

**The Role of Childhood Adversity in the Development of Psychotic
Experiences in Borderline Personality Disorder**

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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.

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Overview

Overall, this thesis focuses on the presence of psychotic experiences (PE) outside of traditional psychotic disorder boundaries, particularly in individuals with Borderline Personality Disorder (BPD). Special emphasis is placed on the potential role of childhood adversity.

Part one presents a systematic literature review on the lifetime prevalence of hearing voices within the adult general population using clearer and more conservative criteria compared to previous reviews. The findings indicated that a significant minority of the general population hear voices. Prevalence varied according to sample characteristics and methodological factors, most notably the definition and measurement of voice hearing. Recommendations for future research and clinical practice are discussed.

Part two presents an original empirical paper exploring the role of childhood adversity in the development of PE in BPD. The results indicated that particular characteristics of adversity, namely cumulative exposure to sexual abuse throughout childhood, may be helpful in understanding susceptibility to PE in BPD. More frequent adversity was also important in a general population control sample, where paternal neglect appeared to be more influential. A number of methodological limitations were identified, which are discussed alongside research and clinical implications.

Part three provides a critical appraisal of the research process and how this may inform future research. The impact of using internet-mediated methodology is discussed, alongside specific reflections on the research process and the ongoing difficulties associated with understanding and supporting individuals with both PE and BPD.

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Part 1: Literature Review

The Lifetime Prevalence of Hearing Voices in the General Adult Population

1.1 Abstract

1.1.1 Aims: This systematic literature review aimed to provide an updated estimate of the prevalence of voice hearing across the adult general population using more conservative criteria compared to previous reviews, particularly the exclusion of vague experiences and non-community representative samples (e.g. students).

1.1.2 Method: A systematic literature search was conducted using PsychINFO, EMBASE, MEDLINE, and Web of Science, alongside hand searches. Studies meeting inclusion criteria were assessed for quality and were first synthesised quantitatively and then narratively to determine sources of heterogeneity.

1.1.3 Results: Fifteen studies met inclusion and quality criteria. Due to overlapping sample data, only nine of these studies were included in the quantitative synthesis. These nine studies contained 10 rates (seven interviews, three questionnaires) and provided a median prevalence estimate of 2.6%. There was high heterogeneity across rates, ranging from 1.9% to 15.3%. There was some indication that sample characteristics may underlie some of this variance. However, methodological considerations had a clearer impact, with lower rates for larger samples, interview studies, and more frequent or certain voice hearing experiences.

1.1.4 Conclusion: This review provides further support for continuum views of psychosis with a significant minority of the general population hearing voices, increasing in range as the breadth of definition broadens. Voice hearing appears to be less common than broader psychotic experiences in more representative community samples. Further more focused research is needed to better understand prevalence and its associations along the continuum of voice hearing.

1.2 Introduction

1.2.1 Prevalence of psychotic experiences and voice hearing

Traditionally, psychotic experiences (PE), particularly hallucinations, have been viewed in a categorical sense as indicative of serious psychological disturbance, primarily psychotic disorder (American Psychiatric Association [APA], 1980; Schneider, 1959). Such diagnosable psychotic disorders have been found to be rare, with estimates between 0.3%-0.7% for schizophrenia (APA, 2013) and around 2.99% for psychotic disorders (Perälä et al., 2007). However, as early as 1969, it has been suggested that psychosis and PE may occur along a continuum (Strauss, 1969). Since being revisited in 2000 (Van Os, Hanssen, Bijl, & Ravelli, 2000), this proposal has begun receiving extensive attention and empirical support, leading to a significant paradigm shift in how these phenomena are conceptualised (Johns & van Os, 2001; Kelleher & Cannon, 2011; Linscott & van Os, 2010; 2013; Van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009). Most notably, consistent research finds that PE are relatively common across non-psychotic disorders and psychologically healthy individuals (Peters et al., 2016; Upthegrove et al., 2016). For example, a recent meta-analysis of general population studies provided an estimated median lifetime prevalence of 7.2% for PE (Interquartile range [IQR]=2.5%-15.5%), 4.9% for delusions (IQR=2%-11.6%) and 6% for hallucinations (IQR=2.1%-11.6%) (Linscott & van Os, 2013).

Hallucinations are the most researched PE, defined by the Diagnostic Statistical Manual (DSM-5; APA, 2013) as sensory perceptions without external stimulation with a compelling sense of reality, and are most commonly auditory (typically voices). As with PE, research has consistently found that voices are heard

by a substantial number of people without psychotic disorder (Choong, Hunter, & Woodruff, 2007; de Leede-Smith & Barkus, 2013; Upthegrove et al., 2016; Waters & Fernyhough, 2017). Community-based studies have also demonstrated that voice hearing can occur in the absence of any psychiatric disorder and without associated distress (Johns et al., 2014; Larøi et al., 2012). Beavan, Read, and Cartwright (2011) synthesised seventeen surveys from nine countries providing a median voice-hearing prevalence of 13.2%, however rates ranged from 0.6% to 84% (IQR=3.1%–19.5%). Other reviews have cited similar broad ranges from 10-20% (Laroi et al., 2012) and 5-28% (de Leede-Smith & Barkus, 2013). Collectively these prevalence ranges indicate high variability across voice hearing rates and limited consensus regarding general population voice hearing prevalence.

Hearing voices is no longer sufficient for a diagnosis of schizophrenia (APA, 2013). Instead, research is moving towards the aforementioned dimensional model (Johns, Nazroo, Bebbington, & Kuipers, 2002; Johns, 2005; Kelleher, 2016; Upthegrove et al., 2016; Waters & Fernyhough, 2017). More specific research has indicated that voice hearing may be experienced continually, however need for care may be discontinuous with voices only persisting and leading to impairment according to a complex interaction between genetic, biological, psychological, and socio-environmental risk factors (de Leede-Smith & Barkus, 2013; Johns et al., 2014; Linscott & van Os, 2013). In particular, how people make sense of and cope with voice hearing is viewed as key to distinguishing their clinical significance (Romme, Escher, Dillon, Corstens, & Morris, 2009). This stance has led to the evolution of terminology from psychiatric terms such as auditory verbal hallucinations (AVH) to ‘voice hearers’ (Romme & Escher, 1989).

1.2.2 The characteristics of voice hearers

Specific factors associated with voice hearing are mostly inferred from those associated with psychotic disorders and PE (van Os et al., 2009).

Gender: Research indicates that schizophrenia is strongly associated with male sex and an earlier meta-analysis of subclinical PE indicated a similar association (van Os et al., 2009). However, this association was not indicated in a later more conservative update (Linscott & van Os, 2013). Conversely, in general population samples, research consistently indicates a higher frequency of women reporting hallucinatory experiences (Beavan et al., 2011). This aligns with the tendency for more women to report auditory hallucinations in clinical populations (Goldstein & Lewine, 2000; Read, 2004). Collectively, this suggests that although PE may be more closely associated with males, the more specific experience of hallucinations may be more closely related to females.

Age: Hallucinations, particularly voice hearing, increase in older age (de Leede-Smith & Barkus, 2013; Tien, 1991; Turvey et al., 2001) associated with life events such as the loss of a spouse, medical and neurological conditions, and sensory deficits (Grimby, 1993; van Os et al., 2009). There is also evidence that PEs in the general population are more prevalent in younger ages compared to adulthood (Johns, 2005; Kelleher et al., 2012a; Kelleher et al., 2012b; Linscott & van Os, 2013). However, the association between young age and voice hearing in the general population is less established, aside from the finding that voices commence at earlier ages in non-clinical compared to clinical individuals (Baumeister, Sedgwick, Howes, & Peters, 2017; de Leede-Smith & Barkus, 2013).

Race, ethnicity and environment: Studies have found associations between general population PE and ethnic minority status and urbanicity (Krabbendam & van Os, 2005; Linscott & van Os, 2010; 2013). Migrant status is also frequently associated with increased risk for PE and hallucinations (Cantor-Graae & Selten, 2005; Linscott & van Os, 2010; Vanheusden et al., 2008; van Os et al., 2009). It has been suggested that these sub-population variations could be explained by differing levels of social disadvantage over the lifespan (Morgan et al., 2009). One of the most consistent risk factors for PE and voice hearing is trauma irrespective of need for care (de Leede-Smith & Barkus, 2011; Johns et al., 2014). In particular, sexual abuse and bereavement appear to be strongly associated with hearing voices (Beavan et al., 2011). PE risk is also reportedly greater in the lower paid, less educated, unemployed, unmarried, and individuals with family histories of mental illness and greater exposure to substances (Linscott & Van Os, 2013). However, PE prevalence has also been found to be reduced in lower income countries (McGrath et al., 2015).

Culture: Culture is found to shape how voices are experienced and responded to, both individually and societally (Chang et al., 2015; Larøi et al., 2014). Beavan and colleagues (2011) concluded that voice hearing was more common in some non-Western cultures and cited higher rates in New Zealand Maori and Panay villagers from the Philippines. The authors hypothesised that this was due to voices tending to be regarded as threatening in most Western cultures, compared to voices more likely being encouraged as part of an individual's spiritual or religious development in these non-Western cultures.

1.2.3 Methodological problems

The variance in prevalence estimates also relates to methodological differences between studies (Beavan et al., 2011; Lee et al., 2016; Linscott & van Os, 2010; 2013). Within the previously mentioned general population PE meta-analysis, the systematic error variance introduced by cohort and design variables accounted for up to 10 times the variance explained by demographic risk factors and more than twice the variance explained by the most potent non-genetic environmental risk factor of illicit drugs (Linscott & van Os, 2010).

Definition: There is currently no clear consensus regarding the definition of voice hearing, nor its assessment (Lee et al., 2016; Kelleher, 2016; Upthegrove et al., 2016). Within the domain of psychiatry, voice hearing (AVH) is seen to occur in the absence of any external stimulation, outside of conscious control, and with sufficient impact and conviction such that it is considered reality (David, 2004). Voices should therefore be heard in clear sensorium and be distinguishable from illusions or misperceptions (APA, 2013). In practice these experiences represent a rich, varied phenomenology ranging from false perceptions of sounds to fully developed hallucinations of language and human voices (Hill & Linden, 2013; Laroi, 2012; Rabe-Jaclonska & Pawelczyk, 2013). However, within research, broader definitions can lead to inflated general population rates with more lax criteria limiting the reliability of study results (de Leede-Smith & Barkus, 2013). For example, 17.5% of the general population endorse broadly-defined PE yet only 4.2% endorse narrowly-defined PE (van Os et al., 2009). Similarly, broader definitions of voice hearing, encompassing ambiguous noise, such as hearing one's name in public, are endorsed by the majority of people whilst only around 2% to 4% of adults endorse stricter definitions in a conscious, wakeful state (Beavan et al., 2011; Laroi, 2012). In line with this, voice

hearing can vary according to the measurement tool (Beavan et al., 2011; Johns et al., 2014; Lee et al., 2016) and items considered (Kelleher, Harley, Murtagh, & Cannon, 2011). This has led some authors to conclude that the high rates of voice hearing in informal surveys are at least partially attributable to transient, mundane experiences few would consider hallucinatory (Pierre, 2010). Therefore, researchers highlight the need for voice hearing to be differentiated from illusions and be defined more precisely (Johns et al., 2014; Langer et al., 2015).

Mode of assessment: Prevalence estimates for PE in a recent meta-analysis were notably higher for self-report data (11.9%), compared to interviews (3.8%), with this distinction accounting for the greatest proportion of observed variance in rates (Linscott & van Os, 2013). Interviews are assumed to reduce the rate of false-positive responses by enabling clinical judgement and more control over confounds. However, they can also be too stringent, thus increasing the risk of false negatives (Perälä et al., 2007). Conversely, self-report questionnaire methods are prone to errors, such as recall bias, poor insight, misunderstandings, and social desirability bias. Nevertheless, these biases would more likely lead to an underestimation of PE contradicting the likely overestimation introduced by the limited detail and control associated with self-report (Linscott & van Os, 2013). Furthermore, self-report measures have been found to accurately predict interview determined PE and clinical outcomes (Kaymaz et al., 2012; Kelleher et al., 2011; van Nierop et al., 2011).

Context: The assessment context has also been shown to be influential (Laroui et al., 2014). PE rates are considerably higher in studies using smaller samples or convenience sampling and are lower when the sampling population was a whole nation or dispersed (Linscott & van Os, 2010; 2013). The 'Joanna Briggs Institute' (JBI, 2014) advises that a sample frame may not be appropriate to address a target

population, such as the general population, if only a certain group has been used, such as recruitment through a specific organisation or profession. Student samples are also consistently found to provide higher PE and voice hearing rates (Barrett & Etheridge, 1992; Posey & Losch, 1983). In addition to the above factors, student populations demonstrate higher possibilities of selection bias, substance use, and mental health problems (Pierre, 2010).

1.2.4 The importance of accurate prevalence rates

In recent decades there has been a surge in reviews of PE in the general population. However researching heterogeneous constructs, such as psychosis or collective PE, may mask important features relating to individual types of experiences (Beavan et al., 2011; McGrath et al., 2015). This is particularly relevant for hearing voices, which research indicates may be better understood as an independent experience due to its diverse effects (Lee et al., 2016). Therefore, there is growing awareness of the benefits of researching the prevalence of more homogenous experiences separately (Beavan et al., 2011; Bentall, 2009). This could help improve understanding of the specific associated factors and therefore inform treatment needs and approaches (Beavan et al., 2011; Krakvik et al., 2015; Kaymaz et al., 2012). Given emerging evidence that interpretations of voices predict clinical outcome, better understanding of their commonality could also help reduce stigma which may limit associated distress and need for care (Bak et al., 2005; Beavan et al., 2011; Morrison, Wells, & Nothard, 2003).

Multiple reviewers have explored the experience of voice hearing in the general population. However as the determination of a synthesised prevalence rate has not been their primary focus (with most directed towards comparing clinical and non-

clinical experiences) these reviews have either not referenced or only briefly overviewed prevalence (Baumeister et al., 2017; de Leede-smith & Barkus, 2013; Johns et al., 2014; Kelleher, 2016; Laroi, 2012). Beavan and colleagues (2011) have conducted a more comprehensive review. However their search was limited to the keyword ‘auditory hallucinations’ within the database PSYCHINFO and relevant reviews until September 2009. With the rapid, rising interest in voice hearing, a large number of studies have been published since this time (Upthegrove et al., 2016).

Furthermore, these existing reviews allowed broad inclusion of studies, potentially inflating the rate with ambiguous experiences (e.g. sounds, music, or name called in public) or specific, more extreme physiological or psychological conditions (e.g. sleep-related, sensory deprivation, or mourning) (Waters & Fernyhough, 2017). A recent review compiled by experts in the field, concluded that overall greater methodological rigor, particularly the minimisation of confounds, is needed to advance our understanding of voice hearing (Johns et al., 2014).

1.2.8 Review aims and questions

The present review aims to repeat the review conducted by Beavan and colleagues (2011) using a clearer definition for what constitutes voice hearing and stricter criteria for inclusion. The following review questions are:

1. What is the overall prevalence of voice hearing in the general population?
2. Does a clearer definition of voice hearing and stricter criteria for inclusion influence prevalence estimates?
3. Do the risk factors and methodological variations outlined in the introduction influence the prevalence of general population voices?

1.3 Method

1.3.1 Data sources and search terms

A systematic literature search was carried out using four electronic databases (PSYCHinfo, EMBASE, MEDLINE, and Web of Science). Search terms relating to voice-hearing were combined with terms associated with the general population (Table 1). The search terms were tailored to the individualised systems for indexing keywords of each database (see Appendix A). All database searches were conducted on 25th October 2016. Date parameters for each database are provided in Table 1.

Table 1

Search terms

	General population	Voice-hearing
All databases:	general population.mp ¹ .	hallucinat*.mp.
PSYCHINFO	((normal or healthy or community)	AVH.mp.
(1806 to October 2016	adj (population or individuals or	(voice* adj1 hear*).mp. ³
Week 3: 25.10.16)	sample)).mp. ²	
EMBASE: 1980 to 2016	("non psychotic" or non-psychotic or	
Week 43 (25.10.16)	nonpsychotic).mp.	
MEDLINE: 1946 to	("non clinical" or non-clinical or	
25.10.16	nonclinical).mp.	
WEB OF SCIENCE:	("sub clinical" or subclinical or sub-	
1900 to 25.10.16	clinical).mp.	
PSYCHINFO, EMBASE,	exp EPIDEMIOLOGY/*	exp Hallucinations/
MEDLINE		
PSYCHINFO, EMBASE		exp Auditory Hallucinations/

Notes: Terms within each topic were combined by OR, the two topics were combined by AND; ¹ .mp signifies a keyword search across several fields, including title, abstract, heading word, table of contents, key concepts, original title, tests, measures; ² The ADJ operator finds two terms next to each other in the specified order; ³ The ADJ1 operator finds two terms next to each other in any order.

To ensure greater coverage, hand searches were also conducted, including reviewing reference and citation lists of the obtained articles and the relevant reviews and contacting prominent authors in the field for their knowledge of additional studies.

1.3.2 Search strategy and eligibility criteria

Titles and abstracts for all papers were screened to determine eligibility. If inclusion was unclear, full articles were reviewed. For prevalence reviews, the JBI (2014) recommends categorising inclusion criteria by the condition of interest, the population, and the context or location. The condition was the experience of hearing voices only as they occur naturally without any manipulation. To reduce variability in estimates, it was decided to look specifically at lifetime prevalence and items with a similar general phrasing of ‘hearing a voice/voices’. The population and context were the adult general population living in the community. Studies were excluded if:

- 1) They did not report an exact prevalence rate (or count data from which a rate could be determined) for a general item relating to lifetime voice hearing.
- 2) The item used to determine the rate conflated voice-hearing with other forms of hallucination, other types of auditory stimuli (such as sounds, noises, or music), or when there were clear, plausible explanations, or confounding factors leading to voice-hearing, such as sleep-, substance-, or health-related.
- 3) The sample included clinical populations, or was collectively characterised by a distinguishing feature, such as a psychiatric or health condition.
- 4) The sample was not representative of 18-65 year olds. The proportion of older adults was minimised due to their elevated voice hearing rates and somewhat different risk profile. To avoid being overly restrictive, the criterion provided by Linscott and Van Os (2013) was used, requiring at least 80% of the sample

to be 18-65 years. If percentages could not be established, studies were excluded if the mean age of participants fell outside this range.

- 5) Participants were recruited through a sole, designated setting not representative of the wider general population community context, for example health services, prisons, aged-care facilities, or educational establishments, including student samples.

Furthermore, only studies which were available as a full publication in a peer-reviewed journal and written in English were included.

1.3.3 Bias assessment

Data was extracted from each included study using the form in Appendix B (JBI, 2014). Study quality was then assessed using the JBI (2014) Critical Appraisal tool for prevalence studies (Appendix C). This checklist tool assesses the quality and risk of bias within the methodology of studies. It addresses critical issues of internal and external validity and can be used across study designs (Munn, Moola, Riitano, & Lisy, 2014). As it is designed for use with large scale epidemiological studies, some items required specialist epidemiological knowledge. Therefore some aspects of the tool were adapted (Appendix C). This mostly involved clarification of how items fitted with the current review's purpose and the merging of two items (5 and 9) into a more generalised coverage bias item, as these required more detailed understanding of the demographical composition of populations or countries to enable them to be sufficiently addressed independently. Items were rated either present or not, leading to a maximum score of eight with higher scores indicating better quality.

1.3.4 Quantitative analysis

It is generally advised that data pooling methods, such as meta-analyses, are not suitable when data is known to be significantly heterogeneous (Linscott & van Os, 2013; Saha, Chant, & McGrath, 2008). Instead, Saha and colleagues (2008) advocate that where there are large variations in prevalence rates between sites, distribution plots with medians and quantiles are superior to traditional meta-analysis approaches. In line with previous PE meta-analyses, this approach was used to summarise the rate data (Kelleher et al., 2012a; Linscott & van Os, 2010; 2013; van Os et al., 2009).

Only the studies determined to have sufficient power and methodological quality were included in the analysis. The JBI (2014) recommend that reviewers conduct their own sample size calculation using the formula provided by Daniel (1999) and Naing, Winn, and Rusli (2006) (Munn, Moola, Lisy, Riitano, & Tufanaru, 2015). This provided a required sample size of 240 (See item three in Appendix C). Where samples overlapped (e.g. multiple publications on the same preliminary data), studies which reported on the largest overall sample size were used (Kelleher et al., 2012a). To account for differing sample sizes across studies, medians and quantiles weighted by N were also calculated. The distribution of prevalence estimates was also explored using the Kolmogorov-Smirnov test of normality. All calculations were conducted using Statistical Packages for the Social Sciences (SPSS 24) (IBM Corporation, 2016).

1.4 Results

1.4.1 Corpus of studies

Figure 1 provides full details of the screening and exclusion process. The search yielded 22 studies, which provided 25 prevalence rates across 16 cohorts consisting of 112,617 separate participants. Table 2 summarises the key details regarding the studies, including the samples and rates, to provide context to the following results. The identified studies used a variety of different measures. Thirteen were interview studies, seven self-report questionnaires, and two administered an interview schedule in a self-report questionnaire format. These measures utilised different response options, from dichotomous yes-no to likert scales. Unless already determined, the overall observed rate was calculated by any positive endorsement. Further details of the measures used, the items required for presence of hearing voices, and the endorsement thresholds are provided in Table 3.

Figure 1

PRISMA (2009) Study flow diagram

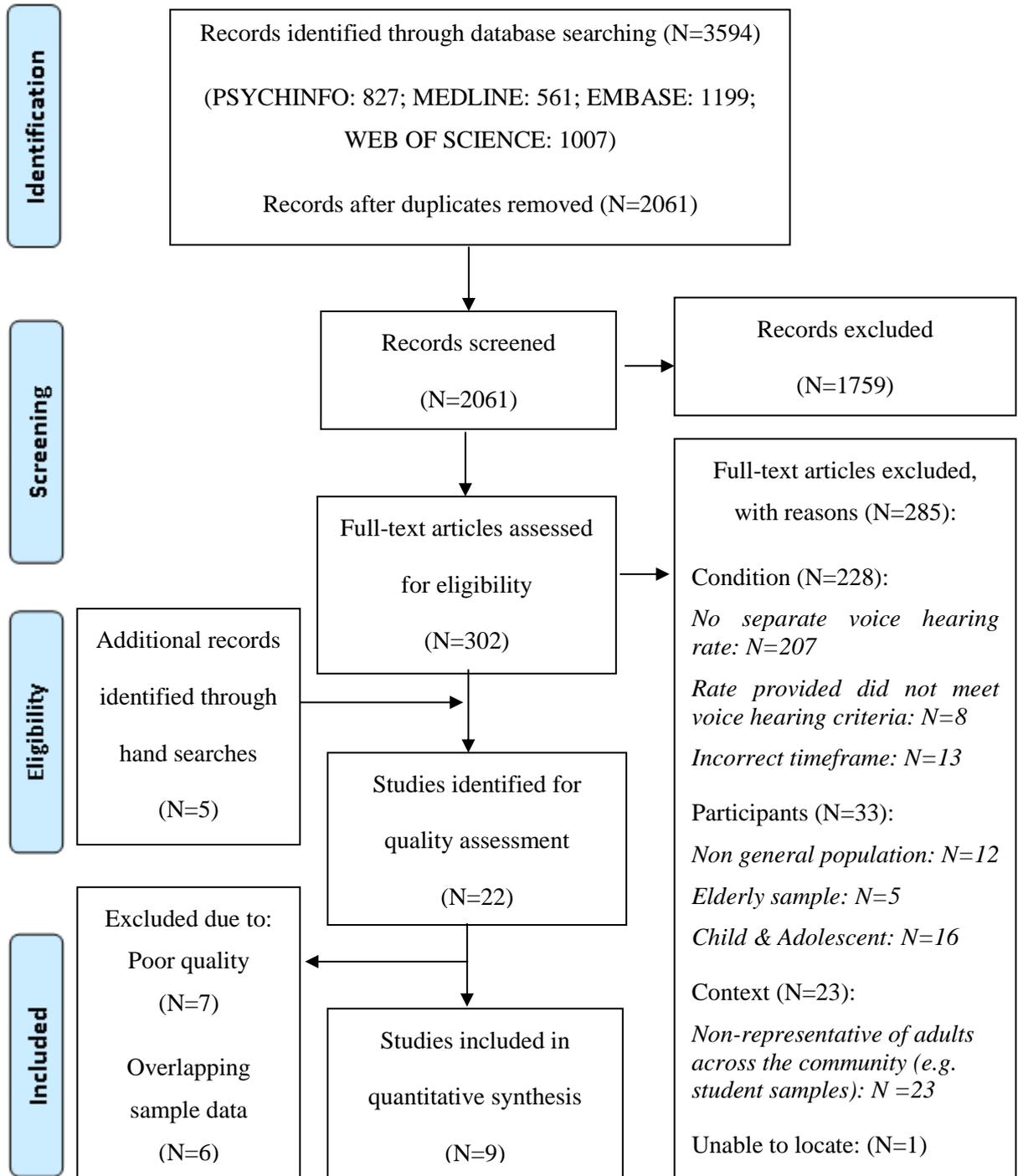


Table 2*Cohorts and data sources for identified studies*

Cohort (duration)	Location	Data source	Recruitment strategy	N	Age range	Measure instrument	Type	Observed rate (95% CI)
WHO World Mental Health Surveys (WMHS) (2001-09)	18 countries (N&S America, Africa, Middle east, Asia, South Pacific, and Europe)	McGrath et al. (2015)	Multistage, clustered-area probability, household sampling design	31261	18-100	CIDI psychosis screen (mixed versions)	INT	2.5% ^w (2.3-2.7 ^c)
Nigerian Survey of Mental Health and Wellbeing (NSMHW) (2001-03)	Nigeria: (Lagos, Ogun, Osun, Oyo, Ondo, Ekiti, Kogi, and Kwara)	Gureje, Olowosegun, Adebayo, & Stein (2010) ⁿ	As above	1419	18+	CIDI 3.0 psychosis screen	INT	0.9% ^w (0.31-1.48 ^c)
New Zealand Mental Health Survey (NZMHS) (2003-04)	New Zealand: throughout	Gale, Wells, McGee, & Browne (2011) ⁿ	As above	7435	16+	CIDI 3.0 psychosis screen	INT	2.8% ^w (2.3, 3.3)
National Comorbidity Survey Replication (NCS-R) (2001-03)	United States of America (USA): throughout	Kessler et al. (2005) ⁿ	As above	2322	18+	CIDI 3.0 psychosis screen	INT	4% ^w (3.02-4.98 ^c)
		Shevlin et al. (2011) ⁿ	As above	2355	18+	CIDI 3.0 psychosis screen	INT	5.22% (-)
		Murphy, Houston, Shevlin, & Adamson (2013) ⁿ	As above	2355	18+	CIDI 3.0 psychosis screen	INT	4% ^w (-)
		Foutz & Mezuk (2015) ⁿ	As above	924	18+	CIDI 3.0 psychosis screen	INT	4.03% ^w (-)

National Latino and Asian American Study (NLAAS) (2002-03)	USA: throughout - Asian / Latino immigrants	DeVylder et al. (2013)	Multistage, disproportionate random probability	2434 (1226/1208)	18-65	CIDI 3.0 psychosis screen	INT	(-) (2.5% ^w (1.32-3.68 ^c) / 4% ^w (2.82-5.18 ^c))
National Survey of American Life (NSAL) (2001-03)	USA: throughout – (African Americans / Caribbean Blacks)	Oh, Cogburn, Anglin, Lukens, & DeVylder (2016)	Multistage, disproportionate random probability	4384 (3025/1359)	18+	CIDI 3.0 psychosis screen	INT	4.93% ^w (-) (5.09% ^w (3.99-6.19 ^c) / 2.66% ^w (1.15-4.17 ^c))
Netherlands Mental Health Survey and Incidence Study 2 (NEMESIS-2) (2007-09)	Netherlands: throughout	Van Nierop et al. (2011)	Multistage, stratified random	6646	18-64	CIDI 3.0 psychosis screen	INT	2.08% (-)
Singapore Mental Health Study (SMHS) (2009-10)	Singapore: throughout	Subramaniam, Abdin, Vaingankar, Verma, & Chong (2014)	Disproportionate stratified	6616	18-89	CIDI 3.0 psychosis screen	INT	1.88% ^w (-)
Zurich Study of Young Adults (ZSYA) (2008)	Switzerland: Zurich	Rosler, Hengartner, Ajdacic-Gross, Haker, & Angst (2013)	Multistage stratified random	335	49-50	SPIKE	INT	2.7% ^w (-)
Scandinavian Women's lifestyle and health cohort (SWLHC) (2003/04)	Sweden: Uppsala region	Therman, Suvisaari, & Hultman (2014)	Random census selection	31822	41-61	CAPE: Italian version	QST	2.3% (-)
Market research company (MRUK) survey (-)	United Kingdom (UK): throughout	Pechey & Halligan (2012)	Quota random digit dialling	1000	18+	CBQ: Anomalous perceptions scale	QST	15.3% (-)
Norwegian general population (-)	Norway: throughout	Krakvik et al. (2015)	Random national statistic selection	2533	18+	LSHS-modified: Norwegian version	QST	7.25% ^w (6.16, 8.35)

