not bound to a specific age of OCD onset.

It was further hypothesized that HA and not NJRE would be related to over-inflated responsibility beliefs. This finding would be an important argument strengthening suppositions of different clinical pathways leading to OCD. It has been proposed that 'feeling responsible' is a learned assumption likely related to early experiences (Salkovskis & Shafran, 1999). In the cognitive behavioural theory of OCD, it is believed that the client's interpretation of an intrusive cognition is a critical driving force and maintaining factor for obsessive compulsive behaviours. HA will be a consequence of feeling responsible for a perceived harmful threat. The obsessive-compulsive symptoms are attempts to neutralise the intrusive cognition, but lead, unintentionally, to heightened anxiety and, hence, to a greater urgency to try to avoid or minimize harm. In the present study HA was associated with responsibility beliefs. NJRE was not related to this learned responsibility in this small sample. It would be interesting to extend this finding and explore to what extent NJRE is related to other learned assumptions, or whether it is, as hypothesized in this study, driven by neurological factors. Overall, it appears that responsibility beliefs are an important characteristic of OCD, but are not relevant for all OCD traits.

Clinical implications

Even though NJRE was not found to be a marker of a subgroup of OCD individuals with autistic traits, this study does suggest that NJRE is related to aspects of atypical development including an earlier age of OCD onset, sensory abnormalities, and possibly aspects of the repetitive and restrictive behaviours as seen in ASD. Acknowledging the role of NJRE in OCD offers alternative theoretical assumptions

about the sustaining factors undermining repetitive behaviours beyond anxiety reduction and encourages treatment considerations aiming to reduce a general sensory discomfort. Summerfeldt (2004) labelled INC (NJRE) as a "sensory-affective dysfunction" (p.1155) and argued similarly, that INC was likely to be internally generated and, hence, less responsive to CBT. In a single case presentation of a male with OCD marked by INC a treatment strategy was successfully implemented to desensitise sensations of discomfort associated with NJRE by focusing on exposure and ritual prevention (ERP) (Summerfeldt, 2004). Obviously, more treatment studies would be needed to verify the success of this behavioural approach to treatments of OCD with NJRE rather than addressing the cognitive components identified in CBT. In this sense, reformulating NJRE as a sensory experience, perhaps related to neurological underpinnings, could help adjust treatment expectations and treatment plans. As in other neurological disorders it may be best to develop compensatory strategies and manage the impact of sensory discomfort on daily activities. A reformulation based on neurological criteria may in itself have a therapeutic value and lead to more realistic expectations. In summary, CBT formulation of OCD is standard treatment but may not address the full complexity of OCD pathology.

Limitations

The present study demonstrated some interesting initial findings, which, however, need to be interpreted with caution due to inherent methodological limitations. Firstly, due to its sample size of n=25, the study lacked statistical power to detect medium to small effects. This issue was particularly pertinent when attempting to compare the correlation coefficients between HA and NJRE. The study may have also missed important associations, for example between NJRE and AQ.

A cross-sectional correlational design was applied to address the research question. Hence, statistical analysis provided important but only preliminary information about the relationships between variables. It is not possible to determine whether factors such as NJRE and sensory abnormalities are sequentially or causally interlinked. A longitudinal design would be helpful in further exploring the hypothesis that NJRE is related to a more neurodevelopmental presentation of OCD along a symptom spectrum of severity. For example, are there signs of sensory processing difficulties and repetitive behaviour seen in young children before the onset of OCD with NJRE (Coles, Hart, & Shofield, 2011)?

The present study was primarily based on self-report questionnaires with only one neuropsychological test. The self-report questionnaires, even though commonly used in research, require sophisticated insight into one's own symptoms. There is little information about the questionnaire's discriminant validity as to whether they can distinguish between, for example, behavioural patterns seen in OCD versus ASD. The AQ and AASP, in particular, could have been falsely inflated with positive answers due to OCD symptoms affecting the internal validity of the study. It would have been useful to verify diagnoses of ASD using standardised clinician rated scales. It is generally challenging to measure autistic symptoms in adult populations as measures have usually been designed to detect symptoms in children (Murphy, Beecham, Craig, & Ecker, 2011). Direct assessment methods of sensory aversions or of NJRE using behavioural experiments may have been a useful supplement to questionnaires. NJRE and HA have been successfully tested using a behavioural paradigm in student populations (Pietrefesa & Coles, 2009). It would additionally be of interest to explore the proposed differences in the motivational mechanisms of NJRE and HA using

neuroimaging techniques to ascertain whether distinct neurocognitive/sensory processing mechanisms can be verified.

The population sample was recruited exclusively from a national OCD service. It is possible that this sample is not representative of the general OCD population due to the complexity and severity of clinical presentations. In addition, all participants were being psychopharmacologically treated. The overall OCD scores were in the moderate range, which is lower than may be expected based on clinical histories and is likely an effect of medical treatment. It is, likewise, unclear as to what extent medications could have affected answers on the questionnaires or outcomes on the neuropsychological testing. As speculated earlier, certain medications can affect scores on the sensory processing measures. It was noted that anecdotally some participants said that they thought they would respond differently if they were not on their medication. These issues may limit the external validity of this study.

This study did not control for a co-morbid tic disorder. Tics are likely a very critical confounding variable as they are frequently associated to NJRE (Leckman et al., 1994; Miguel et al., 2000). It would be important to control for tics as a confounding variable in future research.

In summary, OCD is a heterogeneous clinical disorder. Research endeavours attempt to explain the possible divergent pathways leading to the repetitive behaviours characteristic of OCD. This study has contributed to OCD research by exploring the role of NJRE in OCD presentations as a marker for a phenotypically autistic-like OCD subgroup. Due to the nature of the clinical population and small sample size, there were no controls for medications or co-morbidity. The study provided, nevertheless, interesting preliminary findings, but a number of research questions remain insufficiently answered. NJREs in OCD may be related to non-social symptom

domains of autism with sensory processing difficulties. They may underscore underlying neurological differences as a mechanism in OCD distinct from HA. NJREs may point out an atypical developmental trajectory in OCD. Speculations about an aetiology and pathophysiology differing from HA warrant further research in consideration of improving alternative treatment approaches in OCD.

References

Abramson, R. K., Ravan, S. A., Wright, H. H., Wieduwilt, K., Wolpert, C. M., Donnelly, S. A., … Cuccaro, M. L. (2005). The relationship between restrictive and repetitive behaviors in individuals with autism and obsessive compulsive symptoms in parents. *Child Psychiatry and Human Development, 36,* 155–165.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing.

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): evidence from Asperger Syndrome / high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 17,* 5–17.

Bejerot, S., Nylander, L., & Lindström, E. (2001). Autistic traits in obsessive-compulsive disorder. *Nordic Journal of Psychiatry, 55,* 169–176.

Bienvenu, O. J., Samuels, J. F., Wuyek, L. A, Liang, K.-Y., Wang, Y., Grados, M. A, … Nestadt, G. (2012). Is obsessive-compulsive disorder an anxiety disorder, and what, if any, are spectrum conditions? A family study perspective. *Psychological Medicine, 42,* 1–13.

Bishop, S. L., & Seltzer, M. M. (2012). Self-reported autism symptoms in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42,* 2354–2363.

