

MAKING SENSE OF THE EXPERIENCE OF VISUAL HALLUCINATIONS IN
PSYCHOSIS: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS.

by

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A THESIS SUBMITTED TO THE UNIVERSITY OF BIRMINGHAM FOR THE
DEGREE OF DOCTOR OF CLINICAL PSYCHOLOGY.

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Thesis Overview

This thesis is comprised of two volumes. Volume I consists of the research component whilst Volume II comprises the written clinical component based on work completed during training.

Volume I is comprised of a systematic meta-analysis, an empirical research paper and a press release. The meta-analysis reviews literature that investigated the impact of cognitive behavioural approaches on distress for those with a first or early episode psychosis. No main significant effect was found but, a significant effect was found within non-specialised services. The empirical research paper used interpretative phenomenological analysis to explore how visual hallucinations are experienced and made sense of within a schizophrenia spectrum diagnosis. Five superordinate themes were identified: 'It's not only a visual experience', 'Agency', 'Role of others', 'Coming to know the experience' and 'Creating a narrative'.

Volume II is comprised of five clinical practice reports (CPRs). CPR1 presents the formulation of a young person with low self-esteem from both a cognitive-behavioural and psychodynamic perspective. CPR2 is a service evaluation exploring staff experiences of discharging families within the service framework of the Choice and Partnership Approach. CPR3 is a single case experimental design assessing the effectiveness of a behavioural intervention with a young boy with learning disabilities. CPR4 is a case study of an 81-year-old woman with anxiety who received cognitive-behavioural therapy. An abstract summarising CPR5, a clinical presentation of a young man with first episode psychosis who received psychodynamic therapy is presented.

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VOLUME ONE

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Do Cognitive Behavioural Approaches to First Episode Psychosis Change an Individual's Experience of Distress Beyond that of Treatment as Usual? A Systematic Review and Meta-Analysis of the Literature.

Abstract

Introduction: This systematic review and meta-analysis reviews the literature regarding the impact of cognitive behavioural approaches (CBA) on distress for people with first episode or early psychosis compared to treatment as usual. Acceptable measures of psychological distress were identified from the literature; measures of the impact of psychotic symptoms on distress were also acceptable.

Method: Systematic searches yielded 14 studies to be meta-analysed. Information to calculate standard mean difference was extracted. Studies were rated for their methodological quality using a risk of bias tool. The quality of included studies was varied. Contamination bias and performance bias were domains with the most risk of bias.

Analysis: The generic inverse variance random effects model was calculated. No significant effect main effect was found. The quality effects model was calculated and resulted in a 55% increase in treatment effect size which remained non-significant and negligible. Planned subgroup analyses were carried out: 1) Distress: hopelessness showed a significantly larger effect in the intervention condition, 2) Service context: a significant effect was found in non-specialised services.

Conclusion: Outcomes suffered as the studies were not designed to measure distress or assess the impact of a specific therapy. Furthermore, the lack of effect

may be attributable to the use of specialist early-intervention services as treatment as usual; when the data was considered in light of service context an effect of CBA was found in non-specialised services.

Future research: would benefit from using distress measures as a primary outcome and reporting distress subscales of PSYRATS. Therapies other than CBA would benefit from investigation to consider the unique contribution they could make to service users' care.

Clinical implications: selection of service users for CBA should be carefully considered to weigh up the return for the service user beyond that which they would get from early-intervention services treatment as usual.

Introduction

Cognitive Behavioural Therapy for Psychosis (CBTp) and Distress

Cognitive behavioural therapy for psychosis (CBTp) is accepted as the recommended therapy for individuals struggling with psychosis and schizophrenia, including those experiencing a first episode of psychosis (National Institute for Health and Care Excellence (NICE), (2014). However, there has been debate in the literature regarding the best way to measure the effectiveness of CBTp. Primarily the debate has concerned whether outcome is best captured as symptom reduction or as changes in emotional experience: “The primacy of distress is a core principle of CBT, but CBT for psychosis has not always followed this, given its primary emphasis on psychosis outcomes.” (Birchwood & Trower, 2006 p. 107).

Birchwood and Trower’s (2006) paper marked an important shift away from CBT as a ‘quasi-neuroleptic’ and a return to the human experience of emotion and distress as a primary outcome (Bernard, Jackson & Birchwood, 2015). This is now acknowledged in NICE guidance which recommends that CBT should include a focus on “reducing distress” (NICE, 2014 p. 23).