Mater University of Queensland Study of Pregnancy (MUSP) (2002-04)	Australia: Queensland	Scott et al. (2008) ^e	Restricted opportunistic sampling	2441	18-23	CIDI 2.1 psychosis screen	INT	3.44% (-)
Dutch general population (2006-08)	Netherlands: throughout	Sommer et al. (2010) ^e	Non-random, biased	4135	18+	LSHS-modified: Dutch version	QST	11.54% (-)
Community residents (-)	Korea: no specification	Chang et al. (2015) ^e	(-)	223	18-65	LSHS-Revised: Korean version	QST	4% (-)
Non-clinical general adult population group (-)	Spain: province of Almería and Córdoba	Langer et al. (2015) ^e	(-)	68	(-)	RHS: Spanish version	QST	1.5% (-)
South London general population (2006-07)	UK: South London	Freeman & Fowler ^e (2009)	(-)	200	18-77	CAPS	QST	15.5% (-)
Society for Psychical Research census of hallucinations (1889-92)	UK: throughout (primarily) + high Russian & Brazilian speaking	Sidgwick, Johnson, Myers, Podmore, & Sidgwick (1894) ^e	Non-random, convenience	17000	20-70	Standard interview schedule (created by authors)	QST/ INT	3.62% (-)
“Mass Observation” national panel of voluntary helpers (-)	UK: throughout	West (1948) ^e	Biased random, convenience	1519	(-)	Standard interview schedule (as above)	QST/ INT	8.82% (-)

Key: CIDI = Composite International Diagnostic Interview; SPIKE = Structured Psycho-pathological Interview and Rating of the Social Consequences of Psychological Disturbances for Epidemiology; CAPE = Community Assessment of Psychic Experiences; CBQ = Cardiff Beliefs Questionnaire; LSHS = Launay–Slade Hallucination Scale; RHS = Revised Hallucination Scale; CAPS = Cardiff Anomalous Perceptions Scale; INT = Interview, QST = Questionnaire

Notes: (-) = not stated in paper, c = CI were calculated from standard error rates, e = excluded due to poor quality, n = not included in quantitative synthesis due to overlapping sample, w = rate was weighted by authors

Table 3

Measures used across studies

Measure	No.	Type	Description	Item Response options
World Health Organization (WHO) World Mental Health Composite International Diagnostic Interview (CIDI):	12	INT	<p>The CIDI is a diagnostic tool for epidemiological studies, which expands the Diagnostic Interview Schedule (DIS) to include both ICD and DSM classification, for cross-national comparisons (Cooper, Peters, & Andrews, 1998).</p> <p>CIDI 2.1: It contains a psychosis screen including 17 delusion items and 2 hallucination items.</p> <p>CIDI 3: Due to poor reliability and validity of earlier CIDI versions, a new psychosis add-on instrument was constructed. This includes a carefully worded introduction using normalising language to help improve the accuracy of responses (Kessler, Wittchen, Abelson, & Zhao, 2000). It contains six structured questions about the DSM-IV (APA, 1994) delusions and hallucinations found to more strongly predict clinician-diagnosed non-affective psychosis in the NCS (Kendler, Gallagher, Abelson, & Kessler, 1996; Kessler et al., 2005). These questions were modified with a clinical expert to align with how symptoms are experienced by community cases and therefore capture subclinical psychosis rather than full psychotic disorder.</p>	<p>CIDI 2.1: G18 Have you more than once heard things that other people couldn't hear, such as a voice? G19 Did you ever hear voices others could not hear? <i>Yes / No</i></p> <p>CIDI 3: The next questions are about unusual things, like seeing visions or hearing voices. We believe that these things may be quite common, but we don't know for sure because previous research has not done a good job asking about them. So please take your time and think carefully before answering. [...] The second thing is hearing voices that other people could not hear. I don't mean having good hearing, but rather hearing things that other people said did not exist, like strange voices coming from inside your head talking to you or about you, or voices coming out of the air when there was no one around. Did you ever hear voices in this way? Did this ever happen when you were not dreaming, not half-asleep, and not under the influence of alcohol or drugs?* <i>Yes / No</i></p>
Structured Psychopathological Interview and Rating of the Social Consequences of Psychological Disturbances for Epidemiology (SPIKE)	1	INT	<p>The SPIKE was developed for psychiatric epidemiological surveys (Angst, Dobler-Mikola, & Binder, 1984). In 2008 a new psychotic symptoms section was added to assess the sub-threshold range of these experiences in the general population. It includes four screening questions representing four syndromes.</p>	<p>"To hear voices that others don't" If positively endorsed item is followed by a series of detailed and more specific questions about the pertinent symptoms. <i>Yes / No</i></p>

Standard interview schedule:	2	INT	This standard interview scheduled was developed by Sidgwick and colleagues (1894) for the purpose of their census of hallucinations. It begins with an explanation that the question relates to experiences that Psychologists would describe as “casual hallucinations of sane persons”.	Have you ever, when believing yourself to be completely awake, had a vivid impression of seeing or being touched by a living being or inanimate object, or of hearing a voice; which impression, so far as you could discover, was not due to any external physical cause? Anyone answering yes are given schedule B with follow up questions differentiating the experience. <i>Yes / No</i>
The Launay–Slade Hallucination Scale (LSHS): Revised Hallucination Scale (RHS) / LSHS-Revised (LSHS-R) / LSHS-Modified	4	QST	The original LSHS (Launay & Slade, 1981) consisted of 12 true/false items assessing hallucinatory predisposition. Bentall and Slade’s (1985) LSHS-R added a five-point Likert certainty scale. Morrison and colleagues (2000) added visual hallucination items, resulting in the 16 item RHS endorsed by frequency. Laroi and Van der Linden (2005) incorporated further hallucinatory modalities and modified the items found to pose research problems, resulting in 17 items with the original certainty scale.	In the past I have had the experience of hearing a person’s voice and then found that there was no-one there? ** LSHS-R/modified: <i>Certainly does not/ Possibly does not / Unsure / Possibly / Certainly does apply to me</i> RHS: <i>Never / Sometimes / Often / Almost always</i>
Community Assessment of Psychic Experiences (CAPE):	1	QST	The CAPE (Stefanis et al., 2002), is a modified version of the Peters et al. Delusions Inventory (Peters, Joseph, & Garety, 1999). It contains 42 positive, negative, and depressive items explicitly designed to probe clinically relevant PEs.	Do you ever hear voices when you are alone? <i>Never / Sometimes / Often / Almost always</i>
Cardiff Beliefs Questionnaire (CBQ):	1	QST	The CBQ (Pechey & Halligan, 2011) contains 48-items (27 delusion-like/paranormal/religious beliefs; 13 societal/cultural beliefs; and eight anomalous experiences (four paranormal, two hallucinations, and two delusions)).	How often have you heard voices when no one is around? <i>Never / Rarely / Sometimes / Often</i>
Cardiff Anomalous Perceptions Scale (CAPS)	1	QST	The CAPS (Bell, Halligan, & Ellis, 2006) is a 32-item questionnaire, developed in both non-clinical and psychotic groups, to assess perceptual anomalies.	Do you ever hear voices saying words or sentences when there is no one around that might account for it?*** <i>Yes/No</i>

*Notes: INT = Interview, QST = Questionnaire; *McGrath et al. (2015) included some surveys using versions of CIDI (numbers not provided) containing an item phrased: “Did you ever hear things that other people said did not exist, like strange voices coming from inside your head talking to you or about you, or voices coming out of the air when there was no one around.” However, contact with the lead author confirmed that the final survey rates related to verbal hallucinations only. ** Additional items: Krakvik et al. (2015) “I often hear a voice speaking my thoughts aloud”; Sommer et al. (2010) “I have been troubled by hearing voices in my head” ***Additional items: Freeman & Fowler (2009) “Do you ever hear voices commenting on what you are thinking or doing?”, “Have you ever heard two or more unexplained voices talking with each other?”*

1.4.2 Study quality

Table 4 summarises the study quality scores. An independent rater (a Trainee Clinical Psychologist, UCL) scored 11 randomly selected papers (indicated in bold) using the same tool and guidelines. The independent ratings were compared and discussed. Any differences in ratings were resolved by discussion.

Table 4

Risk of bias assessment scores

Study	Quality rating criteria ^a								Total	Survey	Rate
	1	2	3	4	5	6	7	8			
Gale et al. (2011) ^c	Y	Y	Y	N	Y	Y	Y	Y	7	WHO-WMHS	2.8%
Kessler et al. (2005) ^c	Y	Y	Y	N	Y	Y	Y	Y	7	WHO-WMHS	4%
Murphy et al. (2013)^c	Y	Y	Y	Y	Y	Y	Y	N	7	WHO-WMHS	4%
Subramaniam et al. (2014)	Y	Y	Y	Y	Y	Y	Y	N	7	SMHS	1.88%
DeVylder et al. (2013)	N	Y	Y	Y	Y	Y	U	Y	6	NLAAS	2.5/4.0%
Foutz & Mezuk (2015) ^c	Y	Y	Y	N	Y	Y	Y	N	6	WHO-WMHS	4.03%
Gureje et al. (2010)^c	U	Y	Y	N	Y	Y	Y	Y	6	WHO-WMHS	0.9%
Krakvik et al. (2015)	Y	Y	Y	Y	U	N	Y	Y	6	-	7.25%
McGrath et al. (2015)	U	Y	Y	N	Y	Y	Y	Y	6	WHO-WMHS	2.5%
Shevlin et al. (2011) ^c	Y	Y	Y	Y	U	Y	Y	N	6	WHO-WMHS	5.2%
Van Nierop et al. (2012)	Y	Y	Y	Y	U	Y	Y	N	6	NEMESIS-2	2.08%
Oh et al. (2016)	N	Y	Y	N	Y	Y	U	Y	5	NSAL	4.93%
Pechey & Halligan (2012)	Y	Y	Y	Y	U	N	Y	N	5	-	15.3%
Rossler et al. (2013)	N	Y	Y	Y	U	Y	Y	N	5	ZSYA	2.7%
Therman et al. (2014)	N	Y	Y	Y	N	N	U	N	3	SWHLC	2.3%
Scott et al. (2008)^b	N	N	Y	Y	N	U	U	N	2	MUSP	3.44%
Sommer et al. (2010) ^b	N	N	Y	N	N	N	Y	N	2	-	11.54%
Freeman & Fowler (2009)^b	N	U	N	Y	N	N	U	N	1	-	15.5%
Sidgwick et al. (1894) ^b	U	N	Y	N	U	U	N	N	1	-	3.62%
West (1948)^b	N	N	Y	N	U	N	N	N	1	-	8.82%
Chang et al. (2015)^b	U	U	N	N	U	N	U	N	0	-	4.0%
Langer et al. (2015) ^b	N	U	N	N	U	N	U	N	0	-	1.5%

Note: Scoring: Y= met criteria, N=did not meet criteria, U=unclear; ^a Short hand summary: 1, sample frame; 2, sampling/recruitment, 3, sample size; 4, sample characteristics described; 5, coverage bias; 6, measurement validity; 7, measurement reliability; 8, appropriate statistical reporting; ^b Excluded on the basis of poor methodology; ^c Not included in the quantitative synthesis due to overlapping WHO-MHS samples

On the basis of their quality ratings, seven studies were excluded. The independent rater agreed with all exclusions of studies. Three questionnaire studies were excluded as they did not meet the minimum sample size set out in the critical appraisal tool ($N > 240$). These studies were also rated 'poorly' overall. The lack of detail provided in two of these studies (Chang et al., 2015; Langer et al., 2015) which had sample sizes of 223 and 68 respectively, made it difficult to rate the quality of the methodology and therefore to determine the validity of the prevalence estimate. The third study recruited via leaflet distribution to postcodes scoring highly on indexes of deprivation in South London with a poor response rate (Freeman & Fowler, 2009). This led authors to conclude that the sample of 200 was unlikely to be truly representative of the UK general population. Given the priority placed on estimates reflecting wider general population prevalence within this review, this also lowered its quality rating.

A further two studies, conducted by the Society of Psychical Research, were determined to have poor methodology throughout (Sidgwick et al., 1894; West et al., 1948). The only quality rating that could be confidently asserted was sufficient sample size. In terms of their methodology, their sample frames were unclear and as has been noted by previous reviewers, their recruitment methods were biased and unsystematic (Beavan et al., 2011). In particular, they used primarily friends and society acquaintances (Sidgwick et al., 1894) or a motivationally biased sample of voluntary helpers (West et al., 1948) and their respective personal networks to collect data using their study specific census asked in questionnaire format. The limited monitoring and control over this process led to poor ratings regarding reliability. The latter study also acknowledged numerous misunderstandings and indeterminable cases within their rate.

In another excluded study (Sommer et al., 2010) the overall aim was to recruit voice-hearers for a comparison study. The questionnaire was administered through a website containing information on voice hearing and the lead author confirmed that the design of this recruitment webpage “was not intended to give an exact reflection of the general population” (Email correspondence, I. Sommer, 21.03.17). As such their sample frame and recruitment was biased towards voice hearers. The final excluded study used the MUSP’s CIDI 2.1 results, however the exact item phrasing could not be established and consequently it was unclear whether endorsement related to voices or broader ‘things’ (Scott et al., 2008). Recruitment from the original MUSP study involved identifying women across the antenatal catchment area covered by a single study hospital. Their offspring were then followed up after 21 years, which formed the sample frame for the current study. Due to the nature of the follow up, this meant that the sample was restricted to 21-23 year olds. Recruitment methods that were used to follow up these individuals were also limited by financial constraints and participant availability, further reducing the representativeness of the sample. For these studies, the only quality items that could be confidently asserted were sufficient sample size and consistent web-based questionnaire administration or sufficient MUSP sample description. As such, their overall low quality rating and bias within their methodology led to their exclusion.

The quality ratings were used to structure, critically analyse, and weight the following results. First a quantitative synthesis of the identified prevalence rates is presented. Following this, the studies, their quality and contribution to the overall rate will be described, starting by evaluation of the sampling populations and recruitment methodologies and finishing with appraisal of the methods for measuring the condition.

1.4.3 Prevalence rate

Ten rates from nine studies using separate samples were included in the quantitative synthesis, including seven interview rates and three questionnaire rates. The median prevalence was 2.6% (range=1.88%-15.3%; IQR=2.25%-5.51%). The mean prevalence was 4.54% (SD=4.13%). Prevalence percentiles and quartiles of this estimate are present in Table 5, alongside existing PE estimates. The difference between the median and mean values indicated that the distribution of rates was skewed (Sara et al., 2008). The distribution was found to significantly differ from normality ($D(10)=0.272$, $p=0.034$) with a positive skew ($z=3.43$), particularly influenced by one questionnaire study ($z=2.61$) (Pechey & Halligan, 2012). The 10% to 90% range shows that the central portion of the distribution varies over a six- to seven- fold range. The variation in rates is represented in Figure 2.

Table 5

Prevalence percentiles and quartiles

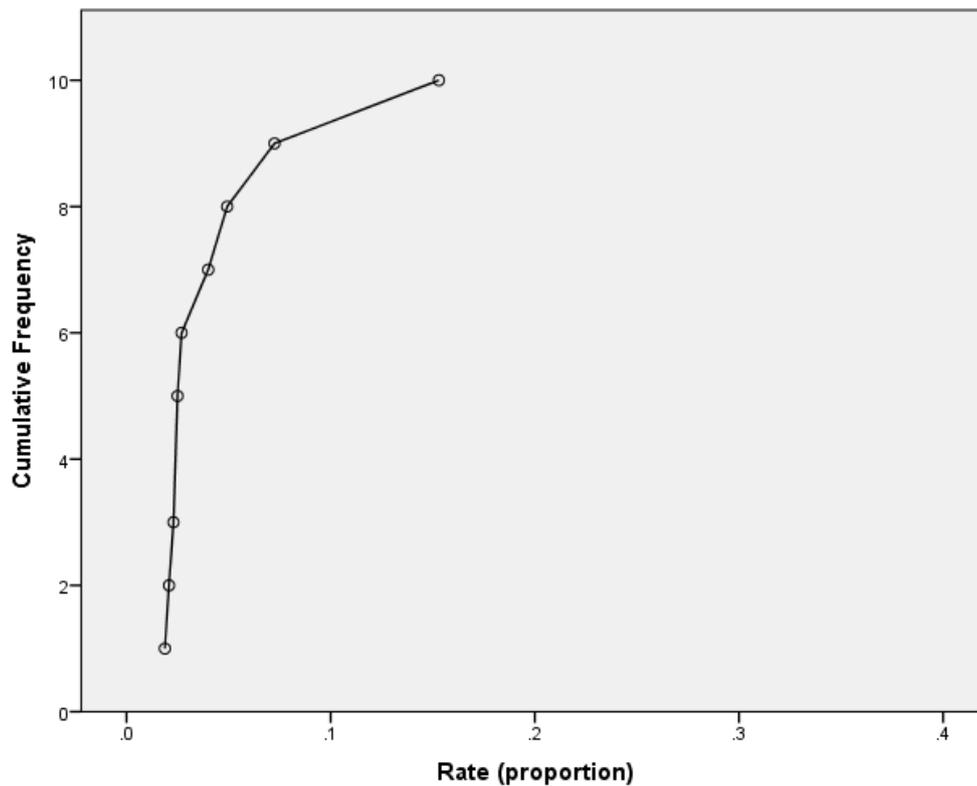
Phenotype	10th percentile	Lower quartile	Median	Upper quartile	90th percentile
Voice-hearing (narrow) ^a	0.0190	0.0225	0.0260	0.0551	0.1450
Voice-hearing (broad) ^b	-	0.031	0.132	0.195	-
Hallucinations (all modalities) ^c	0.012	0.021	0.060	0.0116	0.225
All PE ^c	0.012	0.025	0.072	0.155	0.255

Notes: ^a Rates obtained from present review; ^b Rates obtained by Beavan et al (2011);

^c Rates obtained from Linscott & van Os (2013)

Figure 2

Cumulative frequency of voice-hearing



1.4.4 Sources of heterogeneity

The following section will consider the sources of clinical and methodological heterogeneity which may underlie the established variance.

Sampling and recruitment: The WHO-MHS are a coordinated set of international community epidemiological surveys. A recent synthesis of 18 of the 26 completed WHO-MHS (McGrath et al., 2015) incorporated the estimates from the four USA NCS-R studies (Foutz & Mezuk, 2015; Kessler et al., 2005; Murphy et al., 2013; Shevlin et al., 2011), the NSMHW (Gureje et al., 2010), and the NZMHS (Gale et al., 2011). Most surveys, including the NCS-R and NZMHS, used nationally representative adult community sample frames (e.g. NZMHS covered 99.9% of the total population in New Zealand). However, the NSMHW only focused on particular

regions accounting for about 22% of the Nigerian population. Similarly the 18 country synthesis included surveys which were region specific or excluded rural areas or cities. The WHO-MHS synthesis was the only study in this review to exclude individuals with psychotic disorder (N=140) (McGrath et al., 2015). It could be argued that this may lead to an under-estimation of general population prevalence. However, the nature of psychotic disorder may lead individuals to be less agreeable to any of the identified studies and thus this non-response bias may inadvertently exclude them. WHO-MHS surveys had extensive and robust recruitment methods, using multistage, clustered-area probability, household sampling designs. The surveys were all conducted in two parts. Part II, including the CIDI 3.0 hearing voices item, was administered to all participants meeting criteria for a Part I disorder and a probability subsample of others.

The SMHS used a nationally representative Singaporean population sample (Subramaniam et al., 2014). Participants were randomly selected from a national register using a disproportionate stratified sampling design to provide equal proportions of the three main ethnic groups. Similarly, the NEMISIS-2 used a multistage sampling procedure stratifying by four regions and population densities to obtain a nationally representative Dutch adult sample (Van Nierop et al., 2012).

The USA Collaborative Psychiatric Epidemiology Studies (CPES) includes the NLAAS, the NSAL, and the WHO-MHS NCS-R. Although the CPES were found to have robust designs for representative sampling (Heeringa, Wagner, Torres, Duan, & Adams, 2004), the NSAL and NLAAS were exclusively interested in Asian and Latino immigrants and African Americans and Afro-Caribbeans, so employed disproportionate sampling. These studies were therefore limited in terms of ethnic representativeness. Similarly the ZSYA and the SWLHC used good random recruitment methods but utilised narrow sample frames of 49-50 year olds from the

canton of Zurich (Rossler et al., 2013) and females over 41 years in the Uppsala region of Sweden (Therman et al., 2013).

Unlike these national surveys, which had broader health-related aims, the Norwegian epidemiological study was specifically designed to investigate voice hearing prevalence using a large, randomly selected sample representative of the Norwegian adult population (Krakvik et al., 2015). Similarly another questionnaire study, specifically designed to explore anomalous experiences, demonstrated higher quality in this regards, using an experienced market research company (MRUK) to conduct random digit dialling of British adults with quotas for key demographics and hard to reach groups (Pechey & Halligan, 2012).

Sample size: When the studies were weighted by sample size, the median rate remained equivalent at 2.3%, however the spread of the estimate reduced (mean=2.78%, SD=1.69%; IQR=2.3%-2.5%). This may reflect the comparatively lower sample size of the disproportionately higher questionnaire study rate (N=1000) (Pechey & Halligan, 2012).

Coverage bias: Generally, reporting of response rates was poor. The Norwegian epidemiological survey was the only study to provide an accurate response rate (32.4%) and directly acknowledged that it risked inflating the estimate (Krakvik et al., 2015). Studies that used two phase interviewing methods, reported overall response rates for the first part of the survey not the final sample (WHO MHS=72.1%; NCS-R=70.9%; NSMHW=79.9%; NZMHS=73.3%; NEMISIS-2=65%). For those where staged interviewing did not apply, an overall survey rate was provided (SMHS=75.9%; NLAAS=73.2%; NSAL=72.3%; SWLHC=51.3%). Two studies did not state a response rate (Pechey & Halligan, 2012; ZSYA).

Some studies employed rigorous means to increase sample representativeness and therefore reduce coverage bias. Most large scale epidemiological surveys (WHOMHS; SMHS; NLAAS; NSAL; and the Norwegian survey) employed weightings to account for limitations inherent in their complex survey design (such as differential selection to later stages) and residual discrepancies with socio-demographic distributions in the populations within their sample frames (e.g. the NCS-R weighted to the USA 2000 census). The importance of weighting is highlighted in the NCS-R as the same data (N=2355) provided an estimate of 4% when weighted (Murphy et al., 2013) and 5.2% when not (Shevlin et al., 2011). For the remaining unweighted studies, coverage was unclear (NEMISIS-2; Pechey & Halligan, 2012; ZSYA) and was particularly problematic when response rate was low (SWLHS).

Overall the highest quality studies demonstrated more relevant sampling frames and more robust recruitment methods yet provided both the highest (15.3%, Pechey & Halligan, 2012) and lowest estimates (0.9%, Gureje et al., 2010). Generally the highest estimates came from studies with unclear coverage. However, studies with clearer coverage still varied in rate from 0.9%-5.09%. Therefore, in terms of methodological sampling quality, aside from the influence of sample size, there does not appear to be a clear, consistent overall pattern of influence.

Sample characteristics:

Gender: Seven studies referenced gender. The all-female SWLHC estimate was equivalent to the median rate at 2.3% (Therman et al., 2014). Three studies (Foutz & Mezuk, 2015; Murphy et al., 2013; Shevlin et al., 2011) used the same NCS-R data, all finding that women reported voice-hearing more frequently than men (female NCS-R median=5.43 vs. male NCS-R median=2.9). Two of these studies (Murphy et al., 2013; Shevlin et al., 2011) found this difference to be significant (5% vs. 2.9%,

$X^2=6.77$, $p=0.01$ and 6.1% vs. 4%, $X^2=4.95$, $p=0.03$ respectively). Whereas the remaining NCS-R study, using a smaller subset of this sample (Foutz & Mezuk, 2015), and the NSMHW (Gureje et al., 2010), found no significant difference between females and males, although a trend was indicated in the former (5.43% vs. 2.60%, $X^2=3.45$, $p=.063$ and 0.8% vs. 0.9%, X^2 not stated, $P>.05$ respectively). The likelihood of voice-hearing was also not affected by gender in Asian and Latino immigrants in the NLAAS (Devylder et al., 2013) or in the Norwegian epidemiological study (Krakvik et al., 2015).

Age: Norwegian individuals who heard voices without needing professional help were significantly younger than those who did not hear voices ($p=0.001$) (Krakvik et al., 2015). Overall, voice hearing was most common in younger age groups and declined across the lifespan (14.6% below 30, 7.8% aged 30-39, 6.4% aged 50-59, 6.0% aged 40-49, 4.6% aged 60-69, and 2.8% above 70). Additionally, a significant interaction between age and gender was found ($p=0.04$). In the 50-59 years group, women heard significantly more voices than men (4% vs. 3.8%, $p=0.03$), whilst for those aged 60-69 years, men reported significantly more voices than women (6.4% vs. 1.7%, $p=0.03$). Overall, women who heard voices were significantly younger than males ($p=0.03$). Within the sample of Asian immigrants in the NLAAS, the older age groups had significantly lower odds of hearing voices compared to the 18-29 years group (30-39y: Wald $\chi^2=4.6$, $p=0.033$; 40-49y: Wald $\chi^2=11.7$, $p=0.001$; 50-64y: Wald $\chi^2=12.0$, $p=0.001$) (Devylder et al., 2013). However, all odds ratios and their confidence intervals were minimal (<1). There was no age association in the USA NCS-R (Shevlin et al., 2011).

Race, ethnicity and environment: The probability of hearing voices was significantly increased by being of non-white ethnicity in the USA NCS-R (OR=1.87,

95% CI=1.11–3.14, $p<0.05$) (Shevlin et al., 2011). The NSAL found that African Americans were more likely to report voice-hearing compared to Black Caribbean Americans (5.09% vs. 2.66%, $F=4.46$, $p=.04$) (Oh et al., 2016). The NLAAS found voice-hearing did not significantly differ between USA Asian and Latino immigrants, however a trend was indicated with the Asian sample reporting fewer voices (2.5% vs. 4.0%, Wald $\chi^2=3.4$, $p=0.065$) (Devylder et al., 2013).

Individuals in the Norwegian general population who reported voices also reported higher numbers of severe life events (Krakvik et al., 2015). Similarly, childhood adversity was significantly associated with hearing voices in the NCS-R (physical assault: $X^2=37.26$, $p<0.01$; rape: $X^2=44.43$, $p<0.01$; other sexual assault: $X^2=17.41$, $p<0.01$) with a dose-response effect (Shevlin et al., 2011). This is similar to the significant dose-response linear trend between increasing acculturative stress and voice-hearing amongst NLAAS Asian and Latino immigrants (Wald $\chi^2=11.3$, $p=0.001$; Wald $\chi^2=18.0$, $p<0.001$) (Devylder et al., 2013). Childhood immigration (prior to 12 years) significantly increased the odds of hearing voices in Latino immigrants (Wald $\chi^2=4.4$, $p=0.035$; OR=3.1; 95% CI=1.1–9.4) whereas being in the USA for 10-20 years significantly increased the odds of voice-hearing in Asian immigrants (Wald $\chi^2=3.9$, $p=0.047$; OR=6.0, 95% CI=1.0–37.5). However, racial discrimination as a form of acculturative stress did not impact voice-hearing in the African American and Black Caribbean samples of the NSAL (Oh et al., 2016).

The Norwegian epidemiological study also found that mental health wellbeing gradually deteriorated with the severity of voice hearing (Krakvik et al., 2015). However, a large proportion (84%) of those hearing voices did not seek professional help. Across this sample, voice hearers were more likely to be single and unemployed contrasting with the NCS-R finding that marital status, education, and employment did

not significantly increase voice hearing risk (Shevlin et al., 2011). This NCS-R data also indicated that drug dependency influenced voice-hearing (OR=2.30, 95% CI=1.06–5.02, $p<0.05$) whilst alcohol dependency did not.

Culture: Overall rates tended to vary more across more Westernised cultures, for example, from 2% (Van Nierop et al., 2012) to 7.25% (Krakvik et al., 2015) and 15.3% (Pechey & Halligan, 2012) across Europe. The studies from non-Western cultures provided comparatively lower estimates, including 0.9% in Nigeria (Gureje et al., 2010) and 1.88% in Singapore (Subramaniam et al., 2014). However, the assessment mode, outlined below, may have influenced this variance. Rates could be more easily compared across the WHO-MHS given the close methodology which showed rates steadily increased the more Western the culture became (from 0.9% in Nigeria, to 2.8% in New Zealand, to 4% in USA).

Mode of assessment: The prevalence estimates of the studies using interviews varied across a much narrower range from 1.88% to 4.93% (N=7; median=2.5%; IQR=2.08%-4%; mean=2.94%, SD=1.11%). Whereas studies using questionnaires demonstrated larger variance in their estimates from 2.3% to 15.3% and an overall higher median rate of 7.25% (N=3; IQR=2.3%-13.69; mean=8.28%; SD=6.56%).

The most commonly used interview, the CIDI 3.0, was used across the majority of large scale epidemiological surveys. The psychosis section underwent considerable revisions to reduce misunderstandings by providing clarity and context to the researcher's intent and modifying the language to normalise and motivate responses (Kessler et al., 2000). The voice-hearing item clearly differentiates the condition from other auditory stimuli. The mixture of open and closed follow-up questions also provided context to the reported experience. The built-in clarification and exclusion of sleep- and substance-related experiences provided more control over subthreshold or

mistaken responses (Kessler et al., 2005). Some studies furthered this precision of measurement by excluding voices related to physical illness (van Nierop et al., 2011), organic aetiology (Gale et al., 2011; Gureje et al., 2010), or aging-related medical or neurological causes (Devolder et al., 2013). Generally, most studies using the CIDI 3.0 provided extensive training of professional survey interviewers (bar NSMHW where the researchers conducted the interviews) with strong internal quality control procedures. Due to limited reporting this was not clear for the NLAAS and NSAL. However, consistent interviewer training and procedures are reported to have occurred across all WHO-MHS (McGrath et al., 2015). The only other interview, the SPIKE, included in the ZSYA, did not provide context to the condition, but follow-up items did allow descriptions to be carefully explored and clinically validated. Administration and validation was reliably conducted by extensively trained clinical psychologists (Rossler et al., 2013).