Bishop, S. L., Hus, V., Duncan, A., Huerta, M., Gotham, K., Pickles, A., … Lord, C. (2013). Subcategories of restricted and repetitive behaviors in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43,* 1287–1297.

Bodfish, J. W., Symons, F. J., Parker, D. E., & Lewis, M. H. (2000). Varieties of Repetitive Behavior in Autism: Comparisons to Mental Retardation. *Journal of Autism and Developmental Disorders, 30*, 237–243.

Boyette, L., Swets, M., Meijer, C., & Wouters, L. (2011). Factor structure of the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) in a large sample of patients with schizophrenia or related disorders and comorbid obsessive-compulsive symptoms. *Psychiatry Research, 186,* 409–413.

Brown, C. & Dunn, W. (2002). *Adolescent/Adult Sensory Profile manual.* San Antonio, TX: Psychological Corporation.

Calamari, J. E., Wiegartz, P. S., & Janeck, A. S. (1999). Obsessive–compulsive disorder subgroups: a symptom-based clustering approach. *Behaviour Research and Therapy, 37,* 113–125.

Carmody, T. J., Rush, A J., Bernstein, I., Warden, D., Brannan, S., Burnham, D., … Trivedi, M. H. (2006). The Montgomery Asberg and the Hamilton ratings of depression: a comparison of measures. *European Neuropsychopharmacology : The Journal of the European College of Neuropsychopharmacology, 16,* 601–611.

Cath, D. C., Ran, N., Smit, J. H., van Balkom, A. J. L. M., & Comijs, H. C. (2008). Symptom overlap between autism spectrum disorder, generalized social anxiety disorder and obsessive-compulsive disorder in adults: a preliminary case-controlled study. *Psychopathology, 41,* 101–110.

Chik, H. M., Calamari, J. E., Rector, N. A, & Riemann, B. C. (2010). What do low-dysfunctional beliefs obsessive-compulsive disorder subgroups believe? *Journal of Anxiety Disorders, 24,* 837–846.

Coles, M. E., Heimberg, R. G., Frost, R. O., & Steketee, G. (2005). Not just right experiences and obsessive-compulsive features: experimental and self-monitoring perspectives. *Behaviour Research and Therapy, 43,* 153–167.

Coles, M. E., Hart, A. S., & Schofield, C. A. (2011). Initial data characterizing the progression from obsessions and compulsions to full-blown obsessive compulsive disorder. *Cognitive Therapy and Research, 36,* 685–693.

Constantino, J. N., Davis, S. A., Todd, R. D., Schindler, M. K., Gross, M. M., Brophy, S. L., … Reich, W. (2003). Validation of a brief quantitative measure of autistic traits: Comparison of the Social Responsiveness Scale with the Autism Diagnostic Interview-Revised. *Journal of Autism and Developmental Disorders, 33,* 427–433.

Couteur, A. Le, Lord, C., & Rutter, M. (2003). The autism diagnostic interview–Revised (ADI-R). *Los Angeles, CA: Western Psychological Services*.

Crane, L., Goddard, L., & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. Autism : *The International Journal of Research and Practice, 13,* 215–228.

De Luca, C. R., Wood, S. J., Anderson, V., Buchanan, J.-A., Proffitt, T. M., Mahony, K., & Pantelis, C. (2003). Normative data from the CANTAB. I: development of executive function over the lifespan. *Journal of Clinical and Experimental Neuropsychology, 25,* 242–254.

Deacon, B. J., & Abramowitz, J. S. (2005). The Yale-Brown Obsessive Compulsive Scale: factor analysis, construct validity, and suggestions for refinement. *Journal of Anxiety Disorders, 19,* 573–585.

Do Rosario-Campos, M. C. (2001). Adults with early-onset obsessive-compulsive disorder. *American Journal of Psychiatry, 158,* 1899–1903.

Ecker, W., & Gönner, S. (2008). Incompleteness and harm avoidance in OCD symptom dimensions. *Behaviour Research and Therapy, 46,* 895–904.

Ecker, W., Kupfer, J., & Gönner, S. (2013). Incompleteness as a link between obsessive-compulsive personality traits and specific symptom dimensions of obsessive-compulsive disorder. *Clinical Psychology & Psychotherapy, 3*, 1-8.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41,* 1149-1160.

Ferrão, Y. A., Shavitt, R. G., Prado, H., Fontenelle, L. F., Malavazzi, D. M., de Mathis, M. A., … do Rosário, M. C. (2012). Sensory phenomena associated with repetitive behaviors in obsessive-compulsive disorder: an exploratory study of 1001 patients. *Psychiatry Research, 197,* 253–258.

Fontenelle, L. F., Mendlowicz, M. V, & Versiani, M. (2006). The descriptive epidemiology of obsessive-compulsive disorder. *Progress in Neuro-Psychopharmacology & Biological Psychiatry, 30,* 327–337.

Frost, R. O., & DiBartolo, P. M. (2002). Perfectionism, anxiety, and obsessive-compulsive disorder. In G.L. Flett & P.L. Hewitt (Eds.), *Perfectionism: Theory, research, and treatment* (pp. 341-371). Washington: American Psychological Association.

Geller, D., Biederman, J., & Jones, J. (1998). Is juvenile obsessive-compulsive disorder a developmental subtype of the disorder? A review of the pediatric literature. *Journal of the American Academy of Child & Adolescent Psychiatry, 37,* 420-427.

Ghisi, M., Chiri, L. R., Marchetti, I., Sanavio, E., & Sica, C. (2010). In search of specificity: "not just right experiences" and obsessive-compulsive symptoms

in non-clinical and clinical Italian individuals. *Journal of Anxiety Disorders, 24*, 879–886.

Gillberg, C. (2010). The ESSENCE in child psychiatry: Early symptomatic syndromes eliciting neurodevelopmental clinical examinations. *Research in Developmental Disabilities, 31*, 1543–1551.

Goodman, W. K. (1989). The Yale-Brown Obsessive Compulsive Scale. *Archives of General Psychiatry, 46,* 1006-1011.

Greist, J. H. (1995). Efficacy and tolerability of serotonin transport inhibitors in obsessive-compulsive disorder. *Archives of General Psychiatry, 52*, 53-60.

Happé, F., & Ronald, A. (2008). The "fractionable autism triad": a review of evidence from behavioural, genetic, cognitive and neural research. *Neuropsychology Review, 18,* 287–304.

Hill, E. L. (2004). Evaluating the theory of executive dysfunction in autism. *Developmental Review, 24,* 189–233.

Hoekstra, R. A, Vinkhuyzen, A. A. E., Wheelwright, S., Bartels, M., Boomsma, D. I., Baron-Cohen, S., … van der Sluis, S. (2011). The construction and validation of an abridged version of the autism-spectrum quotient (AQ-Short). *Journal of Autism and Developmental Disorders, 41,* 589–596.

Ivarsson, T., & Valderhaug, R. (2006). Symptom patterns in children and adolescents with obsessive-compulsive disorder (OCD). *Behaviour Research and Therapy, 44,* 1105–1116.

Ivarsson, T., & Melin, K. (2008). Autism spectrum traits in children and adolescents with obsessive-compulsive disorder (OCD). *Journal of Anxiety Disorders, 22,* 969–978.