A recent meta-analysis (Lincoln & Peters, 2019) considered the impact of cognitive behavioural approaches (CBA) to delusions and hallucinations. Twelve studies were eligible for review and most studies utilised a measure of distress as an outcome tool suggesting that literature in this area has indeed shifted.

Distress and First Episode Psychosis (FEP)

The literature investigating the use of CBT at the onset of psychosis has also suffered from a theoretical and philosophical mismatch between the focus of

outcome measurement and the core principles of the cognitive behavioural model (Morrison, 2009). Given the wide-ranging difficulties associated with the onset of psychosis (Birchwood, Todd & Jackson, 1998) the concept of distress is arguably in need of even more urgent attention than in those individuals with long standing psychotic symptoms. Furthermore, emotional experience has been foregrounded as a key underlying psychological process in the experience of psychosis (Vodušek, Parnas, Tomori, & Škodlar, 2014).

Qualitative research into the experience of the onset of psychosis has identified multiple sources of distress that arise with this first episode. A recent meta-synthesis (Griffiths, Mansell, Edge & Tai, 2019) of 33 first-person studies identified two superordinate themes: intrapersonal distress and interpersonal distress. Intrapersonal distress stemmed from the internal experience of the individual, seen in themes of unwanted internal states, conflicts and dilemmas, changes in sense of self and identity, disrupted goals and, physical health difficulties. Interpersonal distress arose from the individuals' perceptions of their interactions with others. This was seen in themes of abusive and traumatic life experiences, contact with health care professionals, personal relationships and, stigma. As such, recovery from early psychosis is arguably more complex than a reduction in a set of symptoms (Tan, Gould, Combes & Lehmann, 2014) and attention must be paid to the role of distress with the aim of reducing emotional dysfunction, rather than on symptom reduction (Bernard et al., 2015).

The aim of CBT to reduce distress, rather than to reduce symptoms, is key not only for professional understanding but is an essential message for service users. Knowing what a therapy aims to change is a key ethical principle and will influence

expectations of therapy which are an important factor in therapeutic process and outcome (Greenberg, Constantino, & Bruce, 2006).

What Constitutes Distress?

The scope of this review is not broad enough to consider all the elements of distress described in the previous section. Nor is the literature advanced enough to report on or have the tools to quantitatively measure all these elements of distress. As such, this review is limited to psychometrically valid and reliable psychological measures of distress that previous literature has identified as important in the psychosis population, specifically:

- Bernard et al. (2015) argue that emotional dysfunction is best targeted through distress. Measures of anxiety, depression, social anxiety and trauma are identified to be useful and important facets of distress in the psychosis population (Bernard et al., 2015). Hopelessness, often associated with depression, has been identified as part of the pathway to emotional dysfunction in psychosis (Birchwood, 2003) and a key predictor of later outcomes in psychosis when the FEP population was followed longitudinally (Aguilar et al., 1997).
- Self-esteem has been found to be a key element of distress in FEP (Vracotas, Schmitz, Joober, & Malla, 2007) and a strong predictor of functional recovery (Vracotas, Srividya, Iyer, Joober & Malla, 2012).
- Broad measures of overall distress and distress caused by the symptoms of psychosis will be considered, as used in a recent meta-analysis of CBT for schizophrenia (Laws, Darlington, Kondel, McKenna

& Jauhar 2018). Namely, the Global severity index of the SCL-90-R and the distress dimensions of the PSYRATS as identified by Woodward et al., (2014).

These outcome measures fit well with Griffiths et al.'s (2019) superordinate theme of intrapersonal distress.

What do we Mean by First Episode Psychosis?

The notion of first episode psychosis as a distinct developmental stage began to be seen in the literature in the 1980s (Targum, 1983) when schizophrenia researchers were searching for a medically untreated population. Since then the term has developed to represent a broader understanding of psychosis that embraces diagnostic uncertainty (Farmer, 2010). Birchwood, Todd and Jackson (1998) identified the early phase of psychosis (i.e. the first two-five years following positive symptom onset) as a distinct and critical period during which time biological, social and psychological factors are most amenable to intervention. This led to the genesis of specialist early intervention for psychosis services that take advantage of this critical period to offer early access to support with the aim of improving long term outcomes.

Examination of the literature suggests that 'first-episode' has been interpreted and applied in many ways. Breitborde, Srihari and Woods (2009) identified three key operational definitions that summarised the majority of the interpretations of 'first-episode': (i) first treatment contact with services; (ii) duration of antipsychotic medication use; (iii) duration of psychosis.