The self-report questionnaire studies used measures designed to avoid clinical vocabulary providing a broader, non-clinically focused context and used less intrusive administration methods of telephone (Pechey & Halligan, 2012) and postal questionnaires (Krakvik et al., 2015; Therman et al., 2014). However, their validity was rated as low due to their reliance on limited context and no follow-up. The item phrasing of the disproportionately highest rate (“How often have you...”) could either be interpreted as leading or normalising. The standardised protocols conducted by the experienced market research company (Pechey & Halligan, 2012) and the structure associated with the Norwegian epidemiological survey aided reliability, but this was not as clear for the remaining questionnaire study, SWHLC (Therman et al., 2014).

The lowest rate overall, 0.9%, used a high threshold of inclusion with researchers clinically validating voice-hearing against DSM-IV criteria (Gureje et al.,

2010). Conversely, the higher questionnaire estimate of 7.25% incorporated a broader response option of ‘possibly applies’ and a vaguer worded item relating to ‘a voice speaking thoughts aloud’ (Krakvik et al., 2015). Across the measures there are also subtle variations from hearing ‘a voice’ (LSHS-R) to hearing ‘voices’ (CIDI, SPIKE, CAPE and CBQ). More frequent voices were less common in the Norwegian epidemiological survey (daily=0.88%; several times a week=1.01%; several times a month=1.00%; monthly or less=3.32% and annually or less=2.77%) (Krakvik et al., 2015). Four further studies (2 CIDI 3.0, CAPE, CBQ) also provided separate comparable frequency rates (Gale et al., 2011; Pechey & Halligan, 2012; Subramaniam et al., 2104; Therman et al., 2014). More frequent voices (many, often/almost always) were heard by fewer individuals ranging from 0.15% to 1.8% (median=1.12%; IQR=0.3%-1.73%; mean=1.05%; SD=0.75). Less frequent (few or rarely/sometimes) voices were heard by a wider range of individuals from 1% to 13.8% (median=1.64%; IQR=1.04%-10.89%; mean=4.52%; SD=6.21%). The study providing the disproportionately highest estimate of 15.3% for any endorsement, found only 1.5% of respondents heard voices often (Pechey & Halligan, 2012).

Estimate precision: Accurate reporting of the rate was generally poor across studies with only two studies providing confidence intervals for their overall prevalence rate (Gale et al., 2011; Krakvik et al., 2015); three providing SE (Gureje et al., 2010; Kessler et al., 2005; McGrath et al., 2015); and three providing SE for prevalence rates by different subpopulations (DeVylder et al., 2013; Oh et al., 2016) or frequencies (Subramaniam et al., 2014).

1.5 Discussion

1.5.1 Summary of the findings

This analysis identified the median estimated prevalence of adults living within the community who have heard a voice or voices not heard by others across their lifetime to be 2.6%. Similar to existing PE reviews, there was a high level of variability across the rates provided, from 0.9% to 15.3%. Therefore the estimate is more accurately represented by the interquartile range of 2.25% to 5.51%. This is considerably lower than existing median prevalence estimates using a broader voice hearing definition (13.2%) (Beavan et al., 2011), and lower than recent hallucination (6%) and PE (7.2%) estimates (Linscott & van Os, 2013). These estimates included more varied sample frames and recruitment settings. Additionally, the current review included more recent research with more sophisticated designs and assessments of voice hearing, compared to the previous voice hearing reviews (Beavan et al., 2011). Collectively, these findings suggest that hearing a voice is less common than hearing other auditory stimuli or having broader anomalous experiences. They also indicate that hearing voices is less common in national, dispersed community settings than in selected subsamples of the general population, particularly students. Similar findings have been found with respect to broader PE (Beavan et al., 2011; Freeman, 2006; Johns et al., 2004; Linscott & van Os, 2013).

This review also sought to determine factors which may influence voice hearing prevalence. As with auditory hallucinations, there was some suggestion of gender differences, particularly that females are more likely to hear voices (Beavan et al., 2011; Read, 2004), preliminarily indicating a reverse gender association to the suggested influence of male sex in PE and Schizophrenia (Read, 2004; van Os et al.,

2009). Similar to PE, associations were identified between trauma and voice hearing, indicating a potential shared environmental risk factor between general population voice hearing and psychosis. There was some early indication that in the general population this association may relate to more persistent, accumulative adversity, such as acculturative stress. Findings of higher rates of trauma (Read, Perry, Moskowitz, & Connolly, 2001; Shevlin et al., 2011) and subsequent dissociation in women (Spitzer et al., 2003) may help explain the potential gender influence. However, inconsistencies across studies indicate that this gender difference may vary in older ages or non-Westernised ethnicities/cultures. There is also some early indication that, like PE, voice hearing is more common in younger ages (Linscott & van Os, 2013). In contrast to previous findings, there was a general trend towards lower rates of voice hearing in non-Western cultures (Beavan et al., 2011). This may relate to the broader epidemiological composition of these countries, particularly income status, rather than solely cultural beliefs (McGrath et al., 2015). However, the reliability of these findings is limited to a restricted subset of studies and there was insufficient information to clearly comment on further risk factors, such as ethnicity or socio-economic factors.

These findings may also be confounded by the more confident associations relating to the measurement of voice hearing across studies. In line with robust PE findings (Linscott & van Os, 2013), voice hearing was less frequent when measured by lay- or clinician-administered interviews compared to self-report questionnaires. Interview studies tended to draw upon larger scale, epidemiological surveys with broader, often psychiatric, outcome aims. Given the resources and scope of these surveys, interview studies generally demonstrated higher quality. However stigma regarding PE and subsequent social desirability influences may have influenced their rates (Johns et al., 2002). Conversely, questionnaire studies with higher rates were

intentionally designed to exclusively explore anomalous experiences in the general population within a non-clinical, as opposed to diagnostic, context. This may have reduced stigma and encouraged more honest responses (Pechey & Halligan, 2012) and may explain the comparatively lower questionnaire rate from a health survey with poorer sampling (Therman et al., 2014).

The different assessment modes may have also been capturing different points along a continuum of voice hearing experience. The broader response options of the questionnaires allowed a more varied threshold of what constitutes voice hearing and likely encompassed less frequent, transient, or uncertain experiences, such as circumstantially explained or thought-like voice experiences. However, the higher endorsement in these questionnaire studies indicates that these are still experienced as sufficiently real and meaningful to the individual (Beavan et al., 2011; Pierre, 2010). Whereas, interview measures provided more clinical validation and consequently their rates may have generally reflected more frequent, enduring voice hearing with similar phenomenological quality to clinical voices (Aleman & Larøi, 2008; APA, 2013; de Leede-Smith & Barkus, 2013). Therefore as with PE, more frequent and severe voices appeared to be less common in the general population (Linscott & van Os, 2013). Discussion regarding the discontinuous nature of risk of clinical outcome goes beyond this review (Johns et al., 2014; Linscott & van Os, 2013). However, these findings may align with the proposed categories of ‘hallucination prone’ individuals, represented within questionnaire studies, versus ‘nonclinical voice hearers’, differentiated by need for care (Johns et al., 2014; Laroi, 2012).

1.5.2 Study limitations

As voice hearing was not the primary outcome of most studies identified, details within these studies tended to be directed towards the wider outcomes assessed. Therefore the most frequent problems with study quality was limited reporting, particularly of sample characteristics, response rates, measurement reliability, and the rate itself. This made inferences regarding quality, accuracy, and generalisability difficult. Furthermore, the subjective self-report nature of questionnaire items can lead to unintentional errors, particularly misunderstandings, leaving it unclear what construct was being measured. The predominant use of protocol-driven lay interviewers also led authors to consider these methods an extension of self-report (Scott et al., 2008; Subramanian et al., 2014; van Nierop et al., 2011; van Os et al., 2009). Post-hoc clinical validation of some of the interview rates found that they also incorporated possible, transient, or circumstantially explained experiences (Gale et al., 2011; Kessler et al., 2005). Therefore, the differentiation between assessment modes may not be as clear cut, or the true prevalence may be even lower than estimated. However, self-report is currently the only means for ascertaining PE within the general population (Lee et al., 2016; Upthegrove et al., 2016).

1.5.3 Review limitations

To increase homogeneity across studies tighter inclusion criteria were imposed, which limits the generalisability of the findings. In particular, it is not definitively clear how these findings may relate to child, adolescent, or older adult samples; more specific contexts, particularly student's samples; and alternative timeframes, for example, incidence or annual prevalence. However it is possible that participants responded on the basis of childhood experiences, potentially blurring the

age criterion. Furthermore timeframe did not significantly influence PE prevalence (Linscott & van Os, 2013). Given the focus on general voice hearing items, subtle nuances regarding the voice hearing experiences were lost. In particular, this review did not consider items solely investigating specific voice content, such as Schneiderian first-rank voices (commenting or conversing), which are thought to be more pathological (Peters et al., 2016). As the exclusion of individuals with psychosis within community samples was not required, the collective prevalence rate includes those with varying diagnoses, levels of distress, and need for care. Despite conducting a broad search strategy, additional estimates, from grey literature and non-English articles, may have been missed. A broader issue across the literature was that numerous studies included hearing voices items yet did not report prevalence as it was not a study aim. This has wider implications in terms of outcome reporting bias (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009).

1.5.4 Research implications

Future reviews should focus more specifically on subtle or specific variations in voice hearing experience, across broader contexts, timeframes, and level of need. More large scale longitudinal, epidemiological studies separately examining the prevalence of voice hearing using consistent methodology are needed. Such studies should consider how voice hearing prevalence varies along the continuum of experience and should aim to help identify risk and protective factors relating to voice hearing both with, and without, need for care (Johns et al., 2014; Laroi, 2012). This evolving research base should help contribute towards more robust definition and assessment of voice hearing and inform prevention and intervention responses (Lee et al., 2016; Linscott & van Os, 2013; Upthegrove et al., 2016). In particular, less

stigmatising and culturally sensitive assessment tools, which consider where endorsed experiences fit along the continuum of experience and need for care, are needed (Johns et al., 2014).

1.5.5 Clinical implications

This review emphasises the importance of conceptualising PE, such as voice hearing, on a continuum of experience. The findings also highlight that it is clinically important to consider voice hearing as a separate construct, which may occur at a separate and lower prevalence, than broader auditory hallucinations and PE. Referring to voice hearing and psychotic disorders interchangeably can draw attention away from other associated outcomes, including potential positive experiences and relationships to voices (de Leede-Smith & Barkus, 2013; Johns et al., 2014; Kelleher, 2016). Instead, clinicians should enquire about the factors more closely associated with clinical significance, most notably distress, coping, and the meaning of the voice (de Leede-Smith & Barkus, 2013; Laroi, 2012; Romme et al., 2009). The integration of continuum terminology within clinical practice may help avoid stigma associated with diagnostic labels, whilst providing individuals with reassurance and understanding (Linscott & van Os, 2013). On a broader societal sense, promoting an awareness of this continuum, and that a significant minority of individuals in the community hear voices, should help reduce public stigma. This cultural shift could help encourage individuals to talk more openly and seek effective support (Krakvik et al., 2015; Lien et al., 2015).

1.5.6 Conclusion

This literature review estimated that the lifetime prevalence of hearing voices falls between 2% and 6%. The findings indicate that hearing a voice is less common than hearing general auditory stimuli or having PE and may be less common in community representative samples compared to student populations (Beavan et al., 2011; Linscott & van Os, 2013). Similar to PE, there was high heterogeneity across studies. Currently, research specifically examining voice hearing risk factors is too sparse to draw firm conclusions. However, the definition and subsequent measurement of voice hearing does appear to have a more consistent influence. As with PE, higher rates tended to be found in self-report questionnaire studies, whose methodology may encourage more open responses with broader thresholds for what constitutes voice hearing, compared to interview studies (Beavan et al., 2011; de Leede-Smith & Barkus, 2013). Overall this review provides further support of the continuum view, with a significant minority of individuals hearing voices with a more clinical quality. This range is slightly broader when transitory, infrequent or vague voice experiences are included (McGrath et al., 2015). A cultural shift toward conceptualising voice hearing in this way will help reduce stigma, improving access to support. However, further large scale, epidemiological studies specifically exploring the prevalence and associations of voice hearing are needed. It is hoped that this research will help establish a clearer consensus regarding how to conceptualise and define voice hearing and inform the development of more sensitive and valid assessment tools.

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Part 2: Empirical Paper

The Role of Childhood Adversity in the Development of Psychotic Experiences in Borderline Personality Disorder

2.1 Abstract

2.1.1 Aims: Psychotic experiences (PE) are regularly experienced by individuals with Borderline Personality Disorder (BPD). Childhood adversity is found to have a significant role in PE in psychotic and general population samples. This study aimed to explore whether this association applies to BPD, particularly whether specific characteristics of adversity may help explain PE in BPD and if these factors are BPD-specific or relevant across the general population.

2.1.2 Method: A web-based survey was used to administer measures relating to BPD symptomology (for allocation to a BPD and non-BPD sample), PE, and childhood adversity to the general population, particularly targeting groups likely to meet criteria for BPD. The study webpage was advertised across social media, NHS services, and through posters/flyers in public places. The resulting sample (N=374) consisted of 178 individuals screening positive for BPD and 196 non-BPD controls.

2.1.3 Results: More frequent adversity, particularly sexual abuse, was associated with more frequent PE in the BPD sample. Frequency of adversity was also significant across the non-BPD sample, however paternal neglect was more important. These findings remained after accounting for potential self-reported confounding disorders. Timing of first adversity was not significantly associated with PE in either sample.

2.1.4 Conclusion: The results indicate that certain characteristics of adversity, particularly cumulative exposure to sexually abusive experiences throughout childhood, may be helpful in understanding susceptibility to PE in BPD. However, replication in larger samples with more robust measurement of the key constructs and confounding factors is needed.

2.2 Introduction

2.2.1 Psychotic experiences in Borderline Personality Disorder

Emerging research is increasingly demonstrating the heterogeneous origin of psychotic experiences (PE). It is now clearly established that PE are not always indicative of an underlying psychotic disorder and are relatively common across many mental disorders (Janca & Balaratnasingam, 2014). Recent estimates also suggest that 7.2% of the general population report PE (Linscott & van Os, 2013). Consequently, traditional diagnostic boundaries are beginning to be reconsidered, with accumulating evidence that these experiences lie on a continuum (American Psychiatric Association [APA], 2013; Kelleher & Cannon, 2011).

Borderline Personality Disorder (BPD) is a common psychiatric condition estimated to affect 0.7% to 5.9% of the general population (APA, 2013; NICE, 2009). BPD is characterised by a pervasive pattern of unstable interpersonal relationships, identity disturbance, emotion dysregulation, and marked impulsivity, which presents by early adulthood. Recent reviews conclude that there is substantial evidence to suggest that around 20-50% of individuals with BPD report PE, with up to 24% experiencing severe PE (Barnow et al., 2010; Merrett, Rossell, & Castle, 2016; Schroeder, Fisher, & Schäfer, 2012; Zonnenberg, Niemantsverdriet, Blom, & Slotema, 2015). However rates can vary and the prevalence across nonclinical populations is not as clear.

Earlier studies described these experiences as distinct from those in psychotic disorders, clearly discriminated by their milder, ‘quasi-psychotic’ nature (Pope, Jonas, Hudson, Choen, & Tohen, 1985; Zanarini, Gunderson, & Frankenburg, 1990). The DSM-5 ninth criteria for BPD, “transient, stress-related paranoid ideation or severe

dissociative symptoms” (APA, 2013), circumscribes PE to periods of extreme stress, particularly interpersonal difficulties, and describes PE as short-lasting, resolving following the return of emotional regulation (Masterson & Rinsley, 1975; Oliva, Dalmotto, Pirfo, Furlan, & Picci, 2014; Suzuki, Tsukamoto, Nakano, Aoki, & Kuroda, 1998). However, considerable evidence indicates that PE in BPD are phenomenologically similar and mostly indistinguishable from those of psychotic disorders, with some indicating that their emotional impact may be even stronger, thus highlighting the clinical importance of understanding these experiences better. (Barnow et al., 2010; Laroi et al., 2012; Schroeder et al., 2012; Waters & Fernyhough, 2017; Zonnenberg et al., 2015).

2.2.2 The role of trauma in developing PE in BPD

Empirical evidence into the mechanisms behind PE in BPD is scarce (Schroeder et al., 2012). Some researchers propose that PE only occurs in BPD in the context of co-morbid substance use or affective disorders (Barnow et al., 2010; Zanarini et al., 1990). However, evidence is limited with indication that these comorbidities cannot explain all occurrences (Gras, Amad, Thomas, & Jadri, 2014; Schroeder et al., 2012). Instead, the role of early life trauma is strongly emphasised in recent reviews (Barnow et al., 2010; Merret et al., 2016; Schroeder et al., 2012).

A substantial body of research indicates a strong association between childhood adversity, namely physical, sexual, emotional abuse (CPA, CSA, CEA), or neglect, and PE (Gibson, Alloy, & Ellman, 2016; Skehan, Larkin, & Read, 2012). Larger scale studies with improved methodological rigour indicate a causal relationship with the presence of childhood adversity temporally preceding PE (Gibson et al., 2016) and increasing the odds of developing a psychotic disorder

(Varese et al., 2012). This strong association has been demonstrated across other psychiatric conditions, such as Bipolar Disorder (Schroeder et al., 2012; Upthegrove et al., 2015) and across the continuum of PE in the general population (Bendall, Jackson, Hulbert, & McGorry, 2008; de Leede-Smith & Barkus, 2013; Johns et al., 2014; Read, van Os, Morrison, & Ross, 2005). The strength of this association is highlighted by its persistence after controlling for other key variables, such as family history of psychotic disorder (Gibson et al., 2016).

Given the interconnected relationships between BPD and psychotic disorders, there is indication that this relationship may apply to BPD (Janca & Balaratnasingam, 2014). Studies of PE in BPD have referenced past traumatic experiences or memories as relevant (Pearse, Dibben, Ziauddeen, Denman, & McKenna, 2014; Yee, Korner, McSwiggan, Russel, & Stevenson, 2005). However, Tschoeke, Steinert, Flammer, and Uhlmann (2014) are the only researchers to directly measure this. They found that childhood adversity positively correlated with suspiciousness and social avoidance, which they hypothesised to be trauma-related avoidance, and negatively correlated with lack of insight and somatic concern. As the sample was restricted to 23 female BPD patients, further research is needed.

2.2.3 Potential moderators to the childhood adversity–PE relationship.

Childhood adversity is a highly prevalent and significant aetiological factor in BPD (Adams & Sanders, 2011). Individuals with BPD are said to experience more frequent, and more varied, childhood adversity, starting earlier in life, and persisting over longer periods compared to comparison groups (Gibson et al., 2016; Schroeder et al., 2012). Estimates indicate that around 44%-59% of individuals with BPD report CPA, 40-76% CSA, 66%-73% CEA, and 90% neglect, (Battle et al., 2004; Schroeder

et al., 2012). As such, childhood adversity is likely to be more prevalent than PE in BPD. Therefore, if this association were to apply, it is not clear why some individuals with BPD and childhood adversity experience PE whilst others do not.

Greater specificity of the relationship between childhood adversity and PE has been a feature of recent research. Several potential mediating mechanisms have been proposed, including information processing biases, threat-based schemas, external locus of control, stress sensitivity, and disrupted attachment style (Bendall et al., 2013; Fisher, Appiah-Kusi, & Grant, 2012; Fisher et al., 2013; Gibson et al., 2016; Kilcommons & Morison, 2005). Growing research has also begun to highlight the role of dissociation, particularly in BPD (APA, 2013). Tschoeke and colleagues (2014) hypothesised that PE in their BPD sample occurred in the context of trauma-related dissociative phenomena, as the pattern of PE overlapped with that found in severe dissociative disorders. Similarly, there is a strong emphasis in recent literature on the role of Post-Traumatic Stress Disorder (PTSD) or associated symptomology (Barnow et al., 2010; Schroeder et al., 2012). Nevertheless, empirical evidence within this area is limited with most studies finding the adversity-PE link persists after adjusting for psychological comorbidities leading reviewers to conclude that that childhood adversity leads to PE through multiple pathways (Bentall & Fernyhough, 2008; Gibson et al., 2016; van Winkel, van Nierop, Myin-Germeys, & van Os, 2013; Varese et al., 2012).

Emerging research has highlighted that specific characteristics of the adversity may moderate its influence and make the development of PE more likely.

Frequency: Methodologically rigorous clinical and general population studies indicate a dose-response relationship between childhood adversity and PE, with risk

of psychotic disorders or PE increasing substantially for each additional adversity (Gibson et al., 2016; Skehan et al., 2012; Varese et al., 2012). Within BPD, it has been suggested that cumulative exposure to childhood adversity may result in a sensitisation process, moderated by neurodevelopmental changes, including dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis and neurotransmitter systems, such as the dopaminergic system (Nicol, Pope, Romaniuk, & Hall, 2015). These systems may become hyperactive under stress, particularly interpersonal problems, making an individual more susceptible to information processing biases leading to PE (Barnow et al., 2010; Gras et al., 2014; Yee et al., 2005). This may explain the higher psychotic reactivity to stress within BPD compared to other populations and the pivotal role of interpersonal functioning in this psychotic sensitivity (Glaser, van Os, Thewissen & Myin-Germeys, 2010; Oliva et al., 2014; Suzuki et al., 1998). It has also been proposed that this process may enhance risk for stress-related disorders, such as PTSD, indirectly enhancing vulnerability to PE (Schroeder et al., 2012).

Type: Within the psychotic disorder and continuum literature, some large-scale studies find differential influence by adversity type or symptom specificity (Bentall, Wickham, Shevlin, & Varese, 2012). CSA has been found to more strongly associate with hallucinations, especially voice hearing (Bentall et al., 2012; Bentall et al., 2014; Kilcommons & Morrison, 2005; Read, Agar, Argyle, & Aderhold, 2003). CPA has been associated with positive PE more generally (Shevlin et al., 2011; Thompson et al., 2009). Both CSA (Bechdolf et al., 2010; Thompson et al., 2013) and CPA (Fisher et al., 2010; Shevlin, Dorahy, Adamson, 2007) have separately been suggested to be the most influential adversity type in predicting psychotic disorder, when accounting for other adversity types and covariates, thus highlighting some inconsistencies across the literature (Gibson et al., 2016). The associations for CEA are more mixed, with

focus on subthreshold PE, but also hallucinations (Daalman et al., 2012; Velikonja, Fisher, Mason, & Johnson, 2015). Overall, neglect more strongly associates with schizotypal symptoms, paranoia, and general psychopathology in both clinical and general population samples (Bentall et al., 2014; Daalman et al., 2012; Gibson et al., 2016). The most common type of adversity experienced by individuals with PE differs across studies and some studies find no evidence of symptom specificity (Gibson et al., 2016; Janssen et al., 2004; van Nierop et al., 2014). Given these inconsistencies, there is insufficient evidence to definitively conclude which types of childhood adversity are more likely to be associated with PE (Gibson et al., 2016; Varese et al., 2012). Some authors propose that aspects such as persistence and the relationship to the perpetrator are more important (Trauelsen et al., 2015). A more consistent finding is that intentional harm, with an interpersonal element, has a larger impact on psychotic disorder trajectory (Arseneault et al., 2011; Schafer & Fisher, 2012; van Nierop et al., 2014). In particular, childhood adversity is more strongly associated with PE when it is more severe, intrusive, or involves intense fear or helplessness (Gibson et al., 2016; Spauwen, Krabbendam, Lieb, Wittchen, & van Os, 2006).

Timing: Exposure to adversity at very young ages has been linked with more severe and persistent mental health difficulties. There is tentative evidence to indicate that this may apply to PE outcomes (Fisher et al., 2010). Similarly, abuse in adulthood is less strongly related to PE (Barnow et al., 2010; Read et al., 2003).

Research has begun to explore how these variables may interact (Trauelsen et al., 2015). In particular, Fisher and colleagues (2010) examined the timing and frequency of exposure to different types of childhood adversity in 182 individuals presenting with first-presentation psychosis and 246 individuals from the general population using the Childhood Experiences of Care and Abuse questionnaire (CECA-

Q; Bifulco, Bernazzani, Moran, & Jacobs, 2005). Only specific adverse experiences were associated with the presence of psychotic disorder. Maltreatment perpetrated by the mother (including both CPA and antipathy) had a larger impact on the presence of a psychotic disorder than paternal abuse. Individuals with psychotic disorders were three times more likely to report severe maternal CPA that commenced prior to age 12, even after adjusting for other types of adversity and demographic confounders. However, a dose-response effect was not established.

2.2.4 Aims and hypotheses

The presence of PE in BPD is clearly established yet understanding of their development is limited. This has clinical implications, particularly given the potential for these experiences to be severe, persistent, and distressing. Given the strong links between childhood adversity and PE in other populations, this study aimed to explore the relationship between specific adverse childhood experiences and PE in individuals with BPD. In particular, it sought to understand whether the frequency, type, or timing of childhood adversity is associated with the frequency of PE in this population. The study also aimed to establish if any associations found are specific to BPD or whether the same associations might be found in the general population. Based on the existing literature, it was hypothesised that:

1. Individuals who screened positive for BPD would have experienced more childhood adversity compared to those who screened negative.
2. Individuals who screened positive for BPD would have experienced more PE compared to those who screened negative.

3. Individuals who have experienced more childhood adversity would have experienced more PE compared to those with fewer adversities, independent of the presence of BPD.

4. As there was insufficient literature to hypothesize which adversity types would have the most influence and whether this would be dependent on the presence of BPD, the relationship between adversity type and PE was conducted as an exploratory analysis.

5. Individuals who have experienced earlier-onset adversity would experience more PE compared to those with later-onset, independent of the presence of BPD.

6. Any significant findings would persist after controlling for key alternative explanations, namely substance use, mood (e.g. Bipolar Disorder) or trauma disorders (e.g. PTSD), and dissociation (Gibson et al., 2016).

2.3 Method

2.3.1 Overview

This cross-sectional study involved administering a selection of internet based questionnaires relating to BPD symptomology, childhood adversity, PE, and demographic variables to a sample of individuals from clinical and non-clinical populations. Both a BPD and a non-BPD sample were recruited. Group allocation was determined by participant scores on a BPD screening measure.

2.3.2 Participants

Setting: This study was web-based to increase accessibility and provide a broader range of presentation severity. Participants were invited to complete four self-report measures through a Patient Outcome Database (POD), accessed via a website accessible on computers, smart phones, or tablets. POD was specifically designed for the ease and accuracy of large scale research data collection. No personally identifiable information was collected through POD in the hope of increasing participant anonymity and therefore willingness to participate.

Eligibility criteria: Participants were eligible if they self-reported being over 18 years, able to read English, and willing to provide informed consent. Participants were excluded if they self-reported a current diagnosis of schizophrenia or schizoaffective disorder, dementia, or an organic brain disorder. These criteria were set to enable the exploration of PE in the absence of clear psychotic disorder and to remove any undue influences over participants' capacity to consent or comprehend the questionnaires.

Recruitment: Participants were recruited using opportunity and snowball sampling methods. Various methods were used to facilitate recruitment of individuals at high and low risk of BPD.

Recruitment primarily involved advertising the study webpage (www.psychologyresearch2016.com) through social media forums, particularly Facebook and Twitter. For recruitment into the BPD sample, BPD-related social media accounts were targeted, for example BPD or mental health information or support groups and charities (e.g. BPD world, Emergence Plus, MIND). The study was also promoted on multiple online research recruitment platforms (e.g. 'Call for

Participants’, ‘FindParticipants’, ‘Psychology research on the net’, ‘The Inquisitive Mind’). Flyers and posters, which provided an overview of the study and the study webpage (Appendix D), were also circulated throughout the UCL campus and in public places, primarily coffee shops. To target individuals with BPD, these materials were circulated to personality disorder services, psychology departments, and other mental health services across North East London NHS Foundation Trust (NELFT), as well as charitable or support organisations. A covering letter/email (Appendix E) was accompanied by a ‘Staff & Clinicians Information sheet’ providing additional study details (Appendix F). Requests were made for flyers or posters to be suitably distributed to service users who met the study criteria. The lead researcher was also available to attend sites to support recruitment at team meetings; however no service requested a presentation.

All recruitment information specified that the study was open to individuals with and without BPD and with a range of the experiences mentioned. This was designed to capture individuals with varying severity of BPD symptomology and PE. Postal questionnaires were also offered, however no individual requested this method. There was no direct contact between the research team and potential participants, unless participants initiated contact for the purpose of clarification (four individuals requested to participate and two enquired about the study’s results) or feedback (two individuals provided feedback on the questionnaires).

Sample size: A power analysis was conducted using G*Power3.1 (Faul, Erdfelder, Buchner, & Lang, 2009) based on prior work by Fisher and colleagues (2010) given the similarity of the research questions and the absence of research within this area in BPD. Their main effect equated to a medium to large effect. To be more conservative, a medium effect size was used for the power calculation. A conventional

alpha level was set at .05 and desired power at 80%. The largest overall sample size needed was N=159 for the comparative BPD and non-BPD analyses and N=260 for overall analyses.