Ketelaars, C., Horwitz, E., Sytema, S., Bos, J., Wiersma, D., Minderaa, R., & Hartman, C. A. (2008). Brief report: adults with mild autism spectrum disorders (ASD): scores on the autism spectrum quotient (AQ) and comorbid psychopathology. *Journal of Autism and Developmental Disorders, 38,* 176–180.

Kloosterman, P. H., Summerfeldt, L. J., Parker, J. D. A., & Holden, J. J. A. (2013). The obsessive-compulsive trait of incompleteness in parents of children with autism spectrum disorders. *Journal of Obsessive-Compulsive and Related Disorders, 2,* 176–182.

Lawrence, N. S., Wooderson, S., Mataix-Cols, D., David, R., Speckens, A., & Phillips, M. L. (2006). Decision making and set shifting impairments are associated with distinct symptom dimensions in obsessive-compulsive disorder. *Neuropsychology, 20,* 409–419.

Leckman, J. F., Walker, D. E., Goodman, W. K., Pauls, D. L., & Cohen, D. J. (1994). "Just right" perceptions associated with compulsive behavior in Tourette's syndrome. *The American Journal of Psychiatry, 151,* 675–680.

Leckman, J. F., Grice, D. E., Barr, L. C., de Vries, A. L., Martin, C., Cohen, D. J., … Rasmussen, S. A. (1995). Tic-related vs. non-tic-related obsessive compulsive disorder. *Anxiety, 1,* 208–215.

Leckman, J. F., Denys, D., Simpson, H. B., Mataix-Cols, D., Hollander, E., Saxena, S.,… Stein, D. J. (2010). Obsessive-compulsive disorder: A review of the diagnostic criteria and possible subtypes and dimensional specifiers for DSM-V. *Depression and Anxiety, 27,* 507–527.

Lee, J. C., Prado, H. S., Diniz, J. B., Borcato, S., da Silva, C. B., Hounie, A. G., … do Rosário, M. C. (2009). Perfectionism and sensory phenomena: phenotypic

components of obsessive-compulsive disorder. *Comprehensive Psychiatry, 50*, 431–436.

Leonard, H. L., Lenane, M. C., Swedo, S. E., Rettew, D. C., Gershon, E. S., & Rapoport, J. L. (1992). Tics and Tourette's disorder: a 2- to 7-year follow-up of 54 obsessive-compulsive children. *The American Journal of Psychiatry, 149*, 1244–1251.

Lord, C., Risi, S., Lambrecht, L., Jr., E. H. C., Leventhal, B. L., DiLavore, P. C., … Rutter, M. (2000). The Autism Diagnostic Observation Schedule—Generic: A Standard Measure of Social and Communication Deficits Associated with the Spectrum of Autism. *Journal of Autism and Developmental Disorders, 30*, 205–223.

Lowe, C. & Rabbitt, P. (1998). Test/re-test reliability of the CANTAB and ISPOCD neuropsychological batteries: theoretical and practical issues. Cambridge Neuropsychological Test Automated Battery. *Neuropsychologia, 36*, 915–923.

Mandy, W. P. L., Charman, T., & Skuse, D. H. (2012). Testing the construct validity of proposed criteria for DSM-5 autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 51*, 41–50.

Mataix-Cols, D., Pertusa, A., & Leckman, J. F. (2007). Issues for DSM-V: how should obsessive-compulsive and related disorders be classified? *The American Journal of Psychiatry, 164*, 1313–1314.

McKay, D. (2006). Treating disgust reactions in contamination-based obsessive-compulsive disorder. *Journal of Behavior Therapy and Experimental Psychiatry, 37*, 53–59.

Miguel, E. C., do Rosario-Campos, M. C., da Silva Prado, H., do Valle, R., Rauch, S. L., Coffey, B. J., … Leckman, J. F. (2000). Sensory phenomena in obsessive-compulsive disorder and Tourette's disorder. *Journal of Clinical Psychiatry, 61,* 150-156.

Montgomery, S.A., & Asberg, M. (1979). A new depression scale designed to be sensitive to change. *British Journal of Psychiatry, 134,* 382-389.

Murphy, D. G. M., Beecham, J., Craig, M., & Ecker, C. (2011). Autism in adults. New biologicial findings and their translational implications to the cost of clinical services. *Brain Research, 1380,* 22–33.

Newman, L. A., & McGaughy, J. (2011). Adolescent rats show cognitive rigidity in a test of attentional set shifting. *Developmental Psychobiology, 53,* 391–401.

Nutt, D., & Malizia, A. (2006). Anxiety and OCD - the chicken or the egg? *Journal of Psychopharmacology, 20,* 729–731.

Ozonoff, S., Cook, I., Coon, H., Dawson, G., Joseph, R. M., Klin, A., … Wrathall, D. (2004). Performance on Cambridge Neuropsychological Test Automated Battery subtests sensitive to frontal lobe function in people with autistic disorder: Evidence from the collaborative programs of excellence in autism network. *Journal of Autism and Developmental Disorders, 34,* 139–150.

Pallanti, S., & Quercioli, L. (2006). Treatment-refractory obsessive-compulsive disorder: methodological issues, operational definitions and therapeutic lines. *Progress in Neuro-Psychopharmacology and Biological Psychiatry, 3,* 400-412.

Pennington, B. F., & Ozonoff, S. (1996). Executive Functions and Developmental Psychopathology. *Journal of Child Psychology and Psychiatry, 37,* 51–87.

Pietrefesa, A. S., & Coles, M. E. (2009). Moving beyond an exclusive focus on harm avoidance in obsessive-compulsive disorder: behavioral validation for the separability of harm avoidance and incompleteness. *Behavior Therapy, 40,* 251–259.

Pooni, J., Ninteman, A., Bryant-Waugh, R., Nicholls, D., & Mandy, W. (2012). Investigating autism spectrum disorder and autistic traits in early onset eating disorder. *The International Journal of Eating Disorders, 45*, 583–591.

Purcell, R., Maruff, P., Kyrios, M., & Pantelis, C. (1998). Cognitive deficits in obsessive–compulsive disorder on tests of frontal–striatal function. *Biological Psychiatry, 43*, 348–357.

Quednow, B. B., Kühn, K.-U., Stelzenmuelle, R., Hoenig, K., Maier, W., & Wagner, M. (2004). Effects of serotonergic and noradrenergic antidepressants on auditory startle response in patients with major depression. *Psychopharmacology, 175*, 399–406.

Rachman, S. (1997). A cognitive theory of obsessions. *Behaviour Research and Therapy*, *35,* 793–802.

Rasmussen, S. A., & Eisen, J. L. (1992). The epidemiology and differential diagnosis of obsessive compulsive disorder. *Journal of Clinical Psychiatry*, *55,* 5–10.

Robbins, T., & James, M. (1998). A study of performance on tests from the CANTAB battery sensitive to frontal lobe dysfunction in a large sample of normal volunteers: Implications for theories of executive functioning and cognitive aging. *Journal of the International Neuropsychological Society, 4*, 474-490.

Rodgers, J., Glod, M., Connolly, B., & McConachie, H. (2012). The relationship between anxiety and repetitive behaviours in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 42,* 2404–2409.