The first of these refers to the first time a person receives clinical treatment for psychosis and is not equivalent to first attempts to seek help from services. The second refers to the duration of untreated psychosis (DUP), the reduction of which is a routine EIP service goal and identifies a first episode of psychosis as one which has yet to be treated with anti-psychotics. There is variation in the accepted duration of use of anti-psychotic medication to be considered 'first-episode': from a cut-off of no more than three days (Emsley, 1999), to less than six months use (Murray et al., 2008). The third of these definitions, duration of psychosis, identifies a person to be in their 'first episode' if they have experienced psychotic symptoms for less than a specified amount of time. One challenge of this definition is that it relies on service users and their carers to accurately identify the onset of psychotic symptoms. Whilst this can be mitigated with measures and experienced clinical skills, a furthermore challenging difficulty is that the literature does not agree on an end point for a first episode. The critical period hypothesis would suggest that the end point would be some two to five years after symptom onset. However, there is not yet enough evidence to validate an appropriate temporal cut off within this two to five-year period (Breitborde et al., 2009).

Evidently there is considerable variation in the literature regarding how to define a 'first episode' of psychosis. Typically, the term is used to describe: "individuals early in the course of a psychotic illness or treatment rather than individuals who are truly in the midst of a first 'episode' of illness." (Breitborde et al., 2009 pp 259).

The current review embraces the fluidity of this terminology to reflect the current state of the literature, and clinical practice. As such the review will consider

populations described as both ‘first episode’ and early psychosis as seen in Morrison (2009). Early psychosis was taken to be anything within the critical period of less than five years (Birchwood, Todd & Jackson, 1998). Further to this, participants who are under the care of specialised EIP services were eligible for the review (as was seen in Griffiths et al., 2019). These criteria makes the findings directly applicable to individuals experiencing first episode/early psychosis, and to those providing their care.

CBTp or Cognitive Behavioural Approaches?

The distinction of CBT for psychosis (CBTp) from the CBT model applied to reduce distress in individuals experiencing psychosis is somewhat hazy. A recent systematic review of cognitive behavioural approaches for symptoms of psychosis identified a tendency for research groups to brand and package their therapy for psychosis in idiosyncratic ways when there is little discernible difference between the therapies (Lincoln & Peters, 2019). Furthermore, Hayes and Hofmann (2017) argue that the therapeutic process of reducing distress should be emphasised, rather than “trademarked intervention protocols” within diagnostic categories (Hayes & Hofmann, 2017. pp 245). Therefore, in line with Hayes and Hofmann (2017) the current study will follow Lincoln and Peters (2019) and focus on CB approaches rather than on CBTp.

Review Question

The aim of this review is to answer the following question: What impact do cognitive behavioural approaches have on the distress felt by people during their first/early episode of psychosis, above that of routine care?

The 'PICO' framework (Population, Intervention, Control and Outcome) was used to develop the research question and search terms due as recommended by the Cochrane collaboration (Higgins & Green, 2011).

Systematic Search Method

Electronic Database Search

A systematic search of the literature was carried out in March 2018. The search terms were guided by those used in a similar review (Lincoln & Peters, 2019) that reviewed distress and symptom reduction following cognitive behavioural approaches for delusions and hallucinations. The search terms used for the current systemic review are detailed in Table 1 below. The databases Psychinfo, CINAHL, Medline and Web of Science were used to search the literature using the terms in Table 1.

Distress was too broad a construct to be usefully included in the search terms. Therefore, distress was hand searched for in the full text of the articles after the title screen had been completed.

Table 1

Search terms used for systematic review of the literature

Construct (and aspect of PICO framework)	Search strategy number	Search terms	Combined	Combined
Cognitive Behavioural (Intervention)	1	CBT "cognitive-behavior*" "cognitive behavior*" "cognitive"	OR	AND
Approaches (Intervention)	2	therapy intervention treatment trial	OR	

First episode psychosis (Population)	3	"Early psychosis" "first episode psychosis" "first episode of psychosis" "first-episode psychosis" "first episode schizophrenia" "first episode of schizophrenia" "first-episode schizophrenia" FEP "early intervention for psychosis" "early intervention in psychosis"	OR	AND
Distress (Outcome)	4	N/A	N/A	N/A

Note: Limiters of peer reviewed journal and human subjects were used where possible. Searches were not limited by full text or language

Excluding the second search term, which relates to the ‘approaches’ element of the title, was considered. However, preliminary searches without ‘approaches’ search terms did not yield any additional articles. It was therefore decided to include the ‘approaches’ search strategy to map the search terms as closely as possible to the research question.