2.3.3 Measures

1. *Mclean Screening Instrument for Borderline Personality Disorder (MSI-BPD)* (Appendix G): The MSI-BPD is a ten item, true or false, self-report screening instrument for DSM-IV BPD (Zanarini et al., 2003). The questionnaire covers the nine DSM-IV diagnostic criteria, which remain unchanged in the DSM-5, with two items assessing the ninth criterion, paranoia/dissociation (APA, 1994; 2013). The measure demonstrates good internal consistency (Cronbach's α coefficient=0.73-0.86) and test-retest reliability (Spearman's ρ =0.72, $p < 0.0001$) and is valid for use in inpatient and community populations (Gardner & Qualter, 2009; Noblin, Venta, & Sharp, 2014; Patel, Sharp, & Fonagy, 2011). The authors recommend a cut-off of seven or more as this yields good sensitivity (.81) and specificity (.85) for DSM-IV BPD. This cut-off was used to allocate participants to the BPD or non-BPD samples.

2. *Childhood Experiences of Care and Abuse Questionnaire (CECA-Q)* (Appendix H): The CECA-Q is a brief self-report version of the full CECA interview (Bifulco, Brown, & Harris, 1994) which it is validated against (Bifulco et al., 2005). It collects self-reported retrospective information regarding childhood experiences prior to 17 years. It shows acceptable sensitivity (.73) and specificity (.78) against the interview measure. It has also been shown to have good internal consistency (α =.80-0.92) and satisfactory levels of test-retest reliability (r =0.51-0.84) in depressed, psychotic, and community samples (Bifulco et al., 2005; Smith, Lam, Bifulco, & Checkley, 2003). It is significantly associated with the Parental Bonding Instrument

($r=2.61-2.78$) and the Childhood Trauma Questionnaire (Fisher, Barber, & Morgan, under review) with a wider coverage of maltreatment (Smith et al., 2003). Given limitations related to composite measures or those focusing on one or two forms of abuse (Fisher et al., 2010), the CECA-Q was chosen due to the level of detail it provides.

To minimise participant burden (time-efficiency and emotional impact) only the specific subscales which have strong rationale for exploration based on the literature were administered. The administered subscales related to lack of care (neglect, antipathy, and psychological abuse) and physical abuse from either parental figure (figure lived with for the longest or had the most difficulties with) and sexual abuse from any individual five years older than the recipient. Removed subscales include parental loss, lack of a support figure, significant changes in living arrangements, and role reversal.

There were eight antipathy and eight neglect items rated on a five-point scale from 'yes, definitely' to 'no, not at all'. Antipathy relates to hostility, irritation, rejection, and 'scapegoating' behaviour. Neglect relates to a distinct lack of interest in the child's well-being or care, or being emotionally unavailable. For the physical and sexual abuse sections, initial screening questions were followed by more detailed questioning. The four physical abuse items enquired about frequency, use of weapons, and injuries. The seven sexual abuse items enquired about frequency, relationship to perpetrator, and intrusiveness of sexual contact. Participants were also asked about the age at which this physical and/or sexual abuse occurred. For each of these scales, published cut-offs were available to determine the presence of severe adversity.

The original CECA-Q was updated to incorporate the 17-item psychological abuse scale. Given its later addition, the original psychometric information does not apply and equivalent published cut-off scores were not available. The concept of psychological abuse is also reported to overlap with antipathy (Bernstein & Fink, 1998). Therefore, the more validated scale of antipathy was prioritised in the main analysis to represent emotional abuse and the available psychological abuse data was used to provide novel information regarding its reliability.

3. *Community Assessment of Psychic Experiences (CAPE) (Appendix I)*: The CAPE is a self-report questionnaire, modified from the ‘Peters et al. Delusions Inventory’ (Peters, Joseph, Day, & Garety, 2004; Stefanis et al., 2002). It has been extensively used as a measure of PE in clinical and research settings, particularly general population samples (Mark & Toulopoulou, 2016). It has also recently been used with a BPD population (Chanen et al., 2014). A recent meta-analysis found the CAPE to be psychometrically reliable ($\alpha=0.91$) (Mark & Toulopoulou, 2016). It contains 42 items covering frequency and distress across three symptom dimensions: 20 positive items, 14 negative items, and eight depressive items. The CAPE provides an overall score and a score per dimension. The former was chosen to provide a broader assessment of PE. To reduce participant burden, only the frequency scale was administered as this was sufficient for the overall score.

4. *Demographic Information (Appendix J)*: This questionnaire was designed for the purpose of this study. It included variables such as age, gender (an ‘other’ category was added following a participant’s feedback), ethnicity, education, occupational status, current diagnoses, substance use, mental health treatment, and route into the study.

2.3.4 Ethical considerations

Ethical approval was obtained from the National Research Ethics Committee London–Camberwell St Giles on 20th June 2016 (Appendix K). Multi-site ethical permission to advertise across NELFT NHS sites was obtained and local R&D procedures were completed. The study complied with University College London (UCL) Data Protection Act and indemnity was granted through UCL insurance.

Permissions to use the questionnaires as part of this study were granted by their lead authors. As the questionnaires were not diagnostic in nature, participants were told they should seek professional assessment if they had questions regarding diagnoses. The questionnaires did not relate to immediate risk; however participants were clearly alerted to the sensitive nature of the study in the Participant Information Sheet (Appendix L), presented prior to participants consenting. Participants were advised to complete the study in a comfortable setting when not distressed. A help sheet, providing emotional regulation exercises, contact numbers, and distress advice, was available to participants throughout and was presented as debrief information (Appendix M).

2.3.5 Service user consultation

A service user forum was held at IMPART Personality Disorder service to consult about the research rationale and content. The recipients fed back that it was an important area of study and that mental health staff were often less able or confident about supporting individuals with both PE and personality disorder. They also reported being familiar with answering questions about childhood experiences and did not

express particular concern about the issue of potential participant distress, as answering online was less distressing or shaming than in person.

2.3.6 Procedure

Recruitment was open from 25th July 2016 to 15th March 2017. Participants self-identified to the study by first accessing the study webpage, which briefly overviewed the study, and then click on the ‘start survey’ link which directed them to the POD system. The first POD page contained the Participant Information Sheet (Appendix L), which clearly outlined what the study involved and the eligibility criteria. Participants were informed that they were free to withdraw at any time by exiting the survey but due to anonymity this would not be possible once the final questionnaire was submitted. At the end, a series of bulleted statements clearly outlined that by clicking ‘next’ participants were confirming that they had read and agreed with the information sheet; met all eligibility criteria; and were consenting to participate. If participants were unwilling to provide consent, or did not wish to participate, they could click ‘exit’. The electronic questionnaires were then presented in the order outlined above. After clicking ‘next’ on the final demographic questionnaire, data was submitted to the study and assigned to a unique identification number. The questionnaires had to be completed in one sitting as there was no means to store partially completed questionnaires for participants to return to later.

As incentive to participate, all potential participants were advised that £1 would be donated to the National Society for the Prevention of Cruelty to Children (NSPCC) per completed survey, with a maximum cap at £260. This was chosen over participant payment to preserve anonymity and to support recruitment of a larger sample.

Participants were also informed that a summary of the results would be published on the study webpage when available.

2.3.7 Data analysis

Data was retrieved from the POD system into an Excel spreadsheet and was imported to SPSS 24.0 (IBM, 2016) for analysis. All data was checked and scores were calculated. The overall CAPE score was calculated by summing each item score. For the CECA-Q, as recommended by Bifulco and colleagues (2005) and in line with Fisher and colleagues (2010), the most conservative cut-off points were utilised to dichotomise responses into severe adversity ‘present’ or ‘absent’ to represent presence of different adversity types (Table 1). This ensured that the analyses more accurately related to the presence of adversity as opposed to milder or unclear interactions. For the antipathy, neglect, and physical abuse scales, scores were calculated for mother and father figures separately. For the sexual abuse scale, scores were based on whether the cut-off was established for either the first or second experience. For adversity frequency, the number of adversities meeting threshold were summed (range 0-7) and recoded into ‘no adversity’, ‘single adversity’, and ‘multiple adversity’. For timing of adversity, in line with Fisher and colleagues (2010) and common conventions (Thornberry, Ireland, & Smith, 2001; Widom, Czaja, & Dutton, 2008), the reported age of the first severe sexual or physical abuse was categorised into ‘childhood’ (0-11 years) or ‘adolescence’ (12-16 years).

Table 1**CECA-Q cut-offs used to establish the presence of each adversity**

Scale	No. of items	Score range	Cut-off*
Antipathy mother	8	1 – 40	> = 28
Antipathy father	8	1 – 40	> = 30
Neglect mother	8	1 – 40	> = 25
Neglect father	8	1 – 40	> = 26
Physical abuse mother	4	0 – 4	> = 3
Physical abuse father	4	0 – 4	> = 3
Sexual abuse severity	7	0 – 7	> = 2

**Published cut-offs provided by Bifulco et al. (2005)*

The dataset was first analysed for missing items and necessary parametric testing assumptions. The hypotheses were then tested using chi-square tests, t-tests, and ANOVAs for the BPD and non-BPD sample separately. Any disparities between the samples were explored using a Factorial ANOVA on the overall sample with BPD group as a between-group factor, to examine if the BPD group interactions were significant (Gelman & Stern, 2006; Nieuwenhuis, Forstmann, & Wagenmakers, 2011). The assumption of homogeneity of variance was assessed where relevant using the Levene’s test (Levene, 1960). The analyses which highlighted significant effects were also run incorporating the potential confounding factors of self-reported substance use (cannabis, hallucinogens, opioids, sedatives/hypnotics/anxiolytics, or stimulants) (‘present’, ‘absent’) and co-morbid Bipolar Disorder, Trauma Disorder, or Dissociative Identity Disorder (DID) (‘present’, ‘absent’). To account for multiple testing per hypotheses, a Bonferroni correction was applied by dividing the conventional significance threshold ($p=0.05$) by the number of factors considered. For frequency this was $p<0.017$ (three factors: none, single, multiple); for type $p<0.007$

(seven types of adversity); and for timing $p < 0.025$ (two factors: childhood, adolescence). The psychological abuse scale was also examined for reliability as psychometric evaluation data has yet to be made available.

2.4 Results

2.4.1 Sample characteristics

Participants: Overall 509 participants began the study, however only 376 completed and submitted their surveys, resulting in a 26% attrition rate. For those with available data, frequency of individuals screening positive for BPD did not significantly differ between those who dropped out (42%, $N=55$) and those who completed the survey (48%, $N=180$) ($X^2(1)=1.203$, $p=0.273$). As the demographic questionnaire was presented last, after these participants had dropped out, demographic comparisons were not possible. A further two participants were excluded as they self-reported a diagnosis of Schizophrenia or Schizoaffective disorder. This resulted in 374 data sets being available for analysis, including 178 (48%) individuals who screened positive for BPD and 196 non-BPD controls (52%).

Demographic Information: Chi-square tests were used to explore differences between available demographic data across the two samples, as shown in Table 2.

Table 2**Demographic information, including chi-squared tests of difference between BPD and non-BPD samples**

Characteristic	Positive screen for BPD: N = 178 N (%*)	Negative screen for BPD: N = 196 N (%*)	X²	df	p
Gender					
Male	26 (14.9%)	42 (21.9%)	11.280	2	0.004
Female	141 (80.6%)	150 (78.1%)			
Other	8 (4.6%)	0 (-)			
Missing	3 (-)	4 (-)			
Age					
18 to 24 years	75 (42.6%)	61 (31.4%)	20.613	5	0.001
25 to 34 years	55 (31.3%)	83 (42.8%)			
35 to 44 years	28 (15.9%)	25 (12.9%)			
45 to 54 years	17 (9.7%)	10 (5.2%)			
55 to 64 years	1 (0.6%)	11 (5.7%)			
65 years or over	0 (-)	4 (2.1%)			
Missing	2 (-)	2 (-)			
Ethnicity					
British White	114 (64.8%)	126 (64.9%)	8.179	5	0.147
British Asian	3 (1.7%)	6 (3.1%)			
British Black	1 (0.6%)	5 (2.6%)			
British Mixed/ Multiple Ethnicity	7 (4.0%)	1 (0.5%)			
Any other ethnic group e.g. non-British	44 (25.0%)	49 (25.3%)			
Did not disclose	7 (4.0%)	7 (3.6%)			
Missing	2 (-)	2 (-)			
Education					
Less than high school	8 (4.5%)	4 (2.1%)	21.211	6	0.002
High school graduate (GCSEs)	50 (28.4%)	38 (19.6%)			
Completed college or sixth form (A-levels)	33 (18.8%)	23 (11.9%)			
Specialist qualification (NVQ, BTECH)	18 (10.2%)	16 (8.2%)			
University degree	37 (21.0%)	46 (23.7%)			
Postgraduate	26 (14.8%)	64 (33.0%)			
Did not disclose	4 (2.3%)	3 (1.5%)			
Missing	2 (-)	2 (-)			
Marital Status					

Single	68 (38.6%)	73 (37.6%)	2.388	7	0.935
In a relationship, not living with partner	26 (14.8%)	31 (16.0%)			
Living with partner	37 (21.0%)	43 (22.2%)			
Married	35 (19.9%)	33 (17.0%)			
Separated	2 (1.1%)	3 (1.5%)			
Widowed	1 (0.6%)	2 (1.0%)			
Divorced	6 (3.4%)	9 (4.6%)			
Did not disclose	1 (0.6%)	0 (-)			
Missing	2 (-)	2 (-)			
Employment					
Student	57 (32.4%)	57 (29.5%)	30.236	7	<0.001
Unemployed and not looking for work	26 (14.8%)	9 (4.7%)			
Unemployed and looking for work	9 (5.1%)	9 (4.7%)			
Employed part time	21 (11.9%)	16 (8.3%)			
Employed full time	51 (29.0%)	92 (47.7%)			
Home maker	7 (4.0%)	3 (1.6%)			
Retired	0 (-)	6 (3.1%)			
Did not disclose	5 (2.8%)	1 (0.5%)			
Missing	2 (-)	3 (-)			
Clinical status					
In treatment	86 (49.4%)	40 (20.9%)	32.679	1	<0.001
Missing	4 (-)	5 (-)			
Mental disorder	151 (85.8%)	79 (40.5%)	80.508	1	<0.001
Missing	2 (-)	1 (-)			
BPD	99 (56.3%)	9 (4.6%)	119.52	1	<0.001
Missing	2 (-)	1 (-)			
Source					
Mental health charity	5 (2.9%)	2 (1.0%)	12.406	5	0.030
NHS staff	6 (3.4%)	6 (3.1%)			
Social media	77 (44.3%)	69 (35.9%)			
Flyer in public space	2 (1.1%)	2 (1.0%)			
Friend or relative	20 (11.5%)	48 (25.0%)			
Other	64 (36.8%)	65 (33.9%)			
Missing	4 (-)	4 (-)			

* Valid percentage taking into account missing data

Females were over represented within both groups. Only the BPD sample endorsed ‘other’ genders (6 non-binary, 1 agender, 1 transgender male), leading to a significant difference between samples, which was no longer present with male and female only ($X^2=2.313$, $df=1$, $p=0.128$). Younger age groups were more common overall and there were a notable number of students across both samples. Older age ranges and higher educational status were more common in the non-BPD sample, whereas more participants were unemployed not looking for work in the BPD sample. A large proportion of both samples were White British and participants were most commonly single. The BPD sample self-reported more mental health diagnoses, including BPD, and current mental health treatment. Participants most commonly heard about the study through social media, closely followed by “other”. Social media was comparatively more common in the BPD sample and word of mouth in the non-BPD sample.

2.4.2 Preliminarily analyses

Missing data: Missing items were identified in the antipathy and neglect variables. Eight individuals (BPD $N=5$; non-BPD $N=3$) reported no father figure, meaning all paternal antipathy and neglect responses were missing. A further 30 cases (8.2%) (BPD $N=9/5.05\%$, non-BPD $N=21/10.71\%$) had at least one item missing. The highest percentage of missing values within an item was 4%, with most items containing only 1% of values missing. Little’s MCAR test confirmed that these values were missing at random and there was no monotonicity present in the data overall [$\chi^2(428)=453.38$, $p=0.192$] and within the BPD [$\chi^2(61)=75.89$, $p=0.095$] and non-BPD samples [$\chi^2(232)=257.382$, $p=0.121$].

With these cases removed, 164 BPD and 172 non-BPD individuals remained. Analyses involving the antipathy and neglect variables (frequency and type) were run using the reduced dataset. To retain valuable data and increase the statistical power, the full dataset was used for the remaining analyses. An independent sample t-test and chi square tests confirmed that those with and without missing data did not significantly differ in terms of CAPE scores, the remaining CECA-Q variables, and the demographic variables, apart from age. Within the BPD sample, more individuals in the older age ranges (45-54 and 55-64 years) were excluded due to missing data [$\chi^2(4)=19.894, p=0.001$] increasing the noted discrepancy between samples.

Normality assumptions: The Kolmogorov-Smirnov test of normality indicated that CAPE scores for the BPD sample were normally distributed for both the full [$D(178)=0.039, p=0.200$] and reduced datasets [$D(164)=0.042, p=0.200$]. However for the non-BPD sample the distribution significantly differed from normality with a positive skew for both the full [$D(196)=0.115, p<0.001; zSkew=6.65; zKurt=6.04$] and reduced dataset [$D(172)=0.116, p<0.001; zSkew=6.48; zKurt=5.81$], as shown in Figure 1 and 2 respectively.

Figure 1

Distribution of CAPE scores in the non-BPD full dataset (N=196)

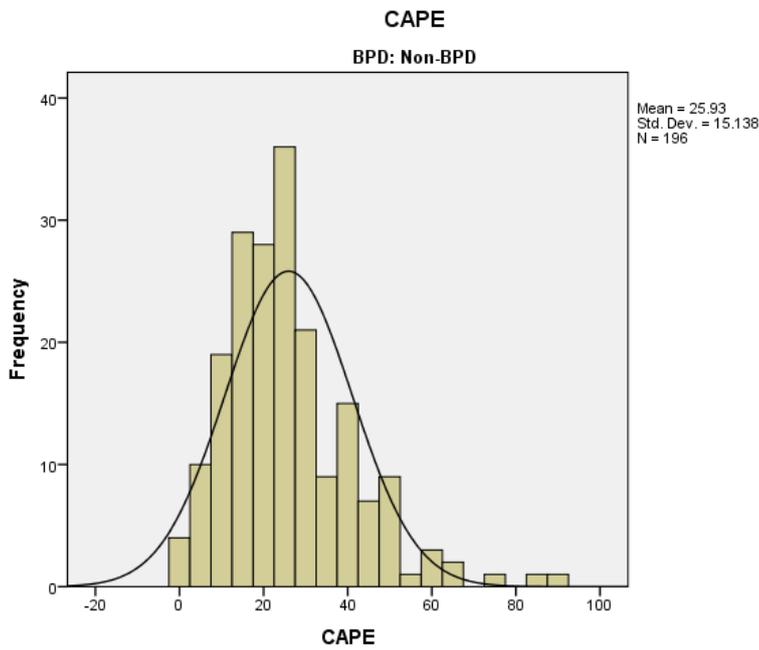
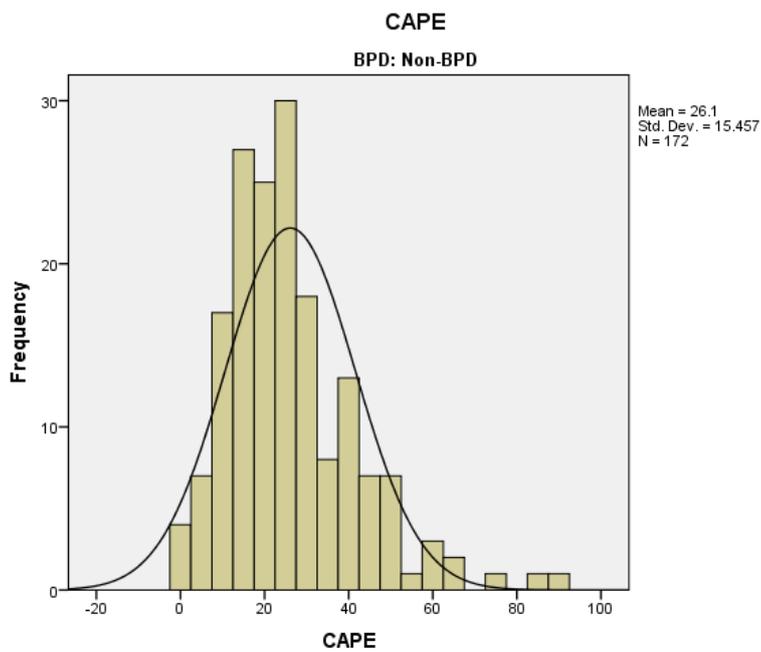


Figure 2

Distribution of CAPE scores in the non-BPD reduced dataset, with individuals with missing data removed (N=172)



Outlier analysis indicated the same three deviant scores across both the full and reduced dataset respectively of 75 ($z=3.24$; $z=3.16$), 83 ($z=3.77$; $z=3.68$) and 88 ($z=4.10$; $z=4.00$). Windorising was first attempted, replacing outlier scores by adding one incrementally to the next highest score of 66 (Field, 2013). The significant positive skew remained for both the full [$D(172)=0.107$, $p<0.001$; $ZSkew=4.79$, $ZKurt=1.69$] and reduced datasets [$D(172)=0.108$, $p<0.001$; $ZSkew=4.67$, $ZKurt=1.65$]. A square root transformation was then applied to the original data, which successfully removed the deviation in both the full [$D(196)=0.056$, $p=0.200$; $ZSkew=-0.66$, $ZKurt=3.06$] and reduced dataset [$D(172)=0.059$, $p=0.200$; $ZSkew=-0.57$, $ZKurt=3.12$], as shown in Figure 3 and 4 respectively. The transformed CAPE scores were used in the analyses involving the non-BPD sample.

Figure 3

Distribution of square root transformed CAPE scores in the non-BPD full dataset (N=196)

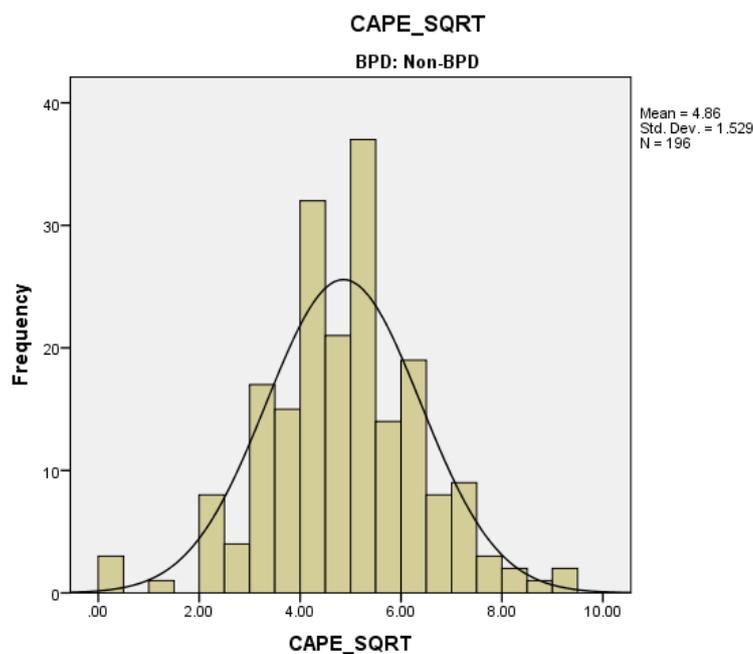
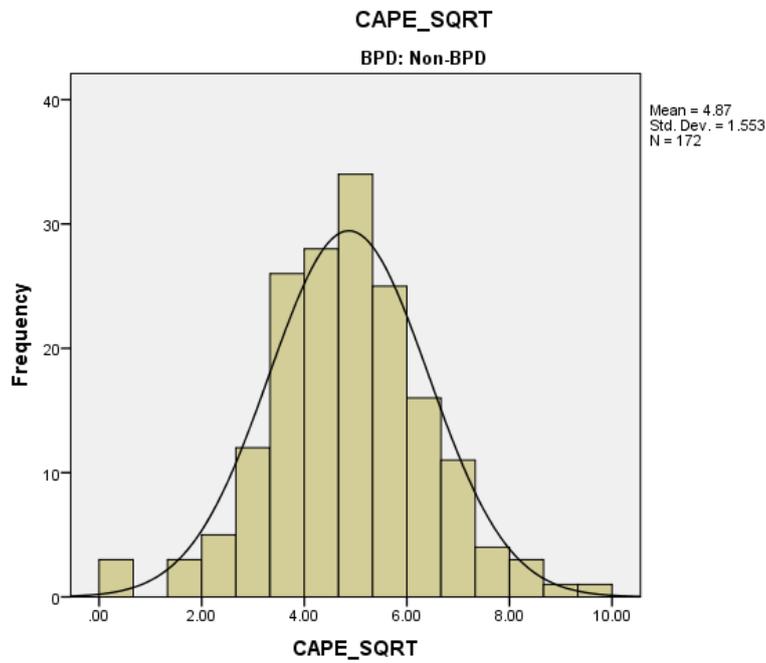


Figure 4

Distribution of square root transformed CAPE scores in the non-BPD reduced dataset, with individuals with missing data removed (N=172)



2.4.3 Hypothesis 1: Individuals who screened positive for BPD would have experienced higher rates of childhood adversity.

As shown in Table 3, the BPD sample reported significantly higher rates of each type of adversity compared to individuals in the non-BPD sample.

Table 3

Differences between the presence of each adversity type across the BPD and non-BPD samples for the full dataset (N=374)

Adversity Type	Positive screen for BPD: n/N (%)	Negative screen for BPD: n/N (%)	X²	df	p	Phi ϕ
Antipathy: Mother	64/174 (36.78%)	28/188 (14.89%)	22.839	1	<0.001**	0.251
Antipathy: Father	61/168 (36.31%)	20/188 (10.64%)	33.265	1	<0.001**	0.306
Neglect: Mother	34/174 (19.54%)	17/188 (9.04%)	8.228	1	0.004**	0.151
Neglect: Father	71/173 (41.04%)	27/189 (14.29%)	32.748	1	<0.001**	0.301
Physical: Mother	33/178 (18.54%)	10/196 (5.10%)	16.553	1	<0.001**	0.210
Physical: Father	41/178 (23.03%)	18/196 (9.18%)	13.467	1	<0.001**	0.190
Sexual Abuse	99/178 (55.62%)	43/196 (21.94%)	44.926	1	<0.001**	0.347

*Notes: * Significant at conventional $p < 0.05$ level; ** Significant at Bonferroni adjusted $p < 0.007$; ϕ : small effect = 0.1; medium effect = 0.3; large effect = 0.5*

2.4.4 Hypothesis 2: Individuals who screened positive for BPD would have experienced more PE.

Individuals in the BPD sample (M=57.38, SD=19.41) reported significantly higher levels of PE on the CAPE compared to the individuals in the non-BPD sample with a large effect (M=25.93, SD=15.14) [$t(372) = -17.564$, $p < 0.001$, Cohen (1988) $d = 1.825$]. The equality of variances assumption was met [$F = 1.393$, $p = 0.239$]. Individuals in the BPD sample also reported significantly higher levels of each of the subscales (positive, negative and depressive) with large effects, as shown in Table 4. The weighted mean score and average endorsement rates were also calculated to enable comparison with general population literature, which are also shown in Table 4. Endorsement rates by each item are provided in Appendix N.

Table 4

CAPE total score and separate dimension scores

Scale	Literature estimate Weighted Mean (SD)	Positive screen for BPD (N=178)				Negative screen for BPD (N=196)				Group Difference		
		Mean (SD)	Weighted Mean (SD)	Mean endorsement N (%)		Mean (SD)	Weighted Mean (SD)	Mean endorsement N (%)		U**	p	r
				Any frequency*	Nearly always			Any frequency*	Nearly always			
Total score	1.73 (0.36) ¹	57.38 (19.41)	2.37 (0.46)	130 (72.82%)	36 (20.24%)	25.93 (15.14)	1.62 (0.36)	88 (45.08%)	6 (3.15%)	-	-	-
Positive	1.6 (0.3) ²	18.47 (11.00)	1.92 (0.55)	97 (54.69%)	19 (10.70%)	7.22 (6.53)	1.36 (0.33)	53 (26.94%)	3 (1.53%)	5909.50	<0.001	0.57
Negative	1.8 (0.4) ²	22.36 (7.63)	2.60 (0.55)	153 (85.71%)	41 (22.87%)	11.06 (6.83)	1.79 (0.49)	112 (57.29%)	9 (4.63%)	4749.00	<0.001	0.71
Depressive	2.0 (0.4) ²	16.55 (4.58)	3.07 (0.57)	170 (95.58%)	70 (39.47%)	7.65 (4.24)	1.96 (0.53)	135 (69.07%)	9 (4.59%)	3034.00	<0.001	0.63

Notes: *Any frequency = sometimes, often or nearly always; 1: Daneluzzo et al. (2009); 2: Brenner et al. (2007); ** In the BPD group, the Kolmogorov-Smirnov test of normality indicated that the Positive [D(178)=0.111, p<0.001; zSkew=3.91; zKurt=-0.44] and Depressive [D(178)=0.106, p<0.001; zSkew=-2.25; zKurt=-1.74] scales significantly differed from normality. In the non-BPD group the Positive [D(196)=0.136, p<0.001; zSkew=11.45; zKurt=16.86], Negative [D(196)=0.118, p<0.001; zSkew=4.80; zKurt=-1.49], and Depressive [D(196)=0.107, p<0.001; zSkew=5.22; zKurt=4.14] scales all significantly differed from normality. As square root or log transformations were not able to correct these violations, the non-parametric Mann-Whitney U test was utilised to compare mean scores. r: small effect=0.1; medium effect=0.3; large effect =0.5

2.4.5 Hypothesis 3: Across both samples, individuals with more childhood adversity would experience more PE.

The frequencies of individuals reporting no, single, or multiple adversities across the reduced datasets, and corresponding CAPE scores, are reported in Table 5. A Chi Square test indicated that these frequencies significantly differed between the BPD and non-BPD samples with a medium effect [$X^2(2)=58.133$, $p<0.001$, $\phi=0.416$]. The BPD sample reported fewer incidences of no adversity, more incidences of multiple adversities, but a similar frequency of single adversity.