Ronald, A., Simonoff, E., Kuntsi, J., Asherson, P., & Plomin, R. (2008). Evidence for overlapping genetic influences on autistic and ADHD behaviours in a community twin sample. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 49,* 535–542.

Rosario, M. C., Prado, H. S., Borcato, S., Diniz, J. B., Shavitt, R. G., Hounie, A. G., … Miguel, E. (2009). Validation of the University of São Paulo Sensory Phenomena Scale: initial psychometric properties. *CNS Spectrums, 14*, 315–323.

Salkovskis, P. M. (1999). Understanding and treating obsessive-compulsive disorder. *Behaviour Research and Therapy, 37,* 29–52.

Salkovskis, P. M., Wroe, A. L., Gledhill, A., Morrison, N., Forrester, E., Richards, C., … Thorpe, S. (2000). Responsibility attitudes and interpretations are characteristic of obsessive compulsive disorder. *Behaviour Research and Therapy, 38,* 347–372.

Salkovskis, P., & Shafran, R. (1999). Multiple pathways to inflated responsibility beliefs in obsessional problems: possible origins and implications for therapy and research. *Behaviour Research and Therapy*, *37*, 1055-1072.

Shafran, R., Watkins, E., & Charman, T. (1996). Guilt in obsessive-compulsive disorder. *Journal of Anxiety Disorders, 10,* 509–516.

Skuse, D., Warrington, R., Bishop, D., Chowdhury, U., Lau, J., Mandy, W., & Place, M. (2004). The developmental, dimensional and diagnostic interview (3di): a

novel computerized assessment for autism spectrum disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 43,* 548–558.

Skuse, D. H., Mandy, W. P. L., & Scourfield, J. (2005). Measuring autistic traits: heritability, reliability and validity of the Social and Communication Disorders Checklist. *The British Journal of Psychiatry: The Journal of Mental Science, 187,* 568–572.

Smith, A. H., Wetterneck, C. T., Hart, J. M., Short, M. B., & Björgvinsson, T. (2012). Differences in obsessional beliefs and emotion appraisal in obsessive compulsive symptom presentation. *Journal of Obsessive-Compulsive and Related Disorders, 1,* 54–61.

Smith, P. J., Need, A. C., Cirulli, E. T., Chiba-Falek, O., & Attix, D. K. (2013). A comparison of the Cambridge Automated Neuropsychological Test Battery (CANTAB) with "traditional" neuropsychological testing instruments. *Journal of Clinical and Experimental Neuropsychology, 35,* 319–328.

South, M., Ozonoff, S., & McMahon, W. M. (2005). Repetitive Behavior Profiles in Asperger Syndrome and High-Functioning Autism. *Journal of Autism and Developmental Disorders, 35,* 145–158.

Spielberger, C.D., Gorsuch,R.L., Lushene, R., Vagg, P.R., Jacobs, G.A., (1983). *Manual for the state-trait anxiety inventory.* Palo Alto: Consulting Psychologists Press.

Starcevic, V., Berle, D., Brakoulias, V., Sammut, P., Moses, K., Milicevic, D., & Hannan, A. (2011). Functions of compulsions in obsessive-compulsive disorder. *The Australian and New Zealand Journal of Psychiatry, 45,* 449–457.

Starcevic, V., & Janca, A. (2011). Obsessive-compulsive spectrum disorders: still in search of the concept-affirming boundaries. *Current Opinion in Psychiatry, 24,* 55–60.

Summerfeldt, L. J., Kloosterman, P. H., Parker, J. D. A., Antony, M. M., & Swinson, R. P. (2001). Assessing and validating the obsessive-compulsive-related construct of incompleteness. *In: Poster presented at the 62nd annual convention of the Canadian Psychological Association, Ste-Foy, Quebec.*

Summerfeldt, L. J. (2004). Understanding and treating incompleteness in obsessive-compulsive disorder. *Journal of Clinical Psychology, 60,* 1155–1168.

Swedo, S. E., Leonard, H. L., Garvey, M., Mittleman, B., Allen, A. J., Ph, D., … Dubbert, B. K. (1998). Associated with streptococcal infections : Clinical description of the first 50 cases. *American Journal of Psychiatry, 155*, 264-271.

Taylor, S. (2010). Dimensional and subtype models of OCD. In J. S. Abramowitz & A. C. Houts (Eds.), *Concepts and controversies in obsessive compulsive disorder* (pp. 27–41). New York: Springer Science and Business Media Inc.

Taylor, S. (2011). Early versus late onset obsessive-compulsive disorder: evidence for distinct subtypes. *Clinical Psychology Review, 31,* 1083–11100.

Tolin, D. F., Brady, R. E., & Hannan, S. (2008). Obsessional beliefs and symptoms of obsessive compulsive disorder in a clinical sample. *Journal of Psychopathology and Behavioral Assessment, 30,* 31–42

Van Ameringen, M., Patterson, B., & Simpson, W. (2014). DSM-5 obsessive-compulsive and related disorders: Clinical implications of new criteria. *Depression and Anxiety,7*, 1–7.

Vasconcelos, A.G., Sergeant, J., Corrêa, H., Mattos, P., & Malloy-Diniz, L. (2014). When self-report diverges from performance: The usage of BIS-11 along with neuropsychological tests. *Psychiatry Research, 218*, 236-243.

Veale, D. M., Sahakian, B. J., Owen, A. M., & Marks, I. M. (2009). Specific cognitive deficits in tests sensitive to frontal lobe dysfunction in obsessive–compulsive disorder. *Psychological Medicine, 26,* 1261-1269.

Woodbury-Smith, M. R., Robinson, J., Wheelwright, S., & Baron-Cohen, S. (2005). Screening adults for Asperger Syndrome using the AQ: A preliminary study of its diagnostic validity in clinical practice. *Journal of Autism and Developmental Disorders, 35,* 331–335.

Zandt, F., Prior, M., & Kyrios, M. (2007). Repetitive behaviour in children with high functioning autism and obsessive compulsive disorder. *Journal of Autism and Developmental Disorders, 37,* 251–259.

Part 3: Critical Appraisal

Introduction

This appraisal will focus on the process of researching the 'not just right experience' (NJRE) in a sample of individuals with obsessive-compulsive disorder (OCD). Motivating interest and preliminary discussions leading to the development of the research question as well as the often unexpected challenges of testing clinical and theoretical ideas in a real life setting will be addressed. The paper will, furthermore, focus on problem solving endeavours to meet challenges of recruitment and time restrictions as well as reflect on the methodological limitations of this study. Lastly, this paper shares the researcher's general experiences and thoughts about conducting research with an OCD population.