Inclusion and Exclusion Criteria

Full inclusion and exclusion criteria are detailed below in Table 2. In order to gain an overview of the impact that cognitive behavioural approaches have on distress for people experiencing a first episode of psychosis the criteria were fairly

broad. This is due to the heterogeneity and relative youth of the literature. The main criteria were any controlled intervention study where the intervention utilises cognitive and/or behavioural approaches with people who meet the criteria for a first episode/early psychosis.

Table 2

Inclusion criteria and rationale

Inclusion criteria	Justification
<p>Participants</p> <p>Studies must have a sample of participants who have a first episode of psychosis or who meet the criteria for a specialist early intervention in psychosis (EIP) service. These specialist services provide care to those experiencing a first episode of psychosis.</p> <p>Where a mixed population is sampled, for example, FEP and chronic schizophrenia the data for the two population groups must be identifiable and separable.</p> <p>Studies that did not provide enough detail for the participant sample to be adequately assessed were excluded.</p>	<p>As in Griffiths et al., (2019) this criterion allows the findings to be directly applicable to services providing care for those experiencing a first episode of psychosis. The more flexible criteria of suitability for EIP services gathers clinically relevant data and is reflective of the varied definition of “first episode” in the research (Breitborde et al., 2009).</p> <p>To reduce heterogeneity in the sample and facilitate the findings of the review to answer the review question.</p> <p>These studies did not allow the relevance of the sample to the review question.</p>

<p>Participants that are classed as ultra high risk/at risk mental state were excluded</p>	<p>These participants do not allow the review question to be answered as they have not experienced psychosis.</p>
<p><i>Intervention</i></p> <p>A cognitive behavioural intervention incorporating belief modification work and/or behavioural/experiential work. The intervention may include other therapeutic elements and need not be focused specifically on psychosis.</p> <p>The intervention must have been provided directly to the participant.</p>	<p>These criteria reflect the heterogeneity of the literature in this population. It allows some specificity to be maintained whilst including interventions outside of formal “CBTp” of which there are few suitable studies in this population.</p> <p>Examples include the involvement of family members and focus on substance use.</p> <p>Studies where the intervention was provided to family members in the service user’s absence were excluded. It is not possible to assess the impact of the CB approach without the mediating factor of the familial relationship.</p>
<p><i>Outcome Measure</i></p> <p>Distress must be reported on by the participant using validated and standardized outcome measures of distress at both the pre and post intervention.</p>	<p>To allow the findings of the review to answer the review question with validity.</p>
<p><i>Outcome data</i></p> <p>The studies are required to report either Means and</p>	<p>To ensure that outcomes can be calculated into an effect size.</p>

Standard Deviations, or F- Test statistics, Cohen's d effect size or an r effect size.	
<p>Study Design</p> <p>Studies without a control group were excluded.</p>	<p>These articles do not allow for the effect of the cognitive behavioural intervention to be assessed separately to standard care, which in EIP services may include family therapy, medication and case management.</p>
<p>Type of article</p> <p>The following article types were excluded: meta-analysis, theoretical papers, reviews, commentaries, opinion pieces, study protocol, clinical guidance, non-outcome focused studies, case studies and qualitative papers.</p>	<p>These articles do not provide the outcome data needed for this meta-analysis.</p>

Several large trials were excluded from the current review. Examples of these include SUPEREDEN (Fowler et al., 2018), OPUS (Jørgensen, Nordentoft, Abel, Gouliaev, Jeppesen, & Kassow, 2000), SOCRATES (Lewis et al., 2002) and the COMMAND trial (Birchwood et al., 2014). Reasons included a mixture of distress measures not reported, type of data not suitable for meta-analysis and participants not meeting the inclusion criteria as detailed above.

Results of Systematic Search

The results of the systematic search are presented in Figure 1. The search identified 546 articles which was reduced to 318 once duplicates were removed. These articles were then screened by title which excluded 79 studies and then by abstract which excluded a further 125. The three most common reasons for exclusion at this stage were non-interventional studies, opinion pieces and reviews. The remaining 114 articles were screened in detail yielding 17 studies that could be eligible for review. The reference lists of these 17 articles and of relevant reviews were screened. A google scholar search was also undertaken. Four further articles were identified from these additional sources, thus yielding 21 potentially eligible studies. This 21 included 2 studies that did not have full English texts available and 5 studies that reported summary scores of outcome measures that could be used to calculate distress if the full data was available. The authors of these 7 studies were contacted via email. Unfortunately, these authors did not respond. This left 14 primary studies to be meta-analysed.