Table 5

Frequency and mean CAPE scores of individuals reporting different frequencies of adversity across the BPD and non-BPD samples

Adversity Level	Positive screen for BPD (N=164)			Negative screen for BPD (N=172)		
	N (%)	CAPE		N (%)	CAPE	
		Mean (SE)	95% CI		Mean (SE)	95% CI
None	32 (19.51%)	48.94 (2.95)	42.92, 54.95	99 (57.56%)	22.40 (1.42)	19.58, 25.23
Single	46 (28.05%)	53.30 (2.60)	48.07, 58.54	40 (23.26%)	28.78 (2.59)	23.53, 34.02
Multiple	86 (52.44%)	62.01 (2.11)	57.82, 66.20	33 (19.19%)	33.94 (2.59)	28.66, 39.22

To assess whether PE scores differed significantly across the adversity frequencies, one-way independent samples ANOVAs were conducted. The homogeneity of variance assumption was met in both the BPD [$F(2,161)=0.369$, $p=0.692$] and non-BPD [$F(2,169)=0.244$, $p=0.784$] samples.

Within the BPD sample, there was a significant main effect of adversity frequency with a medium to large effect [$F(2,161)=7.12$, $p=0.001$, $\eta^2=0.081$].

Bonferroni adjusted pairwise comparisons indicated that individuals who reported multiple adversities reported significantly more PE compared to those who reported a single adversity and no adversity. PE did not differ significantly between single and no adversity.

Within the non-BPD sample there was also a significant main effect of adversity frequency with a medium to large effect [$F(2,169)=8.47$, $p<0.001$, $\eta^2=0.091$]. Similar to BPD, Bonferroni adjusted pairwise comparisons showed that those who reported multiple adversities reported significantly more PE than those who reported no adversity. In contrast to BPD, those reporting a single adversity did report significantly higher PE compared to those reporting no adversity; however they did not report significantly lower PE compared to those reporting multiple adversities. The post hoc significance levels are summarised in Table 6.

Table 6

Significance levels of the Bonferroni adjusted pairwise comparisons between adversity frequency categories across the BPD and non-BPD samples.

Category difference	p value	
	Positive screen for BPD	Negative screen for BPD
None-Single	0.919	0.046*
Single-Multiple	0.032*	0.551
None-Multiple	0.002*	0.001*

*Notes: * Bonferroni adjusted significance at $p<0.05$ level*

To examine whether these variations were significant, a 3x2 independent factorial ANOVA was conducted on the overall sample with BPD (BPD, non-BPD) as an interactor. The homogeneity of variance assumption was met [$F(5,330)=0.317$,

$p=0.903$]. The significant main effect of adversity frequency was present with a small to medium effect [$F(2,330)=49.70$, $p<0.001$, $\eta^2=0.049$]. The interaction between adversity frequency and BPD was not significant [$F(3,330)=1.68$, $p=0.645$].

2.4.6 Exploratory analysis 4: There was insufficient literature to determine which adversity types would have most influence and if this would be specific to BPD.

The frequencies of individuals reporting each type of adversity in the reduced datasets and corresponding mean CAPE scores are reported in Table 7. There were high levels of asymmetry across the group sizes, particularly within the non-BPD sample, with a particularly small group size for presence of maternal physical abuse ($N=7$). In light of these discrepancies, the following analyses should be interpreted with caution.

Table 7**Frequency of individuals reporting different adversity types and mean CAPE scores across the BPD and non-BPD samples**

Adversity Type	Positive screen for BPD (N=164)			Negative screen for BPD (N=172)			Overall sample (N=336)		
	N (%)	CAPE		N (%)	CAPE		N (%)	CAPE	
		Mean (SE)	95% CI		Mean (SE)	95% CI		Mean (SE)	95% CI
Antipathy – Mother									
<i>Not present</i>	106 (64.63%)	54.56 (1.79)	51.05, 58.06	149 (86.63%)	25.01 (1.24)	22.59, 27.43	255 (75.89%)	37.29 (1.38)	34.59, 39.99
<i>Present</i>	58 (35.37%)	61.52 (2.61)	56.40, 66.64	23 (13.37%)	33.17 (3.41)	26.50, 39.85	81 (24.11%)	53.47 (2.54)	48.50, 58.44
Antipathy – Father									
<i>Not present</i>	105 (64.02%)	53.13 (1.80)	49.60, 56.67	152 (88.37%)	25.32 (1.26)	22.85, 27.79	257 (76.49%)	36.68 (1.35)	34.04, 39.33
<i>Present</i>	59 (35.98%)	63.93 (2.42)	59.19, 68.68	20 (11.63%)	32.00 (3.09)	25.95, 38.05	79 (23.51%)	55.85 (2.51)	50.92, 60.77
Neglect – Mother									
<i>Not present</i>	132 (80.49%)	56.02 (1.70)	52.70, 59.35	156 (90.70%)	25.65 (1.26)	23.18, 28.13	288 (85.71%)	39.57 (1.37)	36.89, 42.25
<i>Present</i>	32 (19.51%)	61.13 (3.09)	55.07, 67.18	16 (9.30%)	30.44 (2.82)	24.92, 35.96	48 (14.29%)	50.90 (3.08)	44.86, 56.93
Neglect – Father									
<i>Not present</i>	98 (59.76%)	52.70 (1.91)	48.97, 56.44	147 (85.47%)	24.04 (1.19)	21.71, 26.38	245 (72.92%)	35.51 (1.38)	32.81, 38.20
<i>Present</i>	66 (40.24%)	63.42 (2.21)	59.10, 67.75	25 (14.53%)	38.20 (3.19)	31.94, 44.46	91 (27.08)	56.49 (2.17)	52.24, 60.75

Physical – Mother

<i>Not present</i>	136 (82.93%)	56.27 (1.58)	53.17, 59.37	165 (95.93%)	25.77 (1.20)	23.42, 28.12	301 (89.58%)	39.55 (1.31)	36.99, 42.11
<i>Present</i>	28 (17.07%)	60.64 (4.23)	52.36, 68.93	7 (4.07%)	33.86 (6.11)	21.89, 45.83	35 (10.42%)	55.29 (4.01)	47.44, 63.14

Physical – Father

<i>Not present</i>	126 (76.83%)	54.88 (1.68)	51.58, 58.18	154 (89.53%)	25.84 (1.27)	23.35, 28.33	280 (83.33%)	38.91 (1.34)	36.28, 41.54
<i>Present</i>	38 (23.17%)	64.11 (3.03)	58.17, 70.04	18 (10.47%)	28.28 (2.98)	22.45, 34.11	56 (16.67%)	52.59 (3.19)	46.34, 58.83

Sexual Abuse

<i>Not present</i>	76 (46.34%)	51.01 (1.93)	47.23, 54.80	134 (77.91%)	25.19 (1.33)	22.59, 27.79	210 (62.5%)	34.53 (1.39)	31.81, 37.26
<i>Present</i>	88 (53.66%)	62.20 (2.09)	58.10, 66.31	38 (22.09%)	29.32 (2.53)	24.36, 34.27	126 (37.5%)	52.29 (2.13)	48.12, 56.45

To examine whether the presence of each adversity type led to significantly higher PE, independent samples t-tests were conducted. The homogeneity of variance assumption was met for each t-test. The results are presented in Table 8.

Table 8

Mean CAPE score difference across different adversity types by BPD and non-BPD sample

Adversity Type	Positive screen for BPD (N=164)				Negative screen for BPD (N=172)			
	t	df	p	d	t	df	p	d
Antipathy								
Mother	-2.251	162	0.026*	0.365	-2.175	170	0.031*	0.467
Father	-3.586	162	<0.001**	0.583	-1.765	170	0.079	-
Neglect								
Mother	-1.354	162	0.178	-	-1.497	170	0.136	-
Father	-3.641	162	<0.001**	0.583	-4.349	170	<0.001**	1.000
Physical								
Mother	-1.099	162	0.273	-	-1.419	170	0.158	-
Father	-2.647	162	0.009*	0.492	-0.943	170	0.347	-
Sexual	-3.886	162	<0.001**	0.612	-1.492	170	0.138	-

Notes: *Significant at conventional $p < 0.05$ level; **Significant at Bonferroni adjusted $p < 0.007$; d: small effect=0.2; medium effect=0.5; large effect =0.8

Within the BPD sample, mean CAPE scores were significantly higher when paternal antipathy and neglect and sexual abuse (anyone) were present and showed a similar trend for paternal physical abuse, all with medium to large effects. Within the non-BPD sample, mean CAPE scores were significantly higher for paternal neglect with a large effect. Maternal antipathy met significance at conventional thresholds for both samples with small to medium effects.

To examine whether these effects still remained after adjusting for the other forms of adversity, independent factorial ANOVAs analysing the main effects of each adversity type (2x2x2x2x2x2x2) were conducted. The homogeneity of variance assumption was met in both the BPD [$F(53,110)=1.215$, $p=0.195$] and non-BPD [$F(30,141)=0.955$, $p=0.540$] samples. The results are presented in Table 9.

Table 9

Mean CAPE score difference across different adversity types when other adversities are accounted for by BPD and non-BPD sample

Adversity Type	Positive screen for BPD (N=164)			Negative screen for BPD (N=172)		
	F	df	p	F	df	p
Antipathy						
Mother	2.714	1, 156	0.101	1.697	1, 164	0.195
Father	0.430	1, 156	0.513	0.033	1, 164	0.856
Neglect						
Mother	1.243	1, 156	0.267	0.358	1, 164	0.550
Father	2.920	1, 156	0.089	15.082	1, 164	<0.001**
Physical						
Mother	0.100	1, 156	0.753	1.025	1, 164	0.313
Father	0.802	1, 156	0.372	0.011	1, 164	0.918
Sexual	8.390	1, 156	0.004**	0.235	1, 164	0.628

Notes: * Significant at conventional $p<0.05$ level; **Significant at Bonferroni adjusted $p<0.007$

Within the BPD sample, sexual abuse was the only significant adversity type with a small to medium effect [$F(1,156)=8.39$, $p=0.004$, $\eta^2=0.049$]. After accounting for other adversity types, individuals who met the threshold for sexual abuse reported significantly higher PE compared to those who did not.

Within the non-BPD sample, paternal neglect was the only significant adversity type with a medium to large effect [$F(1,164)=15.08$, $p<0.001$, η^2

squared=0.083]. After accounting for other adversity types, individuals who met the threshold for paternal neglect reported significantly higher PE compared to those who did not.

To examine whether these variations were significant, an independent factorial ANOVA was conducted on the overall sample with BPD (BPD, non-BPD) as an interactor. The homogeneity of variance assumption was met [$F(84,251)=0.938$, $p=0.627$]. The main effects of each adversity type and their interactions with BPD presence are shown in Table 10.

With regards to main effects, the only significant adversity at the Bonferroni adjusted significance level was paternal neglect with a small to medium effect [$F(1,320)=17.92$, $p<0.001$, $\eta^2=0.047$]. As in the non-BPD sample, individuals meeting threshold for paternal neglect reported significantly higher PE compared to those who did not. The main effects of maternal antipathy [$F(1,320)=3.95$, $p=0.048$, $\eta^2=0.010$] and sexual abuse [$F(1,320)=4.01$, $p=0.046$, $\eta^2=0.011$] were significant at the conventional significance level, showing small effect sizes. As in the BPD sample, individuals meeting threshold for sexual abuse reported significantly higher PE compared to those who did not. Unlike either of the samples considered separately, individuals meeting threshold for maternal antipathy reported significantly higher PE compared to those who did not.

Table 10

Mean CAPE score difference across different adversity types for the sample overall and their interaction with BPD group

Overall sample (N=336)			
Adversity Type	F	df	p
Antipathy			
Mother	3.946	1, 320	0.048*
Father	0.044	1, 320	0.835
Neglect			
Mother	1.128	1, 320	0.289
Father	17.919	1, 320	<0.001**
Physical abuse			
Mother	0.678	1, 320	0.411
Father	0.157	1, 320	0.692
Sexual abuse	4.006	1, 320	0.046*
BPD x Type	F	df	p
x Antipathy: Mother	0.067	1, 320	0.796
x Antipathy: Father	0.268	1, 320	0.605
x Neglect: Mother	<0.01	1, 320	0.988
x Neglect: Father	4.530	1, 320	0.034*
x Physical: Mother	1.359	1, 320	0.245
x Physical: Father	0.332	1, 320	0.565
x Sexual abuse	1.427	1, 320	0.233

Notes: * Significant at conventional $p < 0.05$ level; **Significant at Bonferroni adjusted $p < 0.007$

None of the interactions were significant at the Bonferroni adjusted significance level. The interaction between BPD and paternal neglect was significant at the conventional significance level, with a small effect [$F(1,320)=4.53$, $p=0.034$, $\eta^2=0.012$]. As demonstrated in the separate sample analyses, CAPE scores significantly differed in the non-BPD sample but not the BPD sample. The interaction between BPD and sexual abuse was not significant.

2.4.7 Hypothesis 5: Across both samples, individuals with childhood-onset adversity would experience more PE compared to those with adolescence-onset.

Information regarding adversity timing was available for the physical and sexual abuse variables for the subsample of individuals who met threshold for these adversities. There were missing values across all variables, including blank responses and non-categorical comments, for example “can’t remember” and “unsure”. The available data versus missing values for the full dataset is represented in Table 11.

Table 11

Missing data for timing of adversity by adversity type and BPD group

Adversity Type	N	Positive screen for BPD			Negative screen for BPD			
		Data	Missing	Unable to categorise	N	Data	Missing	Unable to categorise
Physical: Mother	33	30	1 (3.03%)	2 (6.06%)	10	8	1 (10%)	1 (10%)
Physical: Father	41	38	2 (4.88%)	1 (2.44%)	18	17	1 (5.56%)	-
Sexual abuse	99	96	2 (2.02%)	1 (1.01%)	43	41	2 (4.65%)	-

For the available data, Table 12 shows category frequencies and the corresponding CAPE scores. Chi-square tests were used to explore differences between the numbers of individuals reporting adversity in childhood versus adolescence across the two samples. As shown in Table 12, there were no significant differences between the BPD and non-BPD for any of the variables. Sample sizes were low throughout, particularly in the adolescent groups. Within the physical abuse variables, group sizes were particularly asymmetric, some with single or no endorsement. To maximise sample size, the overall youngest age was considered. For individuals who met physical and/or sexual abuse thresholds and had relevant timing information, the youngest age provided was used. Frequencies and CAPE scores are also shown in Table 12.

To determine if CAPE scores differed significantly across childhood and adolescence, independent samples t-tests were conducted. Prior to conducting the analyses, the CAPE score distributions were considered. The normality assumption was met within the BPD sample [$D(106)=0.047$, $p=0.200$]. However the non-BPD sample showed significant positive skew ($zSkew=3.72$) and kurtosis ($zKurt=5.23$) [$D(51)=0.142$, $p=0.012$]. Outlier analysis indicated one deviant score of 88 ($z=3.83$), as shown in Figure 5. When this score was windorsied to the next highest score of 61 ($z=2.09$) plus 1, the histogram and normality tests showed a normal distribution had been achieved [$D(51)=0.117$, $p=0.076$; $ZSkew=1.5$, $ZKurt=0.58$] (Kim, 2013). This distribution was utilised in the non-BPD analysis. The equality of variances assumption was met in both the BPD [$F=1.024$, $p=0.314$] and non-BPD samples [$F=0.821$, $p=0.369$].

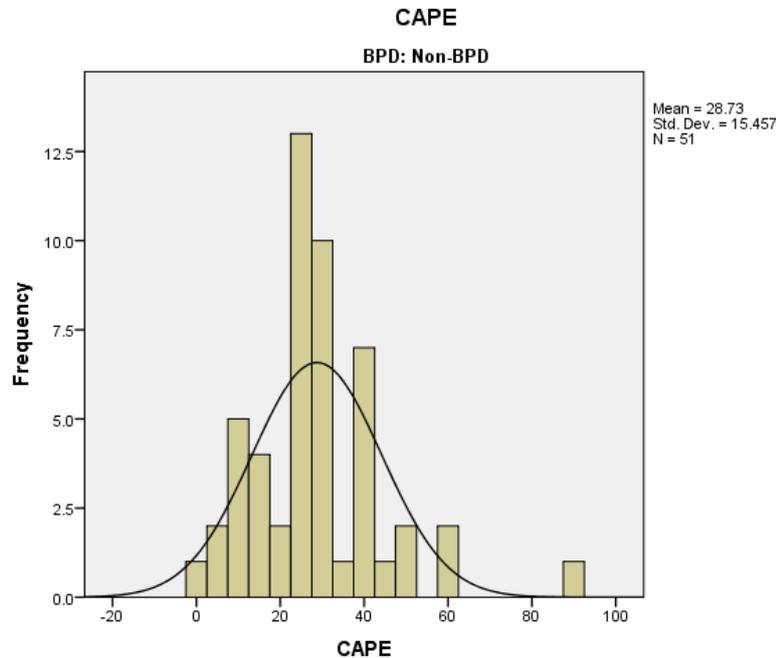
Table 12

Frequency and CAPE scores of those reporting adversity in childhood versus adolescence across the BPD and non-BPD samples

Adversity Type	Positive screen for BPD			Negative screen for BPD			χ ²	df	p
	n/N (%)	CAPE		n/N (%)	CAPE				
		Mean (SE)	95% CI		Mean (SE)	95% CI			
Physical: Mother									
Childhood	28/30 (93.33%)	62.39 (4.69)	52.78, 72.01	8/8 (100%)	34.63 (5.32)	22.05, 47.20	0.563	1	0.453
Adolescence	2/30 (6.67%)	58.00 (17.56)	22.02, 93.98	-	-	-			
Physical: Father									
Childhood	32/38 (84.21%)	64.22 (3.75)	56.61, 71.83	16/17 (94.12%)	28.81 (3.33)	21.72, 35.91	1.038	1	0.308
Adolescence	6/38 (15.79%)	58.83 (8.67)	41.25, 76.41	1/17 (5.88%)	26.00 (-)	-			
Sexual abuse									
Childhood	50/96 (52.08%)	64.02 (2.81)	58.45, 69.59	24/41 (58.54%)	29.17 (3.06)	22.98, 35.36	0.482	1	0.488
Adolescence	46/96 (47.92%)	59.89 (2.93)	54.08, 65.70	17/41 (41.46%)	25.12 (3.64)	17.76, 32.47			
Overall									
Childhood	82/106 (77.36%)	60.95 (2.34)	56.37, 63.29	37/51 (72.55%)	29.16 (2.41)	24.45, 31.57	0.434	1	0.510
Adolescence	24/106 (22.64%)	59.54 (3.57)	52.55, 63.11	14/51 (27.45%)	25.71 (3.06)	19.73, 28.77			

Figure 5

Distribution of CAPE scores in the subsample of the non-BPD sample providing adversity timing information



The independent samples t-tests found that there was not a significant difference between CAPE scores of those reporting adversity in childhood compared to adolescence in either the BPD sample [$t(104)=0.298$, $p=0.767$] nor the non-BPD sample [$t(49)=0.793$, $p=0.432$].

2.4.8 Hypothesis 6: Significant findings would persist after considering co-morbid substance use and disorders.

Potential confounding variables were first explored using independent samples t-tests to determine their influence on CAPE scores. The reduced dataset was used to enable comparison to the earlier analyses. The assumption of homogeneity of variance was met for each t-test. The results for the BPD and non-BPD samples are presented in Table 13 and 14 respectively.

Table 13

Frequency, CAPE scores, and mean difference significance of those reporting potential covariates versus not within the BPD sample

Variable	Positive screen for BPD (N= 164)			t	df	p
	n/N (%)	CAPE				
		Mean (SE)	95% CI			
Substance Use						
Not present	77 (47.0%)	54.17 (2.21)	49.84, 58.50	-1.803	162	0.073
Present	87 (53.0%)	59.54 (2.01)	55.60, 63.48			
Bipolar Disorder						
Not present	146 (89.0%)	56.47 (1.61)	53.31, 59.62	-1.052	162	0.295
Present	18 (11.0%)	61.50 (3.92)	53.81, 69.19			
Trauma Disorder						
Not present	115 (70.1%)	53.49 (1.68)	50.20, 56.77	-3.756	162	<0.001**
Present	49 (29.9%)	65.31 (2.79)	59.84, 70.77			
DID						
Not present	156 (95.1%)	56.54 (1.53)	53.55, 59.53	-1.420	162	0.158
Present	8 (4.9%)	66.38 (7.23)	52.20, 80.55			

Within the BPD sample, self-reported Trauma Disorder was the only significant variable with a medium to large effect [$t(162)=-3.756$, $p<0.001$, $d=0.630$]. To examine its influence as a potential confounding factor, it was included in a 3x2 Factorial ANOVA with the previously significant adversity frequency and in a 2x2 Factorial ANOVA with the previously significant sexual abuse type. The assumptions of equality of variances were met for both analyses [$F(5,158)=0.920$, $p=0.470$ and $F(3,160)=0.267$, $p=0.849$].

When self-reported Trauma Disorder was considered with adversity frequency, the main effect of frequency remained significant, reducing from a medium to large to

small to medium effect [$F(2,158)=4.597$, $p=0.011$, $\eta^2=0.054$]. The effect of Trauma Disorder was no longer significant [$F(1,158)=2.503$, $p=0.116$] and there was not a significant interaction between the two variables [$F(2,158)=0.780$, $p=0.460$]. When self-reported Trauma Disorder was considered with sexual abuse, the main effect of both sexual abuse [$F(1,160)=11.190$, $p=0.001$, $\eta^2=0.063$] and Trauma Disorder [$F(1,160)=5.428$, $p=0.021$, $\eta^2=0.030$] remained significant, with sexual abuse maintaining its medium effect. The interaction between the two was non-significant [$F(1,160)=1.791$, $p=0.183$]. These results suggest that presence of Trauma Disorder did not confound the previous findings.

Within the non-BPD sample, one person was missing all demographic information. As shown in Table 14, presence of substance use [$t(169)=-2.899$, $p=0.004$, $d=0.468$] and Bipolar Disorder [$t(169)=-2.931$, $p=0.004$, $d=1.255$] lead to significantly higher CAPE scores, with medium and large effects respectively. To examine the potential influence of these variables, they were included in Factorial ANOVAs with the previously significant adversity frequency and paternal neglect. However, due to asymmetrical group sizes, particularly for Bipolar Disorder, the following analyses should be interpreted with caution.

Table 14

Frequency, CAPE scores, and mean difference significance of those reporting potential covariates versus not within the non-BPD sample

Variable	Negative screen for BPD (N = 171)					
	n/N (%)	CAPE				
		Mean (SE)	95% CI	t	df	p
Substance Use						
Not present	117 (68.4%)	23.75 (1.24)	21.32, 26.18	-2.899	169	0.004**
Present	54 (31.6%)	31.28 (2.50)	26.38, 36.18			
Bipolar Disorder						
Not present	163 (95.3%)	25.37 (1.20)	23.01, 27.72	-2.931	169	0.004**
Present	8 (4.7%)	41.63 (3.54)	34.69, 48.56			
Trauma Disorder						
Not present	165 (96.5%)	25.99 (1.22)	23.59, 28.39	-0.934	169	0.352
Present	6 (3.5%)	30.00 (2.54)	25.02, 34.98			
DID						
Not present	171 (100.0%)	26.13 (1.19)	23.81, 28.45	-	-	-
Present	0 (0.0%)	-	-	-	-	-

For substance use, the assumption of equality of variances was met for both frequency and type analyses [$F(5,165)=1.412$, $p=0.222$ and $F(3,167)=0.403$, $p=0.752$]. When substance use was considered with adversity frequency, the main effect of frequency [$F(2,165)=6.021$, $p=0.003$, $\eta^2=0.066$] and substance use [$F(1,165)=4.448$, $p=0.036$, $\eta^2=0.024$] remained significant, with frequency maintaining its medium to large effect. The interaction between the two was non-significant [$F(2,165)=0.579$, $p=0.561$]. When substance use was considered with paternal neglect, the main effect of paternal neglect remained significant, maintaining its medium to large effect [$F(1,167)=15.562$, $p<0.001$, $\eta^2=0.084$]. The main

effect of substance use [$F(1,167)=2.558, p=0.112$] and the interaction between the two [$F(1,167)=0.225, p=0.636$] were not significant. These results suggest that presence of substance use did not confound the previous findings.

For Bipolar Disorder, the assumption of equality of variances was met for both frequency and type analyses [$F(5,165)=1.130, p=0.346$ and $F(3,167)=0.913, p=0.436$]. When self-reported Bipolar Disorder was considered with adversity frequency, the main effect of frequency was no longer significant [$F(2,165)=0.108, p=0.898$]. The main effect of Bipolar Disorder remained significant with a small to medium effect [$F(1,165)=7.476, p=0.007, \eta^2=0.042$]. Analyses of estimated margin means indicated that for those who reported having Bipolar Disorder, CAPE scores decreased as the frequency of adversity increased. Those who did not report Bipolar Disorder demonstrated the opposite pattern. However the interaction between the two was not significant [$F(2,165)=1.925, p=0.149$]. When self-reported Bipolar Disorder was considered with paternal neglect, the main effect of paternal neglect was also no longer significant [$F(1,167)=0.382, p=0.538$] neither was the main effect of Bipolar Disorder [$F(1,167)=2.166, p=0.143$]. Within the individuals reporting Bipolar Disorder, CAPE scores were lower for those who met the threshold for paternal neglect, whereas the reverse pattern was shown for those not reporting Bipolar Disorder. However, again the interaction was not significant [$F(1,167)=3.311, p=0.071$]. Due to the small sample of individuals in the non-BPD sample self-reporting Bipolar Disorder ($N=8, 4.7\%$), these results should be interpreted with caution.

2.4.9 Reliability analysis

Due to the limited information available regarding the psychological abuse scale, its reliability was explored using Cronbach's alpha. As good practice, the

remaining variables which were suitable for analysis were also examined. The minimum acceptable Cronbach's alpha value for research is 0.73 (Nunnally, 1978). As shown in Table 15, all variables demonstrated excellent or good internal consistency, with the exception of the physical abuse and sexual abuse variables which demonstrated questionable to unacceptable internal consistency.

Table 15

Reliability analyses

Scale	Items	Cronbach's alpha*			
		Research estimates	Overall	BPD	Non-BPD
MSI-BPD	10	0.73-0.86 ¹	0.87	-	-
CAPE	42	0.91 ²	-	0.93	0.93
Antipathy: Mother	8	0.81-0.90 ³	-	0.92	0.91
Antipathy: Father	8		-	0.91	0.90
Neglect: Mother	8	0.80-0.92 ³	-	0.85	0.85
Neglect: Father	8		-	0.90	0.85
Psychological : Mother	17	-	-	0.91	0.92
Psychological: Father	17	-	-	0.92	0.91

Notes: *Excellent ($\alpha \geq 0.9$), good ($0.9 > \alpha \geq 0.8$), questionable ($0.7 > \alpha \geq 0.6$), poor ($0.6 > \alpha \geq 0.5$), unacceptable ($0.5 > \alpha$); 1. Gardner & Qualter, 2009; Noblin et al., 2014; 2. Mark & Touloupoulou, 2016; 3. Bifulco et al., 2005; Smith et al., 2003

2.5 Discussion

2.5.1 Summary of the main findings

This study aimed to explore the association between childhood adversity and PE in BPD. The findings add to growing evidence highlighting the presence of PE at differing degrees across the general population and clinical and non-clinical BPD populations. The results indicate that there is a relationship between certain

characteristics of adversity and more prevalent PE within these populations. In particular, they point towards the role of cumulative exposure to adversity, particularly sexually abusive experiences, at any stage of childhood in increasing susceptibility to PE in BPD. Adversity frequency appeared to be a more generalised risk factor for PE within this study. However, there was indication that adversity type had some differential impact on the BPD, compared to the non-BPD sample, with paternal neglect being particularly important in the latter. These findings appeared to be of mostly reasonable effect size and were largely robust after accounting for the self-reported potential confounding disorders measured. More specific explorations of the hypotheses are outlined below.

Group differences: The BPD sample reported significantly higher prevalence of each childhood adversity type and noticeably higher rates of PE. This fits with existing literature and emphasises the importance of understanding these experiences in BPD (Barnow et al., 2010; Schroeder et al., 2012).