Research interest

Interest in this project primarily developed from a prior experience working with autistic children. Exploring NJRE in OCD provided an opportunity to expand on previous clinical and research knowledge lending an opportunity to focus on sensory processing difficulties and ritualized behaviours well known to autistic children that seemed to be mirrored in OCD. I was curious if (how) autism was masked in this disorder. It was well known that many persons manifesting symptoms within the autistic spectrum remain misdiagnosed (Bejerot, Nylander, & Lindström, 2001). Treatments not addressing the autistic features are likely to be ineffective. In my first year adult mental health placement I experienced how 'autistic' behaviours went unrecognized in a population with chronic mental health problems. Instead, symptoms were assigned to personality disorders, OCD, or even schizophrenia. Ritualised repetitive behaviour (RRB) was understood to be a challenging behaviour which affected treatment adherence, but RRB was rarely assessed as a manifestation of

autism. I strongly felt that more awareness of the prevalence of ASD was needed in adult mental health, considering that frequency rates are as high as 6/1000 (Baird et al., 2000; Bertrand et al., 2001; Chakrabarti & Fombonne, 2005; Charman, 2002) and autism is a lifelong developmental condition.

I had no previous research or clinical experience with OCD before commencing this project. A first academic challenge was to master the fundamentals of this fascinating, but new clinical area while simultaneously developing enough critical knowledge to attempt to contribute to research developments in the OCD field. In a short period of time, an attempt was made to read as much as possible to develop a novel research question. While combing the OCD literature, I was struck by a paper debating the relevance of NJRE and harm avoidance (HA) in maintaining OCD symptomatology arguing that the current literature focuses primarily on HA, which emphasizes OCD as an anxiety disorder (Ecker & Gönner, 2008). I became further interested in this less studied construct NJRE because it did not match well to traditional cognitive behavioural approaches to understanding OCD and because it seemed to be associated with clinical characteristic similar to ASD. The parallels of NJRE and sensory discomfort triggering autistic-like ritualized repetitive behaviours in OCD were of particular interest to me. In the further literature review it was apparent that besides prevalence studies NJRE had not yet been well researched. At the time of the research proposal, there had been no previous study exploring the link of NJRE to neurodevelopmental disorders. A novel research question could be formulated to explore the link between NJRE in OCD and autistic traits.

Challenges in conducting clinical research

The main challenges of this research project were related to recruitment difficulties and time constraints in collecting the data. Due to a prolonged ethical application process, the research began much later than planned. In addition, it proved challenging to recruit and collect data in the context of a busy National Health Service (NHS) clinic. Lastly, challenges specific to OCD clients were raised in the recruitment and data collection phase. These issues will be discussed in detail below.

Collecting data in a clinical setting

This study was conceptualized to adjoin ongoing research exploring the prevalence of autistic traits in a cohort of treatment seeking adults with OCD conducted by a clinical care team within an OCD outpatient clinic. The recruitment was limited to this specific national OCD service and primarily limited to participants approached for a previous research trial. Collecting data in a clinical context highlighted in what ways economic and organizational pressures within NHS services invariably affect the research process. This research project faced busy clinics, staff turn-over, and limited room availability, all affecting the ease of data collection. Despite several advantages foreseen in recruiting within a clinic, for example, reassurance that clients will receive ongoing clinical care, there were, nevertheless, infinite problems in coordinating clinical routine and research needs. Staff turnover meant that the data collection for the initial larger study was on hold for several months. Consequently, due to time constraints, the recruitment phase and, thus, the number of people contacted were smaller than planned. In addition, inexperienced in research collaboration, both my co-researcher and I needed to show leadership and perseverance in contacting staff to discuss research issues in the context of a busy clinic, factors requiring much time and patience. Lastly, because the research was

understandably not the priority in the hospital clinic, it was difficult to book rooms for testing and interviews.

Overall, the accumulation of factors including the defined and limited allocation of time for research within the clinical psychology program, early delays in starting the initial phases of research, and the difficulties entailed in recruiting the clinical sample and coordinating testing times with clinical staff meant that it was difficult to achieve a large enough sample size to detect smaller effects.

Collecting data from an OCD population

This research project highlighted expected, but also unexpected difficulties, in collecting data from an OCD population. It is important to note that the sample was recruited from a population of OCD individuals receiving treatment whose clinical profiles were often complicated by comorbidity. Acute exacerbations in symptom presentation with urgent treatment needs or/and cancelations affected both the recruitment and testing phase. Presenting clinical issues intensified an experienced dilemma in subordinating a clinical role to that of the researcher and establishing role clarity in testing sessions.

Recruitment difficulties are commonly reported in clinical research and can necessarily lead to budget problems and extension of recruitment time (Lovato, Hill, Hertert, Hunninghake, & Probstfield, 1997). Even though we expected the recruitment management to be difficult, we had not anticipated to what degree the clinical presentation of OCD would affect the recruitment per se. For example, fear of contamination occasionally meant delays in opening letters containing the participant information sheet. More commonly, potential participants appeared anxious of meeting new people and would not pick up the telephone. In addition, reluctance to take part was not an issue of availability, but due to debilitating symptoms of social

anxiety, paranoia, or depression as well as ritualistic behaviours making it difficult to leave the home. If interest in participation was expressed, it was often challenging to find an available time slot due to individual preferences and needs for an appointment to be at a certain time and day. It was difficult to schedule more than one person a day for testing.

This research project has clearly highlighted difficulties in collecting data from a clinical sample when unfamiliar with the clinical population, but also when research testing is not integrated into the clinical team and routine. It was assumed as the participants had taken part in a previous research trial at that hospital that recruitment would be easier; however, the earlier study was run by treating clinicians. Not only did primary clinicians have an existing alliance to these clients, but they could also flexibly administer aspects of their research trial following clinical appointments.

Unlike the unexpected difficulties ensued in recruiting, it had been anticipated that OCD symptoms would impact on testing time. This issue was anticipatorily discussed in the ethics committee meeting and with an external supervisor. Clinical and research experience have shown that many OCD patients compulsively striving to accurately read and respond to questions, would need more than the usual allotted time to complete questionnaires and open-ended neuropsychological tests. As a result, intended testing times for this project were doubled or tripled. Indeed, high levels of anxiety and a fear of getting things wrong meant that participants read questions repeatedly. An uncalculated problem in timing was due to fears of contamination. Questionnaires had to sometimes be filled out for research participants as they could not touch the pens or testing intervals had to be shortened because they could not use the public restrooms. The latter problem meant rescheduling or resulted in missing data.

It became apparent during data collection that the careful scrutiny of the research protocol from an ethics committee was an essential step prior to conducting research with chronically unwell people. In this preparatory stage, the demand for a careful selection of the hypotheses to be tested and measured explicitly tied to acknowledged scientific or clinical values (Chen & Shepherd, 2009; Hoop, Smyth, & Roberts, 2008; Roberts, Geppert, & Brody, 2001) was of utmost importance, as every additional measure would have been a burden for participants. Recalls or a second testing session would have elicited unnecessary personal tension and anxiety in our recruited OCD sample.

Overcoming the recruitment challenges

It quickly became apparent that the most effective recruitment approach within this clinical setting was to arrange a first contact with clinic attendees together with their attending clinicians. Meeting the researchers together with their clinicians allowed for the establishment of rapport in a trusted setting and, hence, led to more clients expressing interest in participation in the collaborative research projects. The personal contact and introduction by the clinical team was undoubtedly helpful in easing a client's anxiety and in improving later participation. The relationship between patients and the clinical setting is considered to be an important factor in clinical research (Chen & Shepherd, 2009). However, this approach raised other organizational and ethical issues including having to make sure participants had more than 48 hours to read the participant information sheet before the introductory contact and ensuring that participants did not feel like they 'owed it' to their clinician or felt 'pressured' by their clinician to take part. Due to logistical difficulties of long travel time to the hospital and balancing research time with clinical placement responsibilities meant

that it was not always possible for researchers to be present on the clinic days to optimize this recruitment strategy.