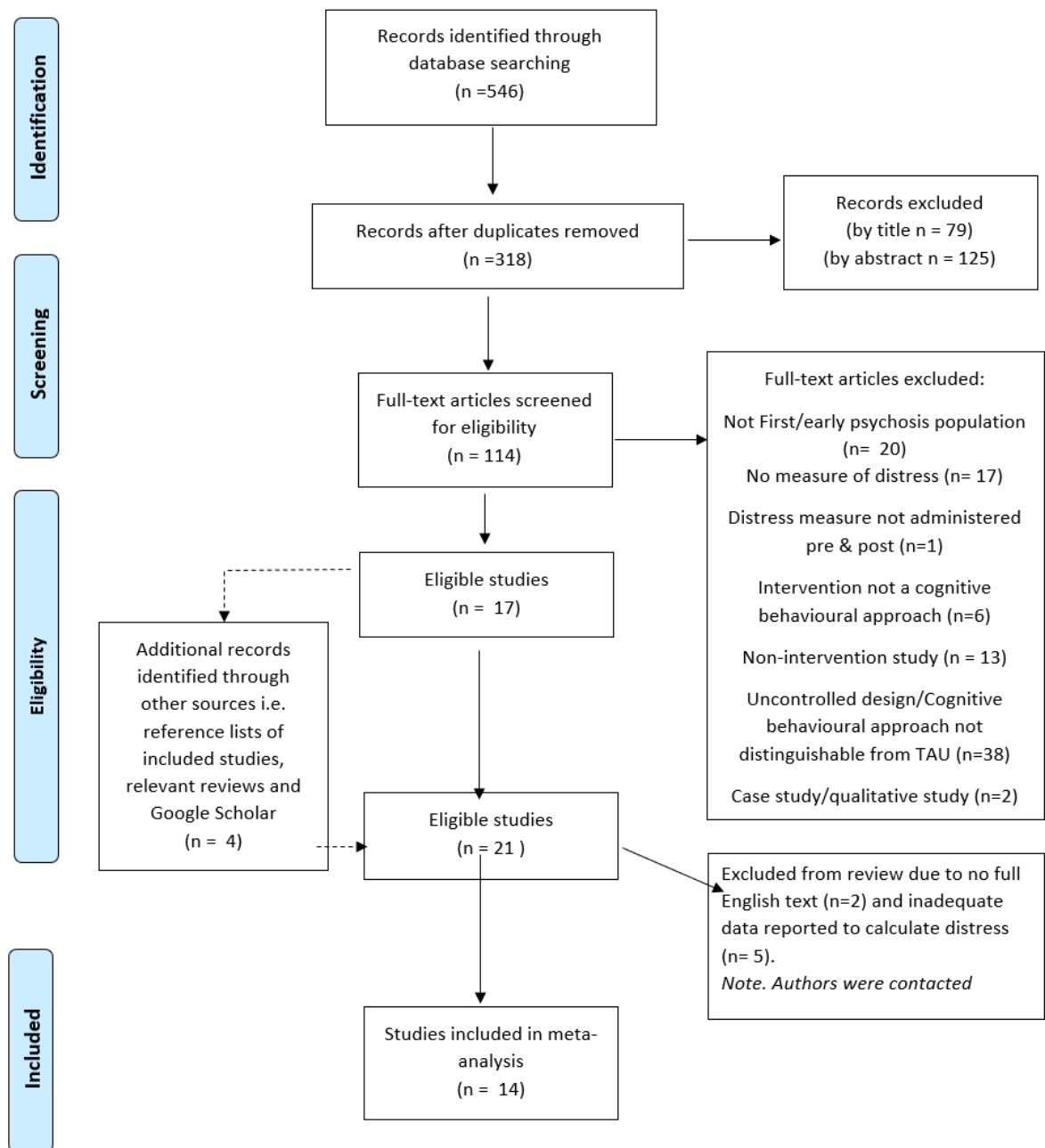


Figure 1. Study selection: Adapted PRISMA flow diagram (Moher, Liberati, Tetzlaff, Altman, 2009)

Data Extraction and Quality Ratings

Data Extraction

All data was extracted by the author. The reliability of quality ratings was cross validated by a second rater using a 15% random sample. Items where disagreements occurred were discussed and final ratings were agreed.