Frequency of Adversity: Within the BPD sample, the process of multiple adversities was associated with significantly higher PE with one adversity alone being insufficient to result in a statistical difference. This fits with suggestions that PE in BPD may result from a cumulative sensitisation process, whereby the accumulative effect of multiple adversities leads to physiological sensitivity, leaving an individual more susceptible to psychotic-like inferences in response to stress (Barnow et al., 2010; Gras et al., 2014). In contrast, single adversity was associated with significantly higher PE in the non-BPD sample with no cumulative effect of moving from single to multiple adversities. Despite fitting with the findings of Fisher and colleagues (2010), this contradicts previous general population findings of a cumulative dose response pattern (Gibson et al., 2016). The current findings could potentially be explained by a

lower threshold for sensitisation in individuals without BPD symptomology, with the presence of adversity itself, regardless of frequency, being important, compared to a higher threshold in those with BPD, where repetitive adversity is more influential. However, as the samples did not significantly differ, the influence of adversity frequency may be general rather than BPD specific.

Type of Adversity: Across both samples, multiple adversity types were significantly important independently. Within the BPD sample, these related to the father's influence and sexual abuse. However, these independent effects mostly diminished after accounting for the influence of other adversities (Trauelsen et al., 2015), providing support for the indication that separately considering childhood adversities may obscure their overall impact (Gibson et al., 2016; van Nierop et al., 2014).

Within the BPD sample, the only adversity type to maintain its independent influence with a medium effect was sexual abuse. However, the findings indicate that this is not necessarily a unique finding to BPD. This contrasts with Fisher and colleagues (2010) who found childhood-onset maternal physical abuse to be the most robust indicator of psychotic disorder, potentially providing early indication of possible differential risk factors across these disorders. It fits with the accumulating research base showing strong associations between childhood sexual abuse and PE (Bebbington et al., 2004; Hammersley et al., 2003; Heins, Gray, & Tennant, 1990; Shevlin et al., 2007). Sexual trauma may represent a more repeated, severe, and intrusive form of abuse (Cutajar et al., 2010; Thompson et al., 2013). This aligns with the findings that more intrusive forms of adversity with intent to harm more closely relate to PE development (Gibson et al., 2016). It may be that sexual abuse is a clearly intentional violation of intrusiveness, incorporating elements of other adversities

(Fisher et al., 2010). This accumulation effect may feed into the earlier sensitisation process, thus enhancing an individual's susceptibility to PE, particularly given the accumulative interpersonal aspect of sexual abuse (Oliva et al., 2014; Suzuki et al., 1998). As sexual abuse was the only adversity type to extend outside of the parental relationship, perpetrator-related factors may have also contributed. However the influence of perpetrator relationship on mental health outcomes is inconsistent and unclear for PE (Cashmore & Shackel, 2013; Paolucci, Genuis, & Violato, 2001). Furthermore, only around a quarter (28%) of BPD individuals reporting sexual abuse reported no other parental adversity.

Within the non-BPD sample, paternal neglect was associated with higher PE after accounting for the influence of other adversities, with a notably large effect. Again, this contrasts with Fisher and colleagues (2010) who highlight the important role of maternal attachment in psychotic disorder presence. Neglect is noted to be an area where mothers can receive predominant focus, at the exclusion of men and the risks that paternal neglect can pose (Daniel & Taylor, 2005). Some research indicates a link between overall neglect and paranoia (Bentall et al., 2014), which is relatively prevalent in general population samples (prevalence range: 1.5% to 28%; Bebbington et al., 2013; Freeman et al., 2011). However, the influence of neglect on PE tends to be more attenuated with stronger links between neglect and general psychopathology (Heins et al., 2011; van Dam, Korver-Nieberg, Velthorst, Meijer, & de Haan, 2014). It is therefore possible that paternal neglect may have been related to the more general aspects of psychopathology assessed across the CAPE questionnaire.

Timing of Adversity: Childhood- versus adolescent-onset adversity did not lead to significantly different PE rates in either sample. Therefore, timing may not be an influential factor in explaining PE in BPD. Some researchers suggest that stronger

associations between adversity in childhood and PE, compared to adolescence or later life, could relate to more prolonged abuse or increased exposure to other adversities, with discontinuation of adversity significantly reducing PE (Fisher et al., 2010; Kelleher et al., 2013). Thus persistence and duration of adversity may be useful characteristics to explore further.

Confounding disorders: The persisting importance of adversity frequency and sexual abuse after controlling for self-reported Trauma Disorder in the BPD sample provides some early evidence against suggestions that the aforementioned stress sensitivity process is mediated by comorbid stress-related disorders, such as PTSD (Barnow et al., 2010; Schroeder et al., 2012). The low prevalence of those self-reporting most confounding factors, particularly in the non-BPD sample (for example, 0%, 3.5%, and 4.7% for DID, Trauma Disorder, and Bipolar Disorder respectively), make it difficult to comment on this area further.

2.5.2 Limitations

Web-based surveys are becoming increasingly popular in psychological research, however this methodology can introduce problems (Lefever, Dal, & Matthíasdóttir, 2007). Typical to internet-mediated research there was a notable degree of sample attrition (26%) and a number of cases were lost to missing data (APA, 2004). This can influence sample representativeness (Peng, Harwell, Liou, & Ehman, 2006) and introduce bias into statistical estimates (Becker & Powers, 2001; Kim & Curry, 1977). Despite a reasonable sample remaining, the asymmetry and particularly low sample sizes across groups, particularly in the non-BPD sample and the adversity type, timing, and confounding factors analyses, had implications in terms of statistical accuracy, power, and the conclusions that can be drawn (Keppel, 1982; Levin, 1967).

Coupled with the high number of analyses, thus increasing risk of spurious associations, the study results should be interpreted with caution. The cross-sectional study design also means that causal inferences cannot be drawn.

Across both samples, there was a bias towards females over males (ratio 4:1). This fits with findings of higher female response rates in web-surveys (Smith, 2008) and higher female prevalence in BPD (around 75%) (APA, 2013; ten-Have et al., 2016). However this potentially limits generalisability, particularly given findings of a more significant adversity-dysregulation-PE pathway in females (Gibson et al., 2016). Older ages were also under-represented, particularly within the BPD sample. Older adults may also be under-represented within online methodology and within BPD (APA, 2013). PE frequency may have also been influenced by the relatively high prevalence of self-reported mental health diagnoses across both samples, including diagnoses not controlled for (Jacobi et al., 2004; Maj, 2005). The BPD and non-BPD samples were also found to significantly differ across the majority of the demographic variables considered, particularly age, educational and employment status, and route into the study. These between sample differences may have had a confounding influence on the group difference analyses. It would have therefore been beneficial to control for the influence of these demographic factors. This would be better enabled in larger scale replication studies which are more robust against biases or errors associated with multiple testing.

Due to the remote administration of online surveys, self-report measures were used. This may have been at the detriment of accuracy, particularly in relation to diagnostic specificity for BPD allocation and monitoring of exclusion criteria (e.g. schizophrenia) or co-morbidities (e.g. Trauma Disorder or substance use). For example, nine non-BPD allocated individuals self-reported this diagnosis. As the MSI-

BPD is found to be a valid and reliable screening tool, including good reliability within this study, it was judged to be a more robust measure of BPD compared to reliance on a single yes or no self-report question, which may be particularly vulnerable to misunderstanding, inaccuracies, and false reporting. Therefore, these nine individuals were included within the non-BPD sample. However, this may have led to bias within this sample, potentially limiting the strength of the conclusions that can be made regarding group differences and the specificity of particular findings to individuals without BPD, for example the importance of paternal neglect in the non-BPD sample. A more robust measure of such diagnoses, for example the Structured Clinical Interview for DSM-5 (First, Williams, Karg, & Spitzer, 2015), would have increased the validity of the findings and therefore the conclusions that can be drawn. Nevertheless, all relevant scales were found to be reliable within the current samples. The excellent reliability of the newer psychological abuse scale across both those with, and without BPD, also provides support for its use within these populations.

The reliance on retrospective recall for childhood adversity potentially influenced validity, for example through reluctance or forgetfulness (Hardt & Rutter, 2004; Susser & Widom, 2012). This may explain why the BPD sample adversity rates were generally lower than literature estimates, with the exception of sexual abuse (Battle et al., 2004; Schroeder et al., 2012; Zanarini, 2000). Highly traumatised individuals may be less likely to access online surveys, particularly when alerted to the content on abuse. Literature estimates also tend to utilise inpatient or treatment seeking populations, who may have been underrepresented within the predominant social media recruitment strategy. However, adversity type estimates for the non-BPD sample were largely equivalent to UK and international estimates (Office for National Statistics, 2016; World Health Organisation, 2002; 2006). The categorical allocation

of adversity frequencies, types, or timings, with a particularly high threshold for what constitutes adversity presence, may have influenced findings and masked more subtle effects at less severe levels, for example the regularly cited cumulative general population dose-response effect. The exclusion of specific CECA-Q scales, and the lack of exploration of broader adversities, such as bullying or serious accidents, and non-caretaker abuse, also limit the scope of these findings (Gibson et al., 2016).

For both samples, PE rates appeared to be largely equivalent to those found in the literature (Barnow et al., 2010; Brenner et al., 2007; Daneluzzo et al., 2009; Linscott & van Os, 2013; Schroeder et al., 2012). However as the overall CAPE was used, as opposed to the more psychometrically robust sub-dimensions (Mark & Touloupoulou, 2016), the potential association between childhood adversity and symptom specificity is not clear (Bentall et al., 2012). The general psychopathology aspects of the depressive dimension may have also influenced findings, given the strong associations between childhood adversity and depressive symptomology (Bifulco et al., 2005). Furthermore, only PE frequency was considered with adversity being associated with more frequent PE, not necessarily an established threshold of PE or the level of distress caused by PE.

2.5.3 Research implications

The study findings need replication, preferably on an epidemiological scale, to increase reliability and improve sample representativeness and statistical power. Important factors to consider include the use of prospective longitudinal cohort designs to help establish the temporal precedence of any replicated effects. This could involve identifying children with adversity, for example through child protection services, compared to those without, and examining PE rates over time. Given the unbalanced

nature of adversity presence, future studies would benefit from targeting recruitment at those who are more likely to have experienced abuse, for example abuse self-help sites. Further research could also benefit from more robust measurement of the key constructs, particularly improved diagnostic specificity of BPD, exclusion diagnoses, and the presence of key co-morbid mental disorders, as well as considering the influence of key demographic factors. Given the associations between the main findings (sexual abuse, cumulative abuse, and subsequent interpersonal stress sensitivity) and BPD symptomology more broadly, further more sophisticated exploration of risk or moderating factors is likely to be important in enhancing understanding of the development of PE in BPD (Gibson et al., 2016).

2.5.4 Clinical implications

The findings add to the growing literature base highlighting the importance of acknowledging and understanding PE in BPD (Barnow et al., 2010; Merret et al., 2016; Schroeder et al., 2012). It is important for those supporting individuals with BPD to directly enquire about PE through systematic screening and functional assessments (Barnow et al., 2010; Schroeder et al., 2012; Zonnenberg et al., 2016). The strong reliability of the CAPE within this BPD sample indicates that this could be a suitable screening measure (Mark & Touloupoulou, 2015). Similarly, clinicians should routinely enquire about the frequency of specific early adverse experiences, particularly sexual abuse, and the accumulative influence of this on an individual's response to stress. Clinicians should be mindful that the presence of such factors could indicate a higher vulnerability to PE. The importance of screening for PE and trauma histories also extends to broader mental health services. This information should then be used to formulate the most appropriate interventions, adapted to incorporate PE (Schroeder et al., 2012). At present, evidence-based treatments tailored to psychotic disorders, such

as antipsychotics and cognitive-behavioural therapy for psychosis, have not been studied systematically for individuals with BPD (Zonnenberg et al., 2016). Therefore further research establishing how these treatments may integrate with BPD treatment is needed.

2.5.5 Conclusion

The presence of PE in BPD is well-established, both clinically and empirically. However, research into why and how these symptoms develop is limited. The current internet based study provides some early indication that specific characteristics of adversity, namely accumulative frequency and specific types of adversity, may be important in understanding the development of PE in BPD populations, including how this may differ to PE in the broader general population. This adds to growing evidence highlighting the importance of directly exploring PE, and its relation to trauma, in BPD. However, further replication is needed to establish the reliability and validity of these findings, particularly using longitudinal designs, with more robust measurement, targeting individuals with histories of childhood adversity.

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Part 3: Critical Appraisal

3.1 Introduction

This critical appraisal provides reflections on issues that arose across the research process. It begins by considering the impact of internet-mediated research (IMR) on ethics and scientific value, particularly difficulties associated with self-report measures. Key challenges across the empirical study are then discussed. The paper concludes by refocusing of the difficulties associated with understanding and supporting psychotic experiences (PE) in Borderline Personality Disorder (BPD).

3.2 Internet-mediated research

IMR has flourished in psychological research due to its ability to expand the scale and scope of research (American Psychological Association [APA], 2004; British Psychological Society [BPS], 2017). Having completed my first IMR, I found it to be an effective means of conducting an exploratory study providing sample sizes higher than those achievable through traditional methods. I particularly enjoyed the creativity it involved, leading researchers to think outside of traditional methodology, for example, designing visually appealing and engaging social media profiles and webpages. I was also encouraged by the emerging support networks for IMR from both individuals and organisations (e.g. The Mental-elf and NHS Research news).

The large proportion of participants from social media indicates its effectiveness as a recruitment strategy for psychological research. The reach of social media platforms, such as Facebook and Twitter, offers significant potential for researchers (Khatri et al., 2015). I found this to be helpful in providing the breadth needed to recruit individuals with both BPD and PE. My primary recruitment strategy utilised ‘derived rapport’ in which the study webpage was disseminated through

individuals, organisations, or communities with existing relationships with potential participants with BPD (Temple & Brown, 2011). The predominant use of these snowball sampling strategies introduces potential biases towards like-minded individuals, who tend to be more cooperative with larger personal networks (Baltar & Brunet, 2012). IMR is generally criticised for poor sample generalisability (Hewson, 2014). Despite expansion and diversification of internet users, recipients are still found to be predominantly white, younger, wealthier, and more highly educated (Dutton & Blank, 2011). Both samples were biased towards younger ages and white British ethnicity. The non-BPD sample also showed some bias towards higher education and employment status. This has ethical implications in terms of the accessibility of research. There is a risk IMR can restrict the opportunities for hard to reach populations to have their voice heard. Attempts were made throughout recruitment to promote the study across a range of sources, including the offer of postal questionnaires. However, reflecting back on my own prioritisation of time and effort into the social media campaign, more could have been done to increase accessibility. For example, providing printed questionnaire packs to services and placing more emphasis on alternative administration methods within the non-electronic recruitment resources.

Across the social media campaign, I encountered numerous BPD support communities (e.g. BPD Planet, Borderline Brave) and many interested individuals on Twitter, who were supportive in sharing the study. I was warmed by the strength and support of the online BPD community. However, I was often surprised and somewhat concerned by the level of self-disclosure expressed by individuals in these public forums, particularly relating to self-harming behaviours. I was very conscious of my dual role as a researcher and clinician, particularly as recruitment efforts involved a

level of interaction with potential participants, for example requests to retweet or posting in public forums. As such, I only promoted the research to individuals who actively followed the study accounts, when judged to be clinically appropriate. In line with good practice, consent was also always sought from group or forum gate-keepers. This highlighted to me the important ethical issues that arise with the blurring of the boundaries between private and public domain in IMR and how crucial it is for IMR researchers to appropriately assess and plan for potential clinical and risk issues (APA, 2004; BPS, 2017).

IMR often has benefits in keeping resources low (APA, 2004; BPS, 2017). In contrast to my experiences using traditional face-to-face methods with allocated time for recruitment or administration, I found this IMR recruitment to be at a lower intensity, yet more persistent. It was also challenging to monitor the effectiveness of recruitment strategies and participant numbers. All questionnaires were downloaded into a central database, accessible from a database administrator when requested. The format meant it was time-consuming to determine the number of participants who had completed all questionnaires. However, there were noticeable increases in response rates during increased advertising efforts. Therefore, regularly dedicating time to a highly targeted social media campaign appeared crucial in maximising participant response and is recommended for future IMR (Khatri et al., 2015).

Remote anonymous administration meant that I had to place trust in participant self-report and authenticity. There was no real means of establishing if participants had fully read the information sheet and thus honestly engaged in the consent and inclusion criteria procedures. A particular concern I had starting out was the length and level of details required in the information sheet. This was necessary to ensure compliance with ethical standards, however, reduced accessibility and potentially

decreased the likelihood of it being read. This introduced ethical dilemmas with participants potentially not being alerted to the sensitive content. To try to overcome this, the potentially upsetting content was mentioned at the beginning of the information sheet. A clear risk plan, including readily available distress tolerance skills and support information, was also incorporated into the study design. However, integrating check-boxes next to key information or consent statements could have aided this process (BPS, 2017).

A number of participants missed questionnaire items, with the majority only missing one item. It was particularly frustrating to have their valuable data omitted and felt ethically concerning not using the data from those who provided consent, hence why the full data set was prioritised wherever possible. The reliance on hardware and software configurations in IMR makes them vulnerable to potential malfunctions. It was not possible to establish whether these were intentional omissions, therefore it is possible they resulted from a technology error. Data imputation methods were considered, however, this is a relatively new area, particularly within psychological research, often involving complex procedures which can risk introducing bias (Lee & Carlin, 2017; Roth, 2004). A focus on prevention of missing data would have been more beneficial, with the use of safeguards which prevent participants from moving to the next page when items were missing. This was done for most measures, however as the childhood adversity and demographic questionnaires involved non-essential follow-up questions, this was not possible. Future IMR may benefit from the use of 'smart forms' enabling this. These were not possible with the data collection system employed in this study.

Attrition rates were low with a drop-out rate of 26%. Response rates to IMR are typically lower compared to traditional methods (APA, 2004), however drop-out

beyond 10% tends to be associated with undesirable experimental designs, particularly survey length (Hoerger, 2010). The questionnaires were specifically ordered with the BPD screening measure (McLean Screening Instrument for BPD) first as this formed the basis for allocation to the different samples and thus underlined all data analyses. The childhood adversity questionnaire (Childhood Experiences of Care and Abuse Questionnaire) was presented second. The majority of drop-outs were noted to occur during this measure (64% of all drop-outs). On reflection, the full childhood adversity measure, with its seven subsections containing sensitive content, may have been somewhat off-putting, particularly if participants had entered the survey due to curiosity. My intention had been that since this was the longest and most sensitive questionnaire, it would have been better to present this earlier within the survey. This was on the basis that participants may have been less likely to be burnt out at this stage, by both the cognitive and emotional demands of the survey, and therefore more likely to be settled and calm. However, it may have been more beneficial to place this questionnaire across separate pages to break it up, as well as, considering shorter, more accessible measures.

A further consideration regarding questionnaire order was that given the particularly sensitive nature of this questionnaire, it felt more appropriate to be upfront regarding this content, rather than leaving it towards the end of the survey. I thought that doing the latter may have risked participants potentially dropping out later in the survey. This could have led to ethical issues as their data would not have been able to be considered. This is because all the measures, bar the demographic questionnaire, were needed for the main analyses. This is what drove the decision to include the demographic questionnaire last, because missing items, potentially brought on by survey fatigue, would not have had as detrimental an impact on the analyses (Hoerger,

2010). Although demographic information is more typically presented first, there is some evidence to suggest that response rate is reduced when surveys begin with the most general questions (Edwards et al., 2001). However the evidence base is somewhat what conflicted, with other studies finding a reverse effect (Drummon, Sharp, Carsin, Kelleher, & Comber, 2008). Future research would benefit from exploring the impact of questionnaire order further, particularly within psychological web-based surveys, to help inform how to most effectively structure future surveys and IMR.

3.3 Measurement of study constructs

IMR relies heavily on the use of self-report measures. It was reassuring to find strong internal reliability across the key continuous scales, particularly given that some of these measures had not been extensively utilised in these contexts, particularly the Psychological Abuse scale and use of the Community Assessment of Psychic Experiences (CAPE) within BPD. However, issues relating to validity arose. Generally, self-report measures can be vulnerable to biases, particularly those with emotive content (Tourangeau, 2009), and imposed timeframes, such as the retrospective recall of childhood adversity (Gibson, Alloy, & Ellman, 2016; Murphy, Houston, Shevlin, & Adamson, 2013; Susser & Widom, 2012). Reluctance or forgetfulness may also be of particular concern amongst those influenced by PE (Hardt & Rutter, 2004).

I was particularly concerned about this issue with the diagnostic measures. The brief BPD screening tool (McLean Screening Instrument for Borderline Personality Disorder) predicts presence of BPD in around 81% of cases (Zanarini et al., 2003). Although high, this still indicates 19% false-negative error rate, which may explain the nine non-BPD allocated individuals who self-reported BPD. However, this may be due

to inaccurate self-report or misinformation. Similarly, the use of self-reported exclusion and confounding diagnoses may have led to inaccuracies related to lack of awareness or misunderstandings. In particular, the use of only self-reported Bipolar Disorder (BiP) to monitor confounding mood disorders may have led to biases, particularly given the complexities with differential diagnosis between BPD and BiP (Basset, 2012).

A specific IMR challenge is guarding against false responding. The limited control over the conditions under which participants responded meant that again I was reliant on the authenticity of participants. This has implications for validity and therefore scientific value of the findings. Methodological precautions, such as validity scales detecting clearly factitious or unreliable responses, are recommended for IMR questionnaires, particularly when assessing PE (Moritz, Van Quaquebeke, Lincoln, Köther, & Andreou, 2013). This was not done within the current questionnaires but would be beneficial for future research.

On a broader level, conceptualising abstract constructs in an accessible questionnaire format has limitations. The categorisation of childhood adversity into 'severe' versus 'not severe/not present' limits the findings to the influence of severe childhood adversity on the development of PE. The use of continuous measurements of childhood adversity may have enabled a more subtle understanding. Similarly, as raised in the literature review, PE can be particularly hard to quantify (Lee et al., 2016; Upthegrove et al., 2016). I chose the CAPE due to its accuracy as a screening measure, frequency of use in research, and validity over the internet (Kelleher, Harley, Murtagh, & Cannon, 2011; Mark & Toulopoulou, 2016; Moritz et al., 2013). Due to the exploratory nature of this study, the broader total score was used to approximate PE presence and only the frequency scale was used to minimise participant burden. This

limits the findings to the influence of childhood adversity on the frequency of PE. From my clinical experiences working with individuals with PE, frequency has only been one element of their experience, with phenomenology and associated distress often being more paramount to the individual. Reviews have also reported that this level of detail is important in understanding PE in BPD, with the clinician-rated Psychotic Symptom Rating Scales (PSYRATS) being recommended as a potentially more effective measure for future research (Merrett, Rossell, & Castle, 2016).

3.4 Personal reflections on the research process

Reflecting on the research process as a whole, I was surprised, and particularly challenged, by the number of decisions involved. This came to the fore during the process of obtaining NHS research committee ethical approval, which involved numerous decisions relating to the study's aims, methodology, and theoretical rationale. This brought with it difficulties in terms of balancing feasibility of the project within the allocated timeframe with the scientific value, ethics, and integrity of the research. Multiple challenges have been noted with the thorough application process, including methodological barriers and procedural delays, particularly for student projects (Hunter, 2008; Soteriou & Hek, 2003). I found this process particularly stressful given the fundamental changes to the application process that were occurring during the period I applied (Health Research Authority, 2016) leading to some inconsistencies across the multiple individuals involved.

Despite these challenges, reflecting back, this rigorous documentation was integral to helping me achieve methodological clarity upfront and provided a strong framework to proceed with implementing the project. I was able to bring this thoroughness to the consideration of my systematic literature search strategy, helping

me to more effectively structure this process. Nevertheless, given the volume of decisions to consider in the preliminary stages, it is difficult to ensure all elements are considered. For example, the psychological abuse scale seemed a useful scale to include due to the role of emotional abuse in PE. Yet it was not until the later stages, after administration had started, that the potential overlap with antipathy, the lack of cut-off scores, and lack of validation information were fully appreciated. With hindsight this would have benefitted from more thoughtful consideration earlier on to avoid the ethical dilemma of not using available data from consenting participants. With this in mind, it was important to make use of this data to provide novel information regarding its psychometric properties, with useful findings of its reliable use with BPD and general population samples.

Another challenging stage for me was statistical analysis. The asymmetry across groups in my analysis was particularly concerning. Unbalanced data is common in epidemiological surveys, particularly research into abuse where prevalence rates are lower (Shaw & Mitchell-Olds, 1993). The asymmetry across those reporting adversity versus not was similar to published studies also examining the impact of childhood adversity (Fisher et al., 2010; Trauelsen et al., 2015). Understanding the implications of this dilemma involved advanced statistical understanding. This made me reflect on the breadth, and often depth, of skills required throughout the course of a research project, and therefore the benefit of research teams, with individual expertise, in helping to conduct high quality effective studies. For this particular issue, I learnt that statistical software, such as SPSS, automatically corrects formula for key components when sample sizes are unequal and as such a lack of balance does not present a serious problem (Milliken & Johnson, 1984). However, unbalanced samples can be more problematic in the interpretation of Factorial ANOVAs, particularly interaction

effects, and extreme groups within a sample may artificially inflate the effect size estimate (Keppel, 1982; Levin, 1967). This meant that high levels of caution needed to be used when interpreting the empirical paper findings, which is somewhat disappointing given the level of effort put into the project. Reflecting back, more consideration of targeting recruitment to all of the project's core constructs, not just BPD, may have reduced this dilemma.

On a broader scale, throughout the process I reflected on how my development as a researcher integrated alongside my development as a clinician. Alongside a need to learn from, and at times be dependent, on others, the research process required a high level of autonomy. The process of developing confidence, leadership skills, and finding my own orientation as a clinician complemented the level of assertion and decision making mentioned above. On a more theoretical level, through my clinical experiences and interest in systemic and narrative approaches (White & Epston, 1990), I developed a growing awareness of my orientation towards a social constructionist stance. This views human experience as profoundly influenced by social constructs such as culture, history, and language (Hoffman, 1990). This intuitively led me to align with the emerging movement towards more fluid continuum views of PE, particularly the hearing voices movement (HVM). This subsequently played a role in determining the focus of my systematic literature review, and likely led me to emphasize these components more strongly across my thesis. The HVM views voice hearing as a meaningful human experience and seeks to empower individuals by being guided by their lived experience and own explanatory frameworks (Escher & Romme, 2012). With this in mind, this research area could benefit from hearing these personal narratives, by giving a 'voice' to participants. Triangulation with qualitative approaches may have provided richer exploration of some of the complexities behind

the development of PE in BPD. Similarly, further service user involvement would have enabled the research focus and design to benefit from the unique perspective of individuals' lived experience.

3.5 Moving towards an understanding of PE in BPD

The empirical paper posed the dilemma that if the robust findings linking childhood adversity and PE from other populations apply to BPD, why do some individuals not experience PE? The paper found promising findings associating frequent abuse, particularly sexual abuse, with more frequent PE. In line with previous reviews, it was hypothesised that this cumulative exposure to adversity may gradually increase sensitivity to stress (Schroeder, Fisher, & Schafer, 2010). However, these factors also relate to BPD symptomology more broadly (Gibson et al., 2016). Alongside stress sensitivity, Barnow and colleagues (2010) propose that neurobiological changes (e.g. sensitisation of the hypothalamic-pituitary-adrenal axis), dissociation, and emotional instability collectively enhance susceptibility to BPD and that PE then develop through disturbed information processes following daily hassles and interpersonal problems. The potential mediation of these factors will be important areas for future research.

BPD patients with high levels of dissociation are found to have heightened neurobiological stress sensitivity, including greater cortisol and noradrenergic reactivity (Barnow et al., 2010). Therefore as well as playing a crucial role in BPD development, dissociation could be an important mechanism in understanding how stress sensitivity may lead to PE. There is a strong evidence base highlighting the mediating role of dissociation within the childhood adversity and PE relationship (Gibson et al., 2016). Tschoeke, Steinert, Flammer and Uhlmann (2014) interpreted

that the PE in their BPD sample occurred in the context of trauma-related dissociative phenomena. Furthermore, research has also drawn particular links between dissociation, sexual abuse, and PE. Early sexual abuse may lead to a dissociative-detached reaction, resulting in a disrupted sense of self. Intrusions from these detached aspects of self into an individual's conscious are then thought to underlie overt PE (Allen, Coyne, & Console, 1997; Varese, Barkus, & Bentall, 2012). This may provide context to the significant influence of sexual abuse within the BPD sample. Self-reported Dissociative Identity Disorder did not significantly influence PE in this BPD sample and the significance of sexual abuse remained when self-reported trauma disorders were accounted for. However, this crude self-report may not capture the possible dissociative processes involved in this mediation, and the numbers self-reporting this diagnosis were too low to allow for statistical certainty. This is a promising area for further exploration with more sophisticated measurement, for example using scales such as the Dissociative Experience Scale (Merrett et al., 2016).

3.6 Supporting individuals with PE in BPD

PE in BPD pose a significant diagnostic and treatment challenge (Merrett et al., 2016). They can often incorrectly lead to a clinical diagnosis of primary psychotic disorder, which has implications given the contrasting treatment approaches shown to be effective across these disorders. The complex nature of psychotic disorders, such as schizophrenia, requires comprehensive interventions with medication adherence at their core (Merret et al., 2016; Sommer et al., 2012). However, psychotherapy is consistently prioritised over medication in the treatment of BPD, and there is limited and inconsistent research regarding the effect of medication on PE in BPD (Barnow et al., 2010; Schroeder et al., 2012; Stoffers et al., 2010). Due to fluctuating insight during mental state deterioration within schizophrenia, individuals usually require more

intensive community support. Conversely, individual responsibility is a key focus in the management of BPD symptomology (Merret et al., 2016). When a diagnosis of psychotic disorder is inappropriately applied, this responsibility emphasis can blur leading to detrimental outcomes (Paris, 2004).