Study limitations

There were a number of methodological limitations in this empirical study, with some, but not all, related to time constraints affecting both the planning stage in choosing valid testing measures and in optimising the research design and the recruitment phase. Adjustments were necessarily made in progress related to recruitment problems. The challenges of conducting the research, as discussed above, affected to a varying degree the working study design, the power of the study, and the external validity of the study.

Research design

The design of the study had to be adjusted during the first phase of the recruitment process. Originally the research study aimed to compare groups of individuals with OCD defined by the presence or absence of Autism Spectrum Disorder (ASD) traits based on the Autism Quotient (AQ) (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). Research groups matched for demographic and clinical symptoms were to be formed to determine whether the underlying motivational process ("not just right experience" and harm avoidance) differed between patients with OCD+ ASD traits (AQ score >25) and an OCD only group (AQ<20). The AQ was to be followed up with a clinician rated interview. In order to 'control' for the effects of ASD it would have been essential to adhere to matching the study groups as closely as possible. However, within the recruitment pool available, few individuals matched for inclusion criteria and many of those matched proved difficult to recruit. Overcoming these hurdles within time constraints meant

widening inclusion criteria and changing the research proposal to a correlational design of an exploratory nature assessing the association of NJREs and HAs with autistic traits. Even though the correlational design provided some interesting findings, this design was not able to specifically look at whether NJRE was particularly prominent in an OCD group with clinically significant autistic traits.

Sample: power and external validity

Within the abbreviated time frame it was possible to recruit a sample size of n=25. The small sample size undoubtedly affects the power of the study. This was particularly apparent when attempting to compare correlation coefficients between the motivational processes HA and NJRE. It is also possible that small-moderate relationships remained undetected. In addition to the sample size, the convenience sample will have likely affected the external validity of this study. All participants were treatment seeking and had voluntarily agreed to take part in the research despite lack of payment. Based on initial telephone contacts, it appeared that non-responders were either severely incapacitated, for example, in struggles to leave the house due to their compulsive rituals or social anxiety, or were higher-functioning e.g. in employment and were, hence, reluctant to take time off from work. However, reasons for non-participation are merely speculative and were not verified.

Measures

Research measures were based on self-report measures and one neuropsychological measure of set-shifting. In addition to inevitable limitations associated with the validity of self-report measures, questionnaires employed in this research assessed 'general' OCD and ASD traits so that measures may not have reliably detected possibly existing relationships between specific autism traits and OCD symptoms. In addition, the Autism Quotient (AQ) (Baron-Cohen et al., 2001),

may not have reliability indentified individuals with clinically relevant autistic traits (Bishop & Seltzer, 2012; Ketelaars et al., 2008). Initially, the research protocol called for a follow-up to the AQ score using a clinician based assessment, which could have helped to verify autistic traits. However, due to time constraints it was not possible for the clinicians to complete all these follow-up interviews. It would have also been interesting to include a more detailed measure of repetitive behaviour.

Experiences in conducting and analysing the research invoked questions about the usefulness and validity of several other test measures. It appeared that the intra-extra dimensional shift task from the Cambridge Automated Neuropsychological Test Battery (CANTAB) may not have been a sensitive enough measure to detect difference within an OCD population. Perhaps it would have been more useful to use the Wisconsin Card Sorting task, a previous measure which has been able to detect variable neuropsychological profiles within OCD (Lawrence et al., 2006). In addition, it would have been useful to follow-up the Adolescent /Adult Sensory Profile (AASP) (Brown & Dunn, 2002) using qualitative interviews or behavioural paradigms to elicit whether the sensory experiences trigger NJRE specifically or whether it is a more general relationship.

Overall, the current measures highlighted interesting clinical characteristics associated with NJRE. Future research should continue to explore these relationships in more detail in order to best inform treatment models.

Controlling for confounding variables

Even though this study attempted to control for a range of confounding variables including anxiety, depression, and OCD severity, it was unable to control for other important confounding variables including a comorbid tic disorder and the effects of psychotropic medications.

Patient data available to this study included an assessment for comorbid psychiatric conditions from hospital clinicians using a semi-structured interview to collate a list of all disorders. Infrequent diagnoses were placed into the category of 'other' diagnosis. Clinicians did not explicitly ask about tic disorders meaning that the presence of tics may have been underreported. Due to frequent co-occurrence with NJRE (Leckman, Walker, Goodman, Pauls, & Cohen, 1994), future research should employ a specific questionnaire measuring the presence and severity of tics in the cohort OCD groups. Tic disorder is a known neurological disorder and could have possibly accounted for any neurological differences which were tentatively inferred from the sensory processing differences.

It is not possible to statistically control for the effect of medication in a small sample size. All study participants were treated with a range of different psychotropic medications. Psychotropic medication may affect neurological thresholds of sensory processing by leading to changes in the somatosensory cortex (Quednow et al., 2004). Hence, it may be that the severity and frequency of sensory processing difficulties in this sample are due to medication effects, which, in turn, affect the strength of the relationship between NJRE and sensory processing difficulties. Psychotropic medication likely has a complex effect on cognition. Most studies exclude patients on medications as they affect neuropsychological performance. On other hand, it has been found that serotonin reuptake inhibitors (SRI) do not affect neuropsychological performance in an OCD sample (Mataix-Cols, Alonso, Pifarré, Menchón, & Vallejo, 2002). Relevant to this study, there has been evidence suggesting that antidepressants can slow reaction times (Allen, Curran, & Lader, 1991). Hence, set-shifting performances on the computerised neuropsychological assessments may have been influenced by the medications taken. It would have been unethical in this clinical

population to have designed a research protocol altering medications and treatment "packages"; hence, the observational results need to be interpreted with caution.

General reflections on clinical research

Importance of clinical skills

It became very apparent that clinical skills are of outmost importance when conducting research within a chronically unwell mental health population. I was underprepared for the severity of the comorbid mental health difficulties and the associated longstanding poor quality of life. Unfortunately we did not collect information regarding actual social/familial relationships, but it appeared that many participants were socially isolated. Approximately two thirds were not in employment. Some of the participants had lost their jobs due to OCD. Several of the participants had very low self-esteem and existential fears. Most participants were either currently depressed or had in the past experienced depression and episodes of high suicidal ideation, intent or even attempts. Lifetime prevalence of suicidal thoughts has been reported in over a third of OCD individuals (Torres et al., 2011). More than once emergent risk issues arose during testing that necessitated immediate consultation with the clinical care team. Even though there had been opportunities to discuss risk issues with clinical leads, additional opportunities for informal supervision as they arose were invaluable. It was clinically more expedient and constructive to book research appointments on the day the clinic care team were present. Similar to clinical practice (Knudsen, Ducharme, & Roman, 2008), supervision in a clinical research setting is an important protective factor for both the participants and researchers. I, furthermore, benefited by conducting the research with a fellow UCL trainee. We could de-brief after each testing session, as these were emotionally and physically draining.