Preference of data to be extracted. It is anticipated that treatment outcome will be reported as a mean or mean difference, a standard deviation and number of participants (n) for each of a treatment and control group. From these Cohen's d effect size and standard error will be calculated for each eligible outcome measure. If standard deviations for each group are not reported individually the pooled standard deviation may be substituted. If means, standard deviation and n-sizes are not reported inferential test statistics will be transformed into estimates of Cohen's d. Finally, if neither summary statistics nor inferential test statistics are reported then effect sizes as calculated within the primary studies will be considered. It should be noted that effects sizes as reported in primary studies are frequently calculated from data that has been adjusted for the association with one or more covariates. Such adjustments may result in dissimilarity with the effects reported within the other primary studies. The contribution of adjusted effect size to overall heterogeneity will be examined empirically if problematic heterogeneity is identified in the random effects model.

For clarity, effect size directions will be altered so that a negative effect size (reduction in score) represents an improvement across all measures. Specifically,

this was applied to outcome measures assessing self-esteem (Jackson, Trower et al., 2009 c; Lecomte et al., 2008).

Reporting multiple outcomes from a primary study. It is anticipated that some studies will report more than one measure of distress. In these cases, all measures meeting the definition of distress as described in the section ‘What constitutes distress’ will be extracted and multiple effect sizes will be included in the meta-analysis. Multiple effect sizes from one study will be differentiated by alphabetic characters. The inclusion of multiple effect sizes from a primary study may result in a slight reduction in confidence intervals for the random effects model by artificially inflating the sample size within the meta-analysis, i.e. this will increase type I error. Measures from the same study were not combined to allow subgroup analysis of the different elements of the broader concept of distress.

It is anticipated that some studies may report multiple depression measures such as both the Beck Depression Inventory (BDI) and the Calgary Depression Scale (CDS). The CDS has stronger validity than the BDI in the target population, due in part to the confound of negative symptoms (Kim, Kim, Yoon, Kim, Shin, Hwang, & Yoon, 2006). Therefore, in studies where a more psychometrically sound measure is used, such as the CDS, only the CDS data is extracted. In studies where the only measure of depression reported was the BDI this data will be extracted and the impact on validity is reflected in the ‘detection bias’ domain of the quality rating.

Quality Ratings

Quality appraisal tool. A quality appraisal tool was designed to assess risk of bias within this literature. The Cochrane Collaboration’s tool for assessing risk of bias in

randomised trials (Higgins et al., 2011) and the Risk of Bias Assessment Tool for Non-randomised Studies (Kim et al., 2013) were modified to include questions of generalisability, contamination bias and treatment fidelity. The framework assessed risk of bias across nine domains: Selection bias, performance bias, contamination bias, treatment fidelity, detection bias, attrition bias, reporting bias, and generalisability. Each extracted effect size was assessed on each domain and given the rating low, unclear or high risk. The quality appraisal tool is detailed in Table 3 below.

Table 3
Quality appraisal tool

Domain	Low risk of Bias	Unclear risk of bias	High risk of bias
Selection Bias	True randomisation at individual level. Demographics reported and no significant differences between groups OR differences were controlled for OR differences between groups were found to have no impact on findings.	Non-randomised or Pseudo-randomised. Demographics not reported OR demographics reported and no significant differences between groups OR differences were controlled for OR differences between groups were found to have no impact on findings.	Non-randomised or Pseudo-randomised. Significant difference exists between groups at baseline and are likely to have an impact upon the findings.

Domain	Low risk of Bias	Unclear risk of bias	High risk of bias
Performance Bias.	Allocation concealed from participant. No confounding variables across intervention and control groups (e.g. length of intervention or delivered by same person) OR confounding variables present across control and intervention group but controlled for. Clear attempt to measure and/or compensate for impact of social desirability.	Unclear if allocation is concealed from participant. Control condition not adequately described. Non-reporting of how social desirability was either measured or compensated for.	Allocation is not blinded. Confounding variables (e.g. length of intervention or delivered by same person) across control and intervention group are present but not controlled for. Social desirability measured and shown to have an effect yet not controlled for.
Contamination Bias	Control condition and intervention clearly described with no cross over of intervention elements to control condition	Control condition not clearly described