Individuals with both diagnoses present with worse outcomes compared with patients with psychotic disorders alone (Schroeder et al., 2012). During my clinical experiences within forensic contexts, I have observed the challenges of providing effective person-centred care within a system that largely separates treatment by mental health wards and personality disorder units, with great crossover of the lived experience in either setting. Similarly, whilst working in a community mental health team, I reflected on the structuring of the NHS Trust I was in into clustering systems which allocate individuals to either psychotic or non-psychotic pathways. This led individuals I worked with to describe feeling as though they “fall through the gap” of services with poor understanding of why these experiences were happening to them and a debilitating fear of “going crazy”. As has been noted in the qualitative research of PE in BPD, I observed low confidence within myself and the teams of how to support these individuals, in particular having no common language to describe these experiences (Adams & Saunders, 2011). Responses to these experiences can be crucial in determining their course, as stigmatising or detrimental reactions, such as neglecting or avoiding conversations or using invalidating “quasi” related terms, can exacerbate their development (Adams & Sanders, 2011; Schroeder et al., 2012).

These collective dilemmas are what originally drove me to want to use research to better understand PE in BPD. At present there is a limited evidence base regarding effective treatment for these individuals (Zonnenberg et al., 2016). Given the phenomenological similarity of PE in BPD compared to psychotic disorders, adapting

cognitive-behavioural approaches for psychosis to the needs of patients with BPD may be useful (Schroeder et al., 2012). Similarly the importance of psychoeducation to help normalise, validate, and begin making sense of these experiences, particularly in relations to childhood experiences, is likely to be beneficial (Escher & Romme, 2012).

3.7 Conclusions and recommendations

Reflections on the process of the empirical study highlighted many of the dilemmas which can emerge across research, particularly internet-mediated studies. Overall, the advantages that IMR brought to this study indicate that it is a useful method for exploratory psychology research. However, careful consideration of ethical and practical challenges is needed. This appraisal reinforced the need for replication of the empirical paper's findings, using more robust multimodal assessment, including qualitative approaches. Further exploration of moderating and mediating factors will also be crucial in helping to understand the occurrence of PE outside of psychotic disorders, particularly within BPD where there is early indication that stress sensitivity, namely dissociative responses, may be important areas to consider.

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Appendix A: Example database search

PSYCHINFO: 1806 to October Week 3 2016 (25.10.16)

1. exp EPIDEMIOLOGY/	43956
2. general population.mp.	23769
3. ((normal or healthy or community) adj (population or individuals or sample)).mp.	15805 ¹
4. ("non psychotic" or non-psychotic or nonpsychotic).mp.	3682
5. ("non clinical" or non-clinical or nonclinical).mp.	9087
6. ("sub clinical" or subclinical or sub-clinical).mp.	3997
7. 1 or 2 or 3 or 4 or 5 or 6	94527
8. exp Auditory Hallucinations/	1729
9. exp Hallucinations/	5575
10. hallucinat*.mp.	14019
11. AVH.mp.	170
12. (voice* adj1 hear*).mp.	872 ²
13. 8 or 9 or 10 or 11 or 12	14460
14. 7 and 13	940
15. limit 14 to (human and English language)	827

Notes: ¹ The ADJ operators finds two terms next to each other in the specified order

¹ The ADJI operators finds two terms next to each other in any order

Appendix B: Data Extraction form

- The proportion of males in the sample –

Significant inclusion and exclusion criteria –

Outcome measurements:

- Name of the measurement instrument –
- Number of items of the instrument that were used –
- Administration format, including details of administrator –
- Classes of excluded experience –

Ethical approval –

How outcome data were handled:

- Any frequency, severity, or likelihood criterion required to reach study threshold for outcome presence:
- Methods for ensuring coverage of identified sample:

RESULTS

Overall outcomes of study –

Prevalence

- Rate denominator n/N –
- Rate itself (%) –

95% Confidence Intervals –

Authors' comments (if contacted) –

Reviewer comments –

Appendix C: Prevalence Critical Appraisal Tool

Reviewer:

Date:

Record Number:

Author:

Year:

- | | Yes | No | Unclear | N/A |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Was the sample frame appropriate to address the target population? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Were study participants sampled in an appropriate way? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Was the sample size adequate? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Were the study subjects and the setting described in detail? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Was the data analysis conducted with sufficient coverage of the identified sample? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Were valid methods used for the identification of the condition? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Was the condition measured in a standard, reliable way for all participants? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Was there appropriate statistical analysis? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Was the response rate adequate, and if not, was the low response rate managed appropriately? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

1. Was the sample frame appropriate to address the target population?

Item guidance: This question relies upon knowledge of the broader characteristics of the population of interest and the geographical area. If the study is of women with breast cancer, knowledge of at least the characteristics, demographics and medical history is needed. The term “target population” should not be taken to infer every individual from everywhere or with similar disease or exposure characteristics. Instead, give consideration to specific population characteristics in the study, including age range, gender, morbidities, medications, and other potentially influential factors. For example, a sample frame may not be appropriate to address the target population if a certain group has been used (such as those working for one organisation, or one profession) and the results then inferred to the target population (i.e. working adults). A sample frame may be appropriate when it includes almost all the members of the target population (i.e. a census, or a complete list of participants or complete registry data).

Review considerations: Specific consideration was given to whether the sample frame appropriately addressed adults, aged 18-65 years, from the general population and did not focus on a specific subset, such as narrow location or only specific ethnicities. Community representativeness was addressed in the inclusion criteria.

2. Were study participants recruited in an appropriate way?

Item guidance: Recruitment is the calling or advertising strategy for gaining interest in the study, and is not the same as sampling. Studies may report random sampling from a population, and the methods section should report how sampling was performed. Random probabilistic sampling from a defined subset of the population

(sample frame) should be employed in most cases, however, random probabilistic sampling is not needed when everyone in the sampling frame will be included/analysed. For example, reporting on all the data from a good census is appropriate as a good census will identify everybody. When using cluster sampling, such as a random sample of villages within a region, the methods need to be clearly stated as the precision of the final prevalence estimate incorporates the clustering effect. Convenience samples, such as a street survey or interviewing lots of people at a public gathering are not considered to provide a representative sample of the base population.

Review considerations: No additional comments.

3. Was the sample size adequate?

Item guidance: The larger the sample, the narrower will be the confidence interval around the prevalence estimate, making the results more precise. An adequate sample size is important to ensure good precision of the final estimate. Ideally we are looking for evidence that the authors conducted a sample size calculation to determine an adequate sample size. This will estimate how many subjects are needed to produce a reliable estimate of the measure(s) of interest. For conditions with a low prevalence, a larger sample size is needed. Also consider sample sizes for subgroup (or characteristics) analyses, and whether these are appropriate. Sometimes, the study will be large enough (as in large national surveys) whereby a sample size calculation is not required. In these cases, sample size can be considered adequate.

When there is no sample size calculation and it is not a large national survey, the reviewers may consider conducting their own sample size analysis using the following formula (Daniel, 1999; Naing et al. 2006).

$$N = \frac{Z^2 P(1-P)}{d^2}$$

Where: N = sample size; Z=Z statistic for a level of confidence; P=Expected prevalence or proportion (in proportion of one; if 20%, P=0.2); d=precision (in proportion of one; if 5%, d=0.05).

Review considerations: The Z statistic of 1.96 for a 95% level of confidence was used; the expected prevalence was based on Linscott & van Os (2013) prevalence of collective hallucinations in the general population which is 0.06; and d was 0.03 following guidance from Naing and colleagues (2006) who recommend using d as half of P when P is below 0.1/10%. This provided a required sample size of 240.74.

4. Were the study subjects and setting described in detail?

Item guidance: Certain diseases or conditions vary in prevalence across different geographic regions and populations (e.g. women vs. men, sociodemographic variables between countries). The study sample should be described in sufficient detail so that other researchers can determine if it is comparable to the population of interest to them.

Review considerations: Based on the variables found in the introduction to be related to psychotic and psychotic-like symptoms, specific consideration was given to whether articles reported information on key demographics relating to age, gender, ethnicity and an approximation of social status.

5. Was data analysis conducted with sufficient coverage of the identified sample?

Item guidance: Coverage bias can occur when not all subgroups of the identified sample respond at the same rate. For instance, you may have a very high response rate overall for your study, but the response rate for a certain subgroup (i.e. older adults) may be quite low.

Review considerations: As there was frequently insufficient information to determine the differences between this item and item 9 (Was the response rate adequate, and if not, was the low response rate managed appropriately?), these items were combined to provide a generalised item regarding coverage bias. This item was rated in terms of whether the final sample used to determine the prevalence rate provided sufficient coverage of the identified sample, in terms of drop out overall and reasons for this and differential drop out within specific subgroups. As outlined in item 4, particular consideration was given to balance of age, gender, ethnicity and social status. When articles referred to analytic methods they used to account for sampling processes, (e.g. weighting), due to limited resources to explore these methods further, a decision was made to judge their weighting as sufficient.

6. Were valid methods used for the identification of the condition?

Item guidance: Here we are looking for measurement or classification bias. Many health problems are not easily diagnosed or defined and some measures may not be capable of including or excluding appropriate levels or stages of the health problem. If the outcomes were assessed based on existing definitions or diagnostic criteria, then the answer to this question is likely to be yes. If the outcomes were assessed using observer reported, or self-reported scales, the risk of over- or under-reporting is increased, and objectivity is compromised. Importantly, determine if the measurement

tools used were validated instruments as this has a significant impact on outcome assessment validity.

Review considerations: As the articles identified measured the condition of hearing voices only using specific items or similar, the following more item specific areas were considered:

- Clarity of item: Was there sufficient context provided to the item to reduce ambiguity and enable the participant to understand what is being asked? (e.g. hearing a voice vs hearing your name being called)
- Level of detail: Was there sufficient detail obtained to determine any ambiguities or misjudged endorsements? (e.g. follow up or clarification questions)
- Excluded experiences: Were any such misjudged endorsements excluded from endorsement rate? (e.g. hearing a voice under the influence of alcohol or sleep state).
- Objectivity of rating: Was the determination of this overall endorsement and potential exclusions based on self/participant rating, rated by lay interviewer or according to clinical judgment?

7. Was the condition measured in a standard, reliable way for all participants?

Item guidance: Considerable judgment is required to determine the presence of some health outcomes. Having established the validity of the outcome measurement instrument (see item 6 of this scale), it is important to establish how the measurement was conducted. Were those involved in collecting data trained or educated in the use of the instrument/s? If there was more than one data collector, were they similar in terms of level of education, clinical or research experience, or level of responsibility

in the piece of research being appraised? When there was more than one observer or collector, was there comparison of results from across the observers? Was the condition measured in the same way for all participants?

Review considerations: No additional comments.

8. Was there appropriate statistical analysis?

Item guidance: Importantly, the numerator and denominator should be clearly reported, and percentages should be given with confidence intervals. The methods section should be detailed enough for reviewers to identify the analytical technique used and how specific variables were measured. Additionally, it is also important to assess the appropriateness of the analytical strategy in terms of the assumptions associated with the approach as differing methods of analysis are based on differing assumptions about the data and how it will respond.

Review considerations: As above, items were required to provide a numerator and denominator, the percentage with confidence intervals or a means of easily computing this (e.g. providing standard error).

9. Was the response rate adequate, and if not, was the low response rate managed appropriately?

Item guidance: A large number of dropouts, refusals or “not founds” amongst selected subjects may diminish a study’s validity, as can a low response rates for survey studies. The authors should clearly discuss the response rate and any reasons for non-response and compare persons in the study to those not in the study, particularly with regards to their socio-demographic characteristics. If reasons for non-response appear to be unrelated to the outcome measured and the characteristics of

non-responders are comparable to those who do respond in the study (addressed in question 5, coverage bias), the researchers may be able to justify a more modest response rate.

Review considerations: This guidance was considered with item 5. See above.

Appendix D: Recruitment Materials: Study Poster and Flyer

An interesting opportunity



Many people have unusual experiences where they **hear, see or believe things** that others around them don't.

People who have these sorts of experiences can also regularly feel **intense and overwhelming emotions**.

We want to understand how these sorts of experiences relate to **childhood experiences**.

Help us to learn more by taking part in our study.

We are interested in people with a **range of these sorts of experiences**.

If you are **over 18 years** and would like to find out more about our study, which involves completing four short questionnaires, **please tear off a slip below**.

We will donate £1 to a NSPCC for every completed survey.

www.xxx.com rebecca.shirley@neft.nhs.uk 0300 555 1213							
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**An interesting opportunity
to contribute to research!**



Many people have unusual experiences where they **hear, see or believe things** that others around them don't.

People who have these sorts of experiences can also regularly feel **intense and overwhelming emotions**.

We want to understand how these sorts of experiences relate to **childhood experiences**.

Help us to learn more by taking part in our study.

We are interested in people with a **range of these sorts of experiences**. If you are **over 18 years** and would like to find out more about our study, which involves completing four short questionnaires, then please visit:

www.TBC.com

We will donate £1 to NSPCC for every completed online survey.

For further information, please contact:



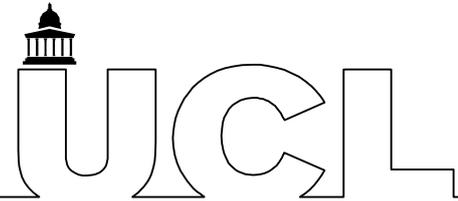
rebecca.shirley@nelft.nhs.uk



0300 555 1213

Appendix E: Covering Letter/Email

**RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY
UNIVERSITY COLLEGE LONDON
GOWER ST
LONDON
WC1E 6BT**



Dear Practice Manager/Team or service manager/Therapist,

We are currently undertaking a research study which seeks to explore the experience of psychotic symptoms in individuals with Borderline Personality Disorder (BPD) and we would like to ask for your support in helping us to recruit to the study.

It is an anonymous online study and all relevant information for potential participants can be found at www.psychologyresearch2016.com. From here, those consenting to participate in the study can access and complete the study questionnaires online. We are hoping to recruit participants with a range of severity of BPD symptoms and psychotic-like experiences from both clinical and non-clinical populations. The study is open to anyone meeting the inclusion criteria (over 18 years; no current diagnosis of schizophrenia, schizoaffective disorder, dementia or organic brain disorder; and able to read English and comprehend the measures). Therefore individuals without BPD can also take part in the study and if a sufficient sample size is recruited this data will be used as a non-BPD comparison group.

This study has been approved by the research committee in the clinical psychology department at UCL, by the NELFT research and development department and by London - Camberwell St Giles Research Ethics Committee.

We would be very grateful if you could support this study and help us to recruit participants. In particular we would be very grateful if you could:

1. Read the attached Project Information Sheet and inform service users who you feel may be suitable for the study by providing them with the attached flyers and/or details of the website to access the study.
2. Display the attached posters for the study in any appropriate areas accessible to service-users e.g. waiting rooms.
3. Circulate the attached Project Information Sheet, flyers and posters to any relevant staff members of your service who can then inform suitable service users of the study.

We are also happy to send out printed coloured copies of the posters and flyers in the post.

If there are other ways your organisation is able to support recruitment to this study it would be really appreciated. For example, by helping us to advertise the study through webpages or social media. The study twitter page is https://twitter.com/BPD_Research or @BPD_Research and the study Facebook page is <https://www.facebook.com/Psychology-research-BPD-and-psychotic-like-experiences-616727281819104/>

If you, your team members or your services users wish to speak to us directly about the study, we can be contacted on the email/phone number provided below. We are very happy to attend a team meeting if that would be helpful.

We very much appreciate your co-operation and support with this research study.

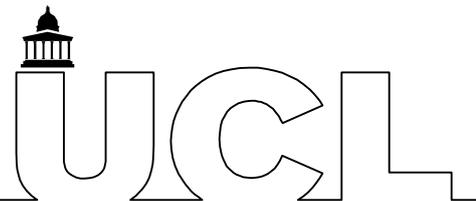
Yours sincerely,

Ms Rebecca Shirley
Principle Investigator
Trainee Clinical Psychologist

Dr Janet Feigenbaum
Chief Investigator, Strategic and Clinical Lead for
Personality Disorder Services, NELFT
Senior Lecturer & Consultant Clinical Psychologist

Email: [REDACTED]
[REDACTED]

Appendix F: Staff and Clinician Information Sheet



An exploration of the relationship between early childhood experiences and psychotic symptoms in borderline personality disorder (BPD) (Student study)

DCLinPsy students' research project

Broad Outline of Research Study

The aim of the study is to explore the experience of psychotic symptoms in individuals with BPD. More specifically it will seek to explore whether there is a relationship between early life experiences and the development of these symptoms in later life.

The presence of psychotic symptoms in BPD is well-established both clinically and within the existing research. However research into why and how these symptoms develop within this population is very limited. This means that our understanding of this phenomenon remains poor which has clinical implications for how clinicians support and treat individuals with BPD and psychotic symptoms. This is particularly important in light of the emerging evidence base which suggests that the phenomenological nature of these symptoms, in terms of their persistence, severity and emotional impact, is similar to those experienced by individuals with psychotic disorders. Please see Barnow and colleagues (2010) and Schroeder, Fisher and Schafer (2012) for recent reviews of the literature into these symptoms in BPD.

There is emerging evidence of a link between the experience of adversity in childhood and the development of psychotic symptoms in later life. This has been found in both the general population (Read, Argyle & Aderhold, 2003; Shevlin, Dorahy, & Adamson, 2007; Spauwen, Krabbendam, Lieb, Wittchen & Van Os, 2006) and in psychotic populations (see Skehan, Larkin & Read, 2012 for a review). However research exploring this link in BPD populations is limited. This study therefore seeks to examine this relationship in a sample of individuals with BPD.

The information gathered from the present study will allow us to learn more about these experiences in BPD and whether the experience of specific types of early life adversity influences their development. We hope to use the information provided by the study to help establish ways to improve services and psychological therapies for individuals with BPD who experience psychotic symptoms.

What does the study entail?

The study will involve participants completing a set of self-report questionnaires through an electronic patient database system. This system will be accessed by following a web link. Participants will first be presented with information about the study and asked to provide consent. If consent is provided they will continue to the following questionnaires:

1. Mclean Screening Instrument for Borderline Personality Disorder (MSI-BPD) (Zanarini et al. 2003)
2. The Childhood Experiences of Care and Abuse questionnaire (CECA-Q) (Bifulco, Brown & Harris, 1994)

3. The Community Assessment of Psychic Experiences (CAPE) (Stefanis et al. 2002)

They will also be asked for some demographic information, any current diagnoses they are aware of and current care they are receiving from mental health services. All participants will be allocated a unique identification number allowing the data to remain fully anonymised.

Due to the sensitive nature of the questionnaires a help sheet will be available to participants throughout the survey. This will contain emotion regulation and relaxation exercises and will provide them with information on where to seek further support if needed. This can be accessed by clicking a 'help' icon which is displayed on each page of the survey. At the end of the study a donation will be made on behalf of each participant to NSPCC as a thank you for their participation.

Who is eligible to take part?

The criteria for inclusion in the study are:

- Participants must be 18 years and older
- Participants must not have a current diagnosis of schizophrenia or schizoaffective disorder or a diagnosis of dementia or an organic brain disorder.
- Participants must be able to read English and comprehend the measures.
- Participants must be willing to provide informed consent

The study will be advertised to all individuals who self-identify as having BPD and experiencing some level of psychotic symptoms. Participants who score above the recommended cut off of seven points on the MSI-BPD will be placed into a BPD group and their data will be used in the main analyses of the study. Those who score below seven will be placed in a non-BPD group and if a sufficient sample size is recruited then the data from this group will be used as a non-BPD comparison sample. Participants will be recruited from a range of NHS mental health services as well from private and charity organisations and the general population. We are hoping to recruit participants with a range of severity of BPD symptoms and psychotic symptoms from both clinical and non-clinical populations.

How can I refer service users to the study?

Flyers and posters detailing the nature of the study and providing the website link to access the study will be circulated around the psychology and personality disorder departments at approved NHS sites; at local GP surgeries; to national PD organisations and through social media. We are asking staff members to display posters and identify and distribute flyers to potential participants whom they feel would be suitable for the study. Potential participants can then access the study online through the web link. If potential participants would prefer to complete the study offline, they can contact the research team to request paper versions of the questionnaires or discuss a face-to-face meeting (there will be limited capacity to accommodate this).

Ethical Approval

This study has been approved by the research committee in the clinical psychology department at UCL, by the NELFT research and development department and by London - Camberwell St Giles Research Ethics Committee (Project ID Number: 195153).

Funding

This study is being funded by UCL Student Research Funds.

Project Team

If you would like more information on the study please do not hesitate to contact a member of the research team using the details provided below.

Ms Rebecca Shirley: Trainee Clinical Psychologist at the Research Department of Clinical, Educational and Health Psychology, UCL.

Tel: 0300 555 1213

Email: [REDACTED]

Dr. Janet Feigenbaum: Strategic and Clinical Lead for Personality Disorder Services, North East London NHS Foundation Trust and Senior Lecturer at the Research Department of Clinical, Educational and Health Psychology, UCL.

Tel: [REDACTED]

[REDACTED]

Dr Niamh Moriarty: Clinical Psychologist, North East London NHS Foundation Trust.

Tel: [REDACTED]

[REDACTED]

References

Barnow, S., Arens, E.A., Sieswerda, S., Dinu-Biringer, R., Spitzer, C., & Lang, S. (2010). Borderline personality disorder and psychosis: a review. *Current Psychiatry Rep*, 12, 186-195.

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Zanarini, M.C., Vujanovic, A.A., Parachini, E.A., Boulanger, J.L., Frankenburg, F.R., & Hennen, J. (2003). A screening measure for BPD: The McLean screening instrument for borderline personality disorder (MSI-BPD). *Journal of Personality Disorders*, 17, 568-573.

Spauwen J, Krabbendam L, Lieb R, Wittchen, H.U., & van Os, J. (2006). Impact of psychological trauma on the development of psychotic symptoms: relationship with psychosis proneness. *British Journal of Psychiatry*, 188, 527–533.

**Appendix G: Mclean Screening Instrument for Borderline Personality Disorder
(MSI-BPD)**

[This scale has been removed for copyright purposes]

**Appendix H: Childhood Experiences of Care and Abuse Questionnaire
(CECA.Q)**

[This scale has been removed for copyright purposes]

Appendix I: Community Assessment of Psychic Experiences (CAPE)

[This scale has been removed for copyright purposes]

Appendix J: Demographic Information Questionnaire

Demographic Information

1. What is your gender?
 1. Male
 2. Female

2. What is your age?
 1. 18 to 24 years
 2. 25 to 34 years
 3. 35 to 44 years
 4. 45 to 54 years
 5. 55 to 64 years
 6. 65 years or older

3. What is your ethnicity?
 1. British White – English/Welsh/Scottish/Northern Irish
 2. British White – Gypsy or Irish Traveller
 3. British White – Any other white background
 4. British Asian – Indian
 5. British Asian – Pakistani
 6. British Asian – Bangladeshi
 7. British Asian – Chinese
 8. British Asian – Any other British Asian background
 9. British Black – African
 10. British Black – Caribbean
 11. British Black– Any other Black British background
 12. British Arab
 13. British – Mixed/Multiple Ethnic Groups - White and Black African
 14. British – Mixed/Multiple Ethnic Groups - White and Black Caribbean
 15. British – Mixed/Multiple Ethnic Groups - White and Asian
 16. British – Mixed/Multiple Ethnic Groups - Any other British mixed/multiple ethnic background
 17. Any other ethnic group i.e. non-British
 18. Do not wish to disclose

4. What is the highest degree or level of education that you have completed?
 1. Less than high school
 2. High school graduate (eg GCSEs)
 3. Completed college or sixth form (eg A Levels)
 4. Specialist qualifications (e.g. NVQ, BTECH, City & Guilds)
 5. University degree
 6. Postgraduate qualification
 7. Do not wish to disclose

- 5. What is your marital status?**
1. Single
 2. In a relationship and not living with your partner
 3. Living with partner
 4. Married
 5. Separated
 6. Widowed
 7. Divorced
 8. Do not wish to disclose

- 6. What is your employment status?**
1. Student
 2. Unemployed and not looking for work
 3. Unemployed and looking for work
 4. Employed part time
 5. Employed full time
 6. Home maker
 7. Retired
 8. Do not wish to disclose

7. Have you been diagnosed by a mental health professional as currently having any of the following disorders? Please tick any that apply.

1. Intellectual disability
2. Communication disorder, autistic spectrum disorder, attention-deficit/hyper-activity disorder (ADHD)
3. Schizophrenia
4. Schizoaffective Disorder
5. Bipolar and Related Disorder
6. Depressive Disorder
7. Anxiety Disorder (including phobia, social anxiety, panic, agoraphobia, generalised anxiety disorder).
8. Obsessive-compulsive disorder, body dysmorphic disorder, hoarding disorder
9. Trauma- and Stressor-Related Disorder (including post-traumatic stress disorder (PTSD))
10. Dissociative identity disorder
11. Anorexia nervosa, bulimia nervosa, binge-eating disorder
12. Personality Disorder – Paranoid, Schizoid or Schizotypal
13. Personality Disorder – Borderline
14. Personality Disorder – Antisocial, Histrionic or Narcissistic
15. Personality Disorder – Avoidant, Dependent, Obsessive-compulsive
16. I do not have any of the above disorders

8. Are you currently receiving any treatment from mental health services?

1. Yes
2. No

9a. Have you used any of the following substances in the past twelve months? Please tick any which apply.

1. Alcohol
2. Cannabis
3. Hallucinogens (a drug that causes hallucinations including LSD, Psilocybin (e.g. magic mushrooms), PCP, Ketamine)
4. Opioids (including heroin, prescription painkillers (e.g. oxycontin, vicodi, codeine, morphine))

5. Sedatives, hypnotics or anxiolytics (including benzodiazepines, barbiturates)
6. Stimulants (including amphetamine, ecstasy, cocaine)
7. Other
8. I do not use any of the above substances (please go to question 10).

9b. If you ticked any of the above substances, please answer the following questions (if you ticked more than three, please answer for the three substances the you use most regularly).

	Substance 1	Substance 2	Substance 3
Please specify the name of the substance:			
In the last <u>12 months</u> have you...			
... used this substance in larger amounts or over a longer period of time than intended?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... had a persistent desire or had unsuccessful efforts to cut down on or control your use of this substance?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... spent a great deal of time trying to obtain, use or recover from this substance?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... had cravings or a strong desire to use this substance?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... has your use of this substance led to a failure to fulfil your major role obligations at work, school or home?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... continued to use this substance despite having persistent or recurrent social or interpersonal problems which have been caused by or made worse by the use of this substance?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... given up or reduced important social, occupational or recreational activities because of this substance?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... continued to use this substance in situations where it has been physically hazardous?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... continued to use this substance despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to be caused by or made worse by the use of this substance?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
.. found that you need noticeably larger amounts of this substance to obtain the desired effect or has the same amount of the substance started to have a markedly smaller effect on you?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No
... found that you experience significant physical or psychological symptoms when you stop taking this substance or do you use this substance to avoid experiencing these symptoms?	1. Yes 2. No	1. Yes 2. No	1. Yes 2. No

10. How did you hear about the study?

1. GP surgery
2. Mental health charity
3. NHS staff
4. Social media
5. Flyer in other public space
6. Friend or relative
7. Other

Appendix K: REC Favourable Opinion



Health Research Authority

London - Camberwell St Giles Research Ethics Committee

Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 02071048055

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

20 June 2016

Dr Janet Feigenbaum
Department of Clinical, Educational and Health Psychology
University College London
Gower Street, London
WC1 6BT

Dear Dr Feigenbaum

Study title:	An exploration of the relationship between early childhood experiences and the development of psychotic symptoms in borderline personality disorder (BPD)
REC reference:	16/LO/0892
Protocol number:	16/0104
IRAS project ID:	195153

Thank you for your letter of 13 June 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the

date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Aiki Sifostatoudaki, nrescommittee.london-camberwellstgiles@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

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

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

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

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 8 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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

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

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

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

Ethical review of research sites

NHS sites

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

Approved documents

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

Document	Version	Date
Copies of advertisement materials for research participants [Study poster]	4.0	05 June 2016
Copies of advertisement materials for research participants [Study flyer]	4.0	05 June 2016
Covering letter on headed paper [Letter outlining amendments following provisional opinion]	1.0	12 June 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Certificate]		13 July 2015
GP/consultant information sheets or letters [Covering letter for clinicians and staff information sheet]	3.1	16 March 2016
GP/consultant information sheets or letters [Staff and clinician information sheet]	3.1	16 March 2016
IRAS Application Form [IRAS_Form_25042016]		25 April 2016
IRAS Checklist XML [Checklist_13062016]		13 June 2016
Non-validated questionnaire [Demographic Information Questionnaire]	4.1	16 March 2016
Other [Participant additional information sheet]	3.1	16 March 2016
Other [Participant help sheet for if distressed]	3.1	16 March 2016
Other [Participant debriefing sheet - participant exited study]	2.1	16 March 2016
Other [Participant debriefing sheet - participant completed study]	2.1	16 March 2016
Other [Website mock up]	1.0	10 June 2016
Participant consent form [Participant consent form (for electronic participants)]	1	16 March 2016
Participant consent form [Participant consent form (for non-electronic participants)]	3	16 March 2016
Participant information sheet (PIS) [Participant Information Sheet (for electronic participants)]	6.0	05 June 2016

Participant information sheet (PIS) [Participant Information Sheet (for non-electronic participants)]	2.0	05 June 2016
Referee's report or other scientific critique report [Peer review form]	1	29 September 2015
Research protocol or project proposal [Research Protocol]	5	15 April 2016
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator (CI)]		
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator (CI)]	1	20 December 2015
Summary CV for student [Rebecca Shirley CV]		
Summary CV for supervisor (student research) [Janet Felgenbaum CV]		
Summary CV for supervisor (student research) [Janet Felgenbaum CV]	1	20 December 2015
Validated questionnaire [Childhood Experiences of Care and Abuse - Questionnaire (CECA.Q)]	3.1	16 March 2016
Validated questionnaire [Community Assessment of Psychic Experiences (CAPE 42)]	2.1	16 March 2016
Validated questionnaire [Molean Screening Instrument for Borderline Personality Disorder (MSI-BPD)]	2.1	16 March 2016

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/LO/0892

Please quote this number on all correspondence

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

Yours sincerely



Chair

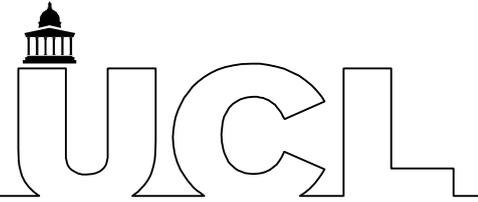
Email: nrescommittee.london-camberwellstgiles@nhs.net

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers" [SL-AR2]*

*Copy to: Ms Suzanne Emerton
Ms. Fiona Horton, R&D Department, North East London NHS Foundation Trust*

Appendix L: Participant Information Sheet

**RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY
UNIVERSITY COLLEGE LONDON
GOWER ST
LONDON
WC1E 6BT**



Title of Project: **An exploration of the relationship between early childhood experiences and psychotic symptoms in borderline personality disorder (BPD) (Student Study)**

This study has been approved by the **London - Camberwell St Giles Research Ethics Committee.** Project ID Number: **195153**

Name, Address and Contact Details: **Ms Rebecca Shirley, Principle Investigator, Trainee Clinical Psychologist
Dr Janet Feigenbaum, Chief Investigator, Senior Lecturer and Consultant Clinical Psychologist**

**Research Department of Clinical, Educational and Health Psychology
University College London
Gower Street
London WC1E 6BT**

**Project Telephone: 0300 555 1213
Project Email: Rebecca.Shirley@nelft.nhs.uk**

We would like to invite you to participate in this research study. You should only complete the study if you want to - choosing not to take part will not disadvantage you in any way.