In addition to identifying and managing risk issues, other clinical issues emerged which clients addressed with researchers. For example, participants who had been recently diagnosed with autism had many unanswered questions, or individuals asked for information about attending support groups for their OCD. Our role required balancing an empathetic stance whilst remaining mindful of our presence in this setting as a researcher. It meant taking time to acknowledge and listen to concerns, but encouraging discussions of clinical matters with assigned clinicians. I often felt drawn into a clinical role and had to consciously reflect on my clinical boundaries and responsibilities in a research setting.

Importance of clinical research

Despite struggles throughout this research process, in retrospect, it was clear that experience of clinical research brings many benefits for the evidence-based practitioner. There was an opportunity to develop research skills which can be incorporated into later clinical practice. It allowed a heightened awareness of methodological difficulties and limitations in adapting clinical research to a clinical setting. A research background permits a more critical, but also realistic appraisal of research findings in peer reviewed journal articles. It is challenging to neatly implement theoretical research designs into a 'real-life' clinical setting. One learns caution in the interpretations of findings, in particular, prior to replication by other research groups. Contemplating ethical issues within clinical research has been insightful and builds sensitivity for the clinical implications of the research process. For example, should the primary investigator also be the clinician?

An exciting feature of the research process was discussions with participants giving opportunities for the emergence of new research ideas. A direct collaboration

in the phase of generating ideas could lead to some interesting and likely ecologically valid research ideas.

Conclusion

The research study was faced with several challenges which made it difficult to implement the original research design and to recruit a sample size with adequate power. There were methodological limitations that affected the validity of the findings. It proved, nevertheless, to be a personally challenging, but also invaluable experience. I developed a heightened awareness of obstacles that emerge in the realities of "testing" theory in a clinical setting. This project has not only contributed to my understanding of research, but its clinical nature has widened my clinical experience in working with OCD individuals. Many of the OCD individuals who agreed to participate in this study, despite being unwell and not being compensated financially (there were marginal funds to contribute to travel expenses), withstood long testing sessions of approximately 2-4 hours, and travel time. The current response rate is likely indicative of the good relationship clients have had with the clinical care team. They expressed a high opinion of the compassionate and good quality of care they were receiving in this national centre.

Nevertheless, many of the participants appeared to volunteer in order to support ongoing research. They spoke about how they felt misunderstood by friends, family, and professionals who often did not appreciate the severity and impact of OCD on their lives. Several OCD clients hoped to contribute to the understanding of OCD so that in the future others could avoid the difficult journeys they had experienced. Their comments and the personal histories shared underscored the necessity of continuous

research efforts to understand the complexity and heterogeneous nature of OCD in order to improve treatment outcomes in this often very disabling disorder.

References

Allen, D., Curran, H., & Lader, M. (1991). The effects of repeated doses of clomipramine and alprazolam on physiological, psychomotor and cognitive functions in normal subjects. *European Journal of Clinical Pharmacology*, *40*, 355-362.

Baird, G., Charman, T., Baron-Cohen, S., Cox, A, Swettenham, J., Wheelwright, S., & Drew, A. (2000). A screening instrument for autism at 18 months of age: A 6-year follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, *39*, 694–702.

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome / high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, *17*, 5–17.

Bejerot, S., Nylander, L., & Lindström, E. (2001). Autistic traits in obsessive-compulsive disorder. *Nordic Journal of Psychiatry*, *55*, 169–176.

Bertrand, J., Mars, A., Boyle, C., Bove, F., Yeargin-Allsopp, M., & Decoufle, P. (2001). Prevalence of autism in a United States population: The Brick Township, New Jersey, investigation. *Pediatrics*, *108*, 1155–1161.

Bishop, S. L., & Seltzer, M. M. (2012). Self-reported autism symptoms in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*, 2354–2363.

Brown, C. & Dunn, W. (2002). *Adolescent/Adult Sensory Profile manual.* San Antonio, TX: Psychological Corporation.

Chakrabarti, S., & Fombonne, E. (2005). Pervasive developmental disorders in preschool children: confirmation of high prevalence. *The American Journal of Psychiatry, 162,* 1133–1141.

Charman, T. (2002). The prevalence of autism spectrum disorders. Recent evidence and future challenges. *European Child & Adolescent Psychiatry, 11,* 249–256.

Chen, D. T., & Shepherd, L. L. (2009). When, why, and how to conduct research in child and adolescent psychiatry: practical and ethical considerations. *The Psychiatric Clinics of North America, 32,* 361–380.

Ecker, W., & Gönner, S. (2008). Incompleteness and harm avoidance in OCD symptom dimensions. *Behaviour Research and Therapy, 46,* 895–904.

Hoop, J. G., Smyth, A. C., & Roberts, L. W. (2008). Ethical issues in psychiatric research on children and adolescents. *Child and Adolescent Psychiatric Clinics of North America, 17,* 127–148.

Ketelaars, C., Horwitz, E., Sytema, S., Bos, J., Wiersma, D., Minderaa, R., & Hartman, C.A. (2008). Brief report: adults with mild autism spectrum disorders (ASD): scores on the autism spectrum quotient (AQ) and comorbid psychopathology. *Journal of Autism and Developmental Disorders, 38,* 176–180.

Knudsen, H. K., Ducharme, L. J., & Roman, P. M. (2008). Clinical supervision, emotional exhaustion, and turnover intention: a study of substance abuse treatment counselors in the Clinical Trials Network of the National Institute on Drug Abuse. *Journal of Substance Abuse Treatment, 35,* 387–395.

Lawrence, N. S., Wooderson, S., Mataix-Cols, D., David, R., Speckens, A., & Phillips, M. L. (2006). Decision making and set shifting impairments are

associated with distinct symptom dimensions in obsessive-compulsive disorder. *Neuropsychology, 20,* 409– 419.

Leckman, J. F., Walker, D. E., Goodman, W. K., Pauls, D. L., & Cohen, D. J. (1994). "Just right" perceptions associated with compulsive behavior in Tourette's syndrome. *The American Journal of Psychiatry, 151,* 675–680.

Lovato, L. C., Hill, K., Hertert, S., Hunninghake, D. B., & Probstfield, J. L. (1997). Recruitment for controlled clinical trials: literature summary and annotated bibliography. *Controlled Clinical Trials, 18,* 328–352.

Mataix-Cols, D., Alonso, P., Pifarré, J., Menchón, J. M., & Vallejo, J. (2002). Neuropsychological performance in medicated vs. unmedicated patients with obsessive-compulsive disorder. *Psychiatry Research, 109,* 255–264.

Quednow, B. B., Kühn, K.-U., Stelzenmuelle, R., Hoenig, K., Maier, W., & Wagner, M. (2004). Effects of serotonergic and noradrenergic antidepressants on auditory startle response in patients with major depression. *Psychopharmacology, 175,* 399–406.

Roberts, L. W., Geppert, C. M., & Brody, J. L. (2001). A framework for considering the ethical aspects of psychiatric research protocols. *Comprehensive Psychiatry, 42,* 351–363.

Torres, A. R., Ramos-Cerqueira, A. T. A., Ferrão, Y. A., Fontenelle, L. F., do Rosário, M. C., & Miguel, E. C. (2011). Suicidality in obsessive-compulsive disorder: prevalence and relation to symptom dimensions and comorbid conditions. *The Journal of Clinical Psychiatry, 72,* 17–26.

Appendices

Appendix A: List of Abbreviations

List of Abbreviations

Table A1

List of abbreviations used in the literature review, empirical paper, and the critical paper

Abbreviation	Meaning
ADHD	attention deficit hyperactivity disorder
ADI-R	Autism Diagnostic Interview, Revised
ADOS	Autism Diagnostic Observation Schedule
ASD	Autism Spectrum Disorder
ASSP	Adolescent /Adult Sensory Profile
AQ	Autism Quotient
CBT	Cognitive Behavioural Therapy
EDS	extradimensional shift
HA	harm avoidance
ID/ED	intra-extra dimensional
IED	intradimensional
INC	incompleteness
MADRS	Montgomery-Asperg Depression Rating Scale
NJRE	'not just right experience'
NJRE-Q	Not Just Right Experiences-Questionnaire-Revised
OC	obsessive compulsive
OCD	obsessive-compulsive disorder
OCI	Obsessive Compulsive Inventory
OCPD	obsessive-compulsive personality disorder
OC-TCDQ	Obsessive-Compulsive Trait Core Dimensions Questionnaire
PTEQ-Revised	The Perceived Threat from Emotions Questionnaire -Revised Questionnaire
RAS	Responsibility Attitudes Scale
RRB	restricted repetitive behaviors
RBS-R	Repetitive Behavior Scale-Revised
SP	sensory phenomena
STAI	State–Trait Anxiety Inventory
TD	tic disorder
3di	Developmental, Dimensional and Diagnostic Interview
TS	Tourette Syndrome
USP-Harvard	University of São Paulo-Harvard Repetitive Behavior Interview
USP-SP	University of São Paulo-Harvard Repetitive Behavior Interview
Y-BOCS	Yale–Brown Obsessive Compulsive Scale

Appendix B: Ethical Approval and Ethical Amendment

Appendix C: Participant Information Sheet

Appendix D: Consent Form

[redacted]

[redacted]

NHS

UCL
Research Department of Clinical, Educational and Health Psychology
1-19 Torrington Place, WC1E 7HB

Centre Number:

Study Number:

Patient Identification Number for this study:

CONSENT FORM

Title of Project: Social style, motivations and reasoning ability of people with OCD
Name of Researcher(s): **Caroline Barber and Josselyn Hellriegel**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 28 August 2013 (Version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by the research members from University College London, the sponsor, Regulatory Authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree for my care team to be informed of any additional difficulties arising from the research assessments. ☐

5. I understand that by completing and returning this form, I am giving consent that the personal information I provide will only be used for the purposes of this project and not transferred to an organisation outside of UCL. The information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998. ☐

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

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Consent form date of issue: 12th June 2013
Consent form version number: Version 2

Appendix E: Details of Joint Project and Test Order

Details of Joint Project

This study was a part of a joint research project with another Trainee Clinical Psychologist, Caroline Barber. Caroline's research question focused on the neurocognitive profiles of participants with OCD and autistic traits. The ethical application, recruitment, and testing were done in collaboration with Caroline. To minimize participants' time commitment, a battery of questionnaires and neuropsychological tests for both projects were administered on one day by either researcher. This meant, for example, my administering neuropsychological tests for Caroline in addition to administering the questionnaires and subtest of the CANTAB for my research study, and vice versa. Twenty participants were included in both studies and an additional five participants were recruited to specifically explore the motivational processes in individuals with OCD and autistic traits. The order of the administration can be found in Table E1.

Table E1

Order of administration of the battery of questionnaires and neuropsychological tests

Order	Measure	Subtest
1	Rey-Osterrieth Complex Figure Test (RCFT) (Osterrieth, 1944)	Copy trial
2	Obsessive Compulsive Trait Core Dimensions Questionnaire (OC-TCDQ) (Summerfeldt, Kloosterman, Parker, Antony, & Swinson,, 2001)	N/A
3	RCFT (Osterrieth, 1944)	Rey immediate recall
4	Responsibility Attitudes Questionnaire (RAS) (Salkovskis et al., 2000)	N/A
5	Adolescent /Adult Sensory Profile (AASP) (Brown and Dunn, 2002)	N/A
6	State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983)	N/A
7	Montgomery-Asperg Depression Rating Scale (MADRS) (Montgomery & Asperg, 1979)	MADRS
8	RCFT (Osterrieth, 1944)	Delayed recall
9	RCFT (Osterrieth, 1944)	Recognition trial
10	Delis-Kaplan Executive Function System (D-KEFS)	Design Fluency
11	Behavioural Assessment of the Dysexecutive Syndrome (Norris & Tate, 2000)	Six Elements
12	Cambridge Automated Neuropsychological Test Battery (CANTAB)	Intra-extra dimensional shift task (ID ED Task)
13	CANTAB	Stop Signal Task
14	Wechsler Abbreviated Scale of Intelligence (WASI – II) (Weschler, 1999)	Vocabulary and matrix reasoning
15	Revised Eyes Test (Baron-Cohen et al., 2001)	N/A

References for Table E1

"Order of administration of the battery of questionnaires and neuropsychological tests"

Baron-Cohen, S., Wheelwright, S., Hill, J., Raste, Y., & Plumb, I. (2001). The 'Reading the Mind in the Eyes' Test revised version: a study with normal adults, and adults with Asperger syndrome or high-functioning autism. *Journal of Child Psychology and Psychiatry,42,* 241–251.

Brown, C. & Dunn, W. (2002). *Adolescent/Adult Sensory Profile manual.* San Antonio, TX: Psychological Corporation.

Montgomery, S.A & Asberg, M. (1979). New Depression Scale Designed to be Sensitive to Change. *British Journal of Psychiatry,134,* 382-389

Norris, G. & Tate, R.L. (2000). The behavioural assessment of the dysexecutive syndrome (BADS): ecological, concurrent and construct validity. *Neuropsychological Rehabilitation,10,* 33-45.

Osterrieth, P. A. (1944). Le test de copie d'une figure complex: Contribution à l'étude de la perception et de la memoir. *Archives de Psychologie, 30*, 286–356.

Salkovskis, P. M., Wroe, A. L., Gledhill, A., Morrison, N., Forrester, E., Richards, C., et al. (2000). Responsibility attitudes and interpretations are characteristic of obsessive compulsive disorder. *Behaviour Research and Therapy*, 38, 347–372.

Spielberger, C.D., Gorsuch,R.L., Lushene, R., Vagg, P.R., Jacobs, G.A., (1983). *Manual for the state-trait anxiety inventory.* Palo Alto: Consulting Psychologists Press.

Summerfeldt, L. J., Kloosterman, P. H., Parker, J. D. A., Antony, M. M., & Swinson, R. P. (2001). Assessing and validating the obsessive-compulsive-related construct of incompleteness. *In: Poster presented at the 62nd annual convention of the Canadian Psychological Association, Ste-Foy, Quebec.*

Wechsler, D. (1999). *Wechsler Abbreviated Scale of Intelligence (WASI).* San Antonio, TX: Harcourt Assessment.