Before you decide whether you want to take part, it is important for you to read the following information carefully. This will help you to understand why the research is being done and what it would involve for you. This is particularly important as this study may involve answering potentially upsetting questions – we have provided further advice on this in the ‘How might taking part affect me?’ section. If you would like more information please contact the researcher via the e-mail address or telephone details provided.

What is this research about?

Studies have shown that psychotic-like symptoms, such as feeling paranoid, being unsure of what is real or not, or hearing or seeing things that other people cannot, are relatively common in the general population and can be particularly common in individuals with Borderline Personality Disorder (BPD). BPD is a complex disorder that can cause unstable moods, behaviours and relationships. The experience of psychotic-like symptoms can have a significant and distressing

impact on an individual's life. However little is known about what causes these symptoms in people with BPD. Our understanding of how to support people with BPD going through these types of symptoms is therefore quite poor. This study aims to explore these sorts of experiences and to look at whether there is a link between negative childhood experiences and developing these experiences later in life. We are interested in understanding the experiences of people with BPD and compare to those without.

Who is organising and funding this study?

The research has been organised by Rebecca Shirley, Trainee Clinical Psychologist as part of her Clinical Psychology Doctorate. The research will be funded by UCL.

Who has reviewed this study?

This study has been reviewed by the research committee in the clinical psychology department at UCL, by the NELFT research and development department and by London – Camberwell St Giles Research Ethics Committee.

Why have I been invited to take part?

This research study has been advertised by flyers and posters which have been circulated to lots of different sites, including NHS sites and other public buildings, as well as online. This is so that potential participants can decide for themselves whether they would like to take part. We are interested in people with a range of the sorts of experiences described above.

Can I take part in this research?

You must be 18 years or older to take part in this research. Anyone who has a current diagnosis of Schizophrenia or Schizoaffective disorder or a diagnosis of dementia or organic brain disorder cannot participate in this research. If you have been told by a mental health professional (e.g. your GP or a psychiatrist) that you have a *current* diagnosis of any of the above disorders or if you are under treatment for any of these disorders, then unfortunately you cannot take part. If you are unsure if these diagnoses apply to you, please click on the relevant diagnosis for additional information.

What will it involve?

This survey contains four questionnaires, which focus on experiences consistent with Borderline Personality Disorder (BPD) and psychotic symptoms, difficult childhood experiences (including abuse and neglect), and some background information about you. Given the difficult topics covered, the questions asked could potentially be very upsetting. Please see the '**How might taking part affect me?**' section for more information and advice on this. Please note that around 5% of the population have experiences consistent with BPD and psychotic disorders - having these experiences does not necessary mean that you have either of these disorders.

This online survey is anonymous and your identity will remain completely unknown. The data from the completed questionnaires will only be seen by researchers in our team and we will not have any means of knowing who has completed the questionnaires.

Why should I get involved?

Your responses will help us to learn more about how common psychotic-like experiences are. We hope to use information provided by the study to help establish ways to improve services and psychological therapies for people with BPD who experience psychotic-like symptoms.

For each participant who completes the survey, £1* will be donated to NSPCC (National Society for the Prevention of Cruelty to Children). Your donation will help to support vulnerable children across the UK.

*This research is funded by UCL. Donations will be capped at a maximum of £260

How might taking part affect me?

The questions you will be asked may cover some topics that might be painful or upsetting to think about. If you feel upset or distressed during the survey, there is a "Help" button at the bottom of every page. This will open up a new tab with an information sheet. This sheet will provide you with strategies on how to relax and feel calm. It will also provide advice and links on how you can seek further support if needed. You can then return to the study – as you have not clicked the exit button- by closing the “Help” information sheet tab and clicking on the tab which has the study open on it.

We would recommend taking the online survey when you feel comfortable and in no way distressed. If you are currently experiencing high levels of distress we would suggest completing this survey at another time. We would also suggest that you complete the survey in a place that is private and has little distraction.

Will my information be kept confidential?

Yes. The study is designed to be anonymous and so we will not be collecting any personally identifiable information about you. For the data that is collected, we will follow ethical and legal practice and all information will be handled in confidence. All data will be stored in secure locations and on computers or flash drives which are password protected. Any published data will also be entirely anonymous meaning individuals cannot be identified. In accordance with the Data Protection Act and UCL Data Protection Policy the anonymous data from this study will be confidentially stored for twenty years after the study finishes.

How do I decide to take part?

If you decide to take part, you will be asked to provide consent for the study. If you agree to provide consent, you will be taken through to the questionnaires. If you decide that you do not want to provide consent for the study you will exit the survey. Remember, taking part in the study is entirely voluntary. It is your choice whether or not you would like to participate. Deciding not to take part in the study will not affect you or the care you receive in any way.

Can I exit the survey any time?

Even after giving consent, you will remain free to leave the study at any time and without giving a reason. On each page you will be able to leave the study by clicking the 'exit' button. This will immediately remove you from the online survey. This study is anonymous and we cannot save any

data from the survey until you have submitted it at the end. This means that if you exit the study before the end, we will be unable to redirect you back to your last completed page. If you choose to exit the study early and would like to complete the study at another time, you will need to start from the beginning. As the study is anonymous this also means that once you have submitted the survey we will be unable to identify you to withdraw your results.

What happens if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask Dr Janet Feigenbaum (Chief Investigator) if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with Dr Janet Feigenbaum, who is the Chief Investigator for the research who is based at University College London, please make the claim in writing to her. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

What if I do not want to use the internet?

Sometimes people have a strong preference or reason for not using the internet to complete questionnaires. If you would rather have a paper copy of these questionnaires sent to you, please use the contact details provided on this page to speak with a member of the research team about this.

How do I find out the results?

This research study will end in autumn 2017. A summary of the results will be uploaded on to the webpage (www.psychologyresearch2016.com) following completion of the study. This will be available for six months. The results of the study will be written up as part of the researcher's thesis for the Clinical Psychology Doctorate at University College London (UCL). The report of the study could also be published in relevant journals outside of UCL. As this survey is anonymous it will not be possible to identify you from any publications that may arise out of this research.

How do I contact the researchers?

If you wish to contact us to discuss any of the information further or any concerns you have about the study, then please do so by ringing [REDACTED]
[REDACTED]

Consent

Thank you very much for taking the time to read this information sheet. Do you wish to proceed? If so, please click 'NEXT'. By clicking 'NEXT', you confirm that you:

1. have understood the information provided in the above information sheet dated 09/03/16 (version 5.0) for the above study.

2. have been advised of an individual to contact for answers to questions about the research, advised of your rights as a participant and what to do and who to contact should you become unduly distressed.
3. have had the opportunity to consider the information in the information sheet and have been advised of your rights as a participant and whom to contact should you become unduly distressed and that you have been provided details of an individual to contact for answers to questions about the research and have had these answered satisfactorily.
4. understand that participation is voluntary and you are free to exit at any time during the study without any impact on your legal rights or any current or future health care you receive
5. understand that the information you provide will be anonymously included in the researcher's doctoral thesis, will be published as a report in a scientific journal and that the anonymous data collected from this study may be used to support other research in the future, and may be shared anonymously with other researchers.
6. confirm that you are over the age of 18 and do not have a current diagnosis or are not currently under treatment from mental health services for schizophrenia, schizoaffective disorder, dementia or any other organic brain disorder.
7. consent to take part in the above study.

If you do not consent to any of the above statement or decide not to participate please click 'EXIT'.

Rebecca Shirley
Trainee Clinical Psychologist

**Research Department of Clinical,
Educational and Health Psychology
University College London
Gower Street
London WC1E 6BT**

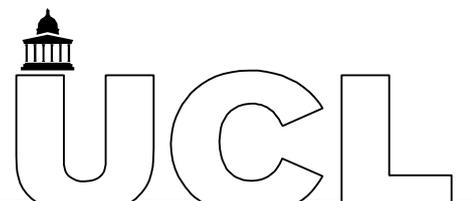
Dr. Janet Feigenbaum
Consultant Clinical Psychologist

**IMPART
Goodmayes Hospital
Barley Lane
Ilford
IG3 8XP**

Appendix M: Help sheet (for if distressed)

This page was displayed when participants clicked on the 'if distressed click here' icon on the bottom of each page of the survey.

RESEARCH DEPARTMENT OF CLINICAL,
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UNIVERSITY COLLEGE LONDON
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LONDON
WC1E 6BT



Help

Close this Tab if you would like to return to the survey

This sheet contains further support if you found any aspect of the survey distressing.

Further support

If you are experiencing any difficult emotions due to your participation in this study please consider the following suggestions to help manage the distress. **Relaxed Breathing, Deep muscle relaxation, Distraction, Visualisation, Mindfulness. Please scroll down to the end of this sheet for examples of each.**

If you would like to speak to someone about the way you feel you can call the Samaritans on **08457 90 90 90** or visit their website at <http://www.samaritans.org/>. They provide a confidential listening service. They are available for anyone in distress, not just for those who may be feeling suicidal.

If you are currently under the care of a mental health team you might find it helpful to contact your therapist or key worker. Alternatively you may find it helpful to **contact your GP** if your distress is ongoing.

If you do not feel you have received adequate support from the above services, you can contact the chief investigator of this project for support, Dr. Janet Feigenbaum (Strategic and Clinical Lead for Personality Disorder Services, North East London NHS Foundation Trust and Senior Lecturer, Research Department of Clinical, Educational and Health Psychology, UCL) on **0300 555 1213** during office hours or by email at janet.feigenbaum@nhs.net.

Additional Resources

Here are some resources where you may find further information about the topics covered in the research study.

Emergence

<http://www.emergenceplus.org.uk/>

Emergence is a service-user led organisation which provides knowledge and experiences of Borderline Personality Disorder (BPD) from a service user and carer perspective.

Mind

<http://www.mind.org.uk/>

Mind is a registered mental health charity which provides advice and support to individuals experiencing mental health problems.

Rethink

<http://www.rethink.org/>

Rethink is a registered mental health charity which provides advice and support to individuals experiencing mental health problems.

NSPCC

<https://www.nspcc.org.uk/>

NSPCC is registered charity which helps to support vulnerable children and young people at risk of, or currently experiencing, abuse or neglect.

Distress Management Exercises

The following exercises are designed to help reduce distress. Not all of these exercises will work for everyone and not all of them will help in every situation. However try to learn and use as many of them as possible as they have helped most people who experience strong emotions and who find them overwhelming.

Relaxed Breathing

Practise deep breathing in a quiet place where you won't be disturbed. Loosen or remove any tight clothes you have on, such as shoes or jackets.

Make yourself feel completely comfortable.

Sit in a comfy chair which supports your head or lie on the floor or a bed. Place your arms on the chair arms, or flat on the floor or bed, a little bit away from the side of your body with the palms up. If you're lying down, stretch out your legs, keeping them hip-width apart or slightly wider. If you're sitting in a chair, don't cross your legs.

Good relaxation always starts with focusing on your breathing. The way to do it is to breathe in and out slowly and in a regular rhythm as this will help you to calm down.

- Fill up the whole of your lungs with air, without forcing. Imagine you're filling up a bottle, so that your lungs fill from the bottom.
- Breathe in through your nose and out through your mouth.
- Breathe in slowly and regularly counting from one to five (don't worry if you can't reach five at first).
- Then let the breath escape slowly, counting from one to five.
- Keep doing this until you feel calm.
- Breathe without pausing or holding your breath.

Practice this relaxed breathing for three to five minutes, or until you feel calmer.

Deep muscle relaxation

This technique takes around 20 minutes. It stretches different muscles in turn and then relaxes them, to release tension from the body and relax your mind.

Find a warm, quiet place with no distractions. Get completely comfortable, either sitting or lying down. Close your eyes and begin by focusing on your breathing; breathing slowly and deeply, as described above.

If you have pain in certain muscles, or if there are muscles that you find it difficult to focus on, spend more time on relaxing other parts.

You may want to play some soothing music to help relaxation. As with all relaxation techniques, deep muscle relaxation will require a bit of practice before you start feeling its benefits.

For each exercise, hold the stretch for a few seconds, then relax. Repeat it a couple of times. It's useful to keep to the same order as you work through the muscle groups:

- **Face:** push the eyebrows together, as though frowning, then release.
- **Neck:** gently tilt the head forwards, pushing chin down towards chest, then slowly lift again.
- **Shoulders:** pull them up towards the ears (shrug), then relax them down towards the feet.
- **Chest:** breathe slowly and deeply into the diaphragm (below your bottom rib) so that you're using the whole of the lungs. Then breathe slowly out, allowing the belly to deflate as all the air is exhaled.
- **Arms:** stretch the arms away from the body, reach, then relax.
- **Legs:** push the toes away from the body, then pull them towards body, then relax.
- **Wrists and hands:** stretch the wrist by pulling the hand up towards you, and stretch out the fingers and thumbs, then relax.

Spend some time lying quietly after your relaxation with your eyes closed. When you feel ready, stretch and get up slowly.

Distraction

Distraction is a good technique to fend off symptoms of anxiety and stress when they feel overwhelming. This can also give you space to deal with a situation in a more considered and positive manner.

Distraction simply involves trying to take your mind off uncomfortable feelings or thoughts. You can do this by trying to focus on something unrelated. Often this helps them to pass.

Ideas to help distract you from your troubling thoughts or anxiety include:

- Try to appreciate small details in your surroundings.
- Count backwards from 1000 in multiples of 7.
- Focus on your breathing, for example, how it feels to breathe in and out.
- Count things that you can see that begin with a particular letter.
- Visualise being in a pleasant, safe and comfortable environment (e.g. being on a beach).
- Listen to your favourite music. Try to pick out all the different instruments and sounds that you can hear.

As with any relaxation exercise, it may take a few minutes before you begin to feel like it is working.

Visualisation

A quick way of getting away from a situation without physically leaving.

- Imagine yourself walking to a door
- Open the door and walk down the 3 steps, taking a deep breath for each of the steps
- You walk into an environment where you feel relaxed and calm. This could be a familiar place, a happy memory, or somewhere in your dream
- What can you see?
- What can you hear?
- What can you smell?
- What can you touch?

Spend a few minutes in this place, enjoying the feeling of relaxation

When you feel ready, start to make your way back up the steps, taking a breath for each of the three steps. Make your way back through the door and back into the present.

Mindfulness

"Leaves on a Stream" Exercise

(1) Sit in a comfortable position and either close your eyes or rest them gently on a fixed spot in the room.

(2) Visualize yourself sitting beside a gently flowing stream with leaves floating along the surface of the water. Pause 10 seconds.

(3) For the next few minutes, take each thought that enters your mind and place it on a leaf... let it float by. Do this with each thought – pleasurable, painful, or neutral. Even if you have joyous or enthusiastic thoughts, place them on a leaf and let them float by.

(4) If your thoughts momentarily stop, continue to watch the stream. Sooner or later, your thoughts will start up again. Pause 20 seconds.

(5) Allow the stream to flow at its own pace. Don't try to speed it up and rush your thoughts along. You're not trying to rush the leaves along or "get rid" of your thoughts. You are allowing them to come and go at their own pace.

(6) If your mind says "This is dumb," "I'm bored," or "I'm not doing this right" place those thoughts on leaves, too, and let them pass. Pause 20 seconds.

(7) If a leaf gets stuck, allow it to hang around until it's ready to float by. If the thought comes up again, watch it float by another time. Pause 20 seconds.

(8) If a difficult or painful feeling arises, simply acknowledge it. Say to yourself, "I notice myself having a feeling of boredom/impatience/frustration." Place those thoughts on leaves and allow them float along.

(9) From time to time, your thoughts may hook you and distract you from being fully present in this exercise. This is normal. As soon as you realize that you have become side tracked, gently bring your attention back to the visualization exercise.

Appendix N: Endorsement of CAPE scores by frequency and dimension

Item: Do you ever...	Non-BPD sample (N=178)					BPD (N=176)				
Positive dimension	Any frequency	Never	Sometimes	Often	Nearly always	Any frequency	Never	Sometimes	Often	Nearly always
2. feel as if people seem to drop hints about you or say things with a double meaning?	118 (60.2%)	78 (39.8%)	88 (44.9%)	27 (13.8%)	3 (1.5%)	166 (93.3%)	12 (6.7%)	51 (28.7%)	61 (34.3%)	54 (30.3%)
5. feel as if things in magazines or on TV were written especially for you?	51 (26.0%)	145 (74.0%)	41 (20.9%)	10 (5.1%)	-	93 (52.2%)	85 (47.8%)	66 (37.1%)	23 (12.9%)	4 (2.2%)
6. feel as if some people are not what they seem to be?	167 (85.2%)	29 (14.8%)	105 (53.6%)	54 (27.6%)	8 (4.1%)	172 (96.6%)	6 (3.4%)	49 (27.5%)	73 (41.0%)	50 (28.1%)
7. feel as if you are being persecuted in some way?	61 (31.1%)	135 (68.9%)	48 (24.5%)	10 (5.1%)	3 (1.5%)	141 (79.2%)	37 (20.8%)	62 (34.8%)	54 (30.3%)	25 (14.0%)
10. feel as if there is a conspiracy against you?	29 (14.8%)	167 (85.2%)	21 (10.7%)	6 (3.1%)	2 (1.0%)	113 (63.5%)	65 (36.5%)	60 (33.7%)	34 (19.1%)	19 (10.7%)
11. feel as if you are destined to be someone very important?	88 (44.9%)	108 (55.1%)	61 (31.1%)	19 (9.7%)	8 (4.1%)	82 (46.1%)	96 (53.9%)	48 (27.0%)	22 (12.4%)	12 (6.7%)
13. feel that you are a very special or unusual person?	101 (51.5%)	95 (48.5%)	70 (35.7%)	24 (12.2%)	7 (3.6%)	117 (65.7%)	61 (34.3%)	63 (35.4%)	31 (17.4%)	23 (12.9%)
15. think that people can communicate telepathically?	51 (26.0%)	145 (74.0%)	39 (19.9%)	9 (4.6%)	3 (1.5%)	83 (46.6%)	95 (53.4%)	56 (31.5%)	21 (11.8%)	6 (3.4%)
17. feel as if electrical devices such as computers can influence the way you think?	46 (23.5%)	150 (76.5%)	28 (14.3%)	16 (8.2%)	2 (1.0%)	61 (34.3%)	117 (65.7%)	39 (21.9%)	14 (7.9%)	8 (4.5%)

20. believe in the power of witchcraft, voodoo or the occult?	43 (21.9%)	153 (78.1%)	26 (13.3%)	12 (6.1%)	5 (2.6%)	84 (47.2%)	94 (52.8%)	41 (23.0%)	17 (9.6%)	26 (14.6%)
22. feel that people look at you oddly because of your appearance?	97 (49.5%)	99 (50.5%)	72 (36.7%)	18 (9.2%)	7 (3.6%)	159 (89.3%)	19 (10.7%)	52 (29.2%)	56 (31.5%)	51 (28.7%)
24. feel as if the thoughts in your head are being taken away from you?	17 (8.7%)	179 (91.3%)	14 (7.1%)	3 (1.5%)	-	64 (36.0%)	114 (64.0%)	33 (18.5%)	23 (12.9%)	8 (4.5%)
26. feel as if the thoughts in your head are not your own?	27 (13.8%)	169 (86.2%)	20 (10.2%)	5 (2.6%)	2 (1.0%)	90 (50.6%)	88 (49.4%)	51 (28.7%)	27 (15.2%)	12 (6.7%)
28. have thoughts so vivid that you were worried other people would hear them?	36 (18.4%)	160 (81.6%)	29 (14.8%)	6 (3.1%)	1 (0.5%)	101 (56.7%)	77 (43.3%)	57 (32.0%)	22 (12.4%)	22 (12.4%)
30. hear your own thoughts being echoed back to you?	40 (20.4%)	156 (79.6%)	34 (17.3%)	4 (2.0%)	2 (1.0%)	103 (57.9%)	75 (42.1%)	54 (30.3%)	27 (15.2%)	22 (12.4%)
31. feel as if you are under the control of some force or power other than yourself?	19 (9.7%)	177 (90.3%)	14 (7.1%)	3 (1.5%)	2 (1.0%)	70 (39.3%)	108 (60.7%)	48 (27.0%)	15 (8.4%)	7 (3.9%)
33. hear voices when you are alone?	21 (10.7%)	175 (89.3%)	17 (8.7%)	2 (1.0%)	2 (1.0%)	90 (50.6%)	88 (49.4%)	55 (30.9%)	24 (13.5%)	11 (6.2%)
34. hear voices talking to each other when you are alone?	14 (7.1%)	182 (92.9%)	9 (4.6%)	3 (1.5%)	2 (1.0%)	52 (29.2%)	126 (70.8%)	29 (16.3%)	15 (8.4%)	8 (4.5%)
41. feel as if a double has taken the place of a family member, friend or acquaintance?	8 (4.1%)	188 (95.9%)	3 (1.5%)	5 (2.6%)	-	38 (21.3%)	140 (78.7%)	29 (16.3%)	6 (3.4%)	3 (1.7%)
42. see objects, people or animals that other people cannot see?	22 (11.2%)	174 (88.8%)	17 (8.7%)	4 (2.0%)	1 (0.5%)	68 (38.2%)	110 (61.8%)	45 (25.3%)	13 (7.3%)	10 (5.6%)

Negative dimension	Any frequency	Never	Sometimes	Often	Nearly always	Any frequency	Never	Sometimes	Often	Nearly always
3. feel that you are not a very animated person?	111 (56.6%)	85 (43.4%)	78 (39.8%)	24 (12.2%)	9 (4.6%)	153 (86.0%)	25 (14.0%)	73 (41.0%)	49 (27.5%)	31 (17.4%)
4. feel that you are not much of a talker when you are conversing with other people?	132 (67.3%)	64 (32.7%)	84 (42.9%)	35 (17.9%)	13 (6.6%)	156 (87.6%)	22 (12.4%)	65 (36.5%)	42 (23.6%)	49 (27.5%)
8. feel that you experience few or no emotions at important events?	93 (47.4%)	103 (52.6%)	61 (31.1%)	21 (10.7%)	11 (5.6%)	151 (84.8%)	27 (15.2%)	62 (34.8%)	47 (26.4%)	42 (23.6%)
16. feel that you have no interest to be with other people?	127 (64.8%)	69 (35.2%)	101 (51.5%)	22 (11.2%)	4 (2.0%)	165 (92.7%)	13 (7.3%)	73 (41.0%)	59 (33.1%)	33 (18.5%)
18. feel that you are lacking in motivation to do things?	166 (84.7%)	30 (15.3%)	106 (54.1%)	48 (24.5%)	12 (6.1%)	174 (97.8%)	4 (2.2%)	32 (18.0%)	66 (37.1%)	76 (42.7%)
21. feel that you are lacking in energy?	174 (88.8%)	22 (11.2%)	107 (54.6%)	42 (21.4%)	25 (12.8%)	175 (98.3%)	3 (1.7%)	33 (18.5%)	71 (39.9%)	71 (39.9%)
23. feel that your mind is empty?	66 (33.7%)	130 (66.3%)	59 (30.1%)	5 (2.6%)	2 (1.0%)	119 (66.9%)	59 (33.1%)	58 (32.6%)	37 (20.8%)	24 (13.5%)
25. feel that you are spending all your days doing nothing?	99 (50.5%)	97 (49.5%)	64 (32.7%)	25 (12.8%)	10 (5.1%)	164 (92.1%)	14 (7.9%)	56 (31.5%)	49 (27.5%)	59 (33.1%)
27. feel that your feelings are lacking in intensity?	76 (38.8%)	120 (61.2%)	57 (29.1%)	15 (7.7%)	4 (2.0%)	114 (64.0%)	64 (36.0%)	66 (37.1%)	35 (19.7%)	13 (7.3%)
29. feel that you are lacking in spontaneity?	113 (57.7%)	83 (42.3%)	92 (46.9%)	15 (7.7%)	6 (3.1%)	141 (79.2%)	37 (20.8%)	71 (39.9%)	49 (27.5%)	21 (11.8%)
32. feel that your emotions are blunted?	73 (37.2%)	123 (62.8%)	57 (29.1%)	12 (6.1%)	4 (2.0%)	137 (77.0%)	41 (23.0%)	78 (43.8%)	41 (23.0%)	18 (10.1%)

35. feel that you are neglecting your appearance or personal hygiene?	81 (41.3%)	115 (58.7%)	66 (33.7%)	11 (5.6%)	4 (2.0%)	153 (86.0%)	25 (14.0%)	83 (46.6%)	51 (28.7%)	19 (10.7%)
36. feel that you can never get things done?	133 (67.9%)	63 (32.1%)	94 (48.0%)	28 (14.3%)	11 (5.6%)	171 (96.1%)	7 (3.9%)	60 (33.7%)	59 (33.1%)	52 (29.2%)
37. feel that you have only few hobbies or interests?	128 (65.3%)	68 (34.7%)	78 (39.8%)	38 (19.4%)	12 (6.1%)	163 (91.6%)	15 (8.4%)	52 (29.2%)	49 (27.5%)	62 (34.8%)

Depressive dimension	Any frequency	Never	Sometimes	Often	Nearly always	Any frequency	Never	Sometimes	Often	Nearly always
1. feel sad?	189 (96.4%)	7 (3.6%)	127 (64.8%)	55 (28.1%)	7 (3.6%)	178 (100%)	-	22 (12.4%)	80 (44.9%)	76 (42.7%)
9. feel pessimistic about everything?	129 (65.8%)	67 (34.2%)	88 (44.9%)	30 (15.3%)	11 (5.6%)	172 (96.6%)	6 (3.4%)	43 (24.2%)	61 (34.3%)	68 (38.2%)
12. feel as if there is no future for you?	89 (45.4%)	107 (54.6%)	67 (34.2%)	17 (8.7%)	5 (2.6%)	168 (94.4%)	10 (5.6%)	59 (33.1%)	53 (29.8%)	56 (31.5%)
14. feel as if you do not want to live anymore?	80 (40.8%)	116 (59.2%)	62 (31.6%)	14 (7.1%)	4 (2.0%)	163 (91.6%)	15 (8.4%)	60 (33.7%)	55 (30.9%)	48 (27.0%)
19. cry about nothing?	108 (55.1%)	88 (44.9%)	87 (44.4%)	19 (9.7%)	2 (1.0%)	155 (87.1%)	23 (12.9%)	68 (38.2%)	59 (33.1%)	28 (15.7%)
38. feel guilty?	170 (86.7%)	26 (13.3%)	114 (58.2%)	44 (22.4%)	12 (6.1%)	172 (96.6%)	6 (3.4%)	38 (21.3%)	50 (28.1%)	84 (47.2%)
39. feel like a failure?	141 (71.9%)	55 (28.1%)	94 (48.0%)	35 (17.9%)	12 (6.1%)	176 (98.9%)	2 (1.1%)	28 (15.7%)	41 (23.0%)	107 (60.1%)
40. feel tense?	177 (90.3%)	19 (9.7%)	99 (50.5%)	59 (30.1%)	19 (9.7%)	177 (99.4%)	1 (0.6%)	20 (11.2%)	62 (34.8%)	95 (53.4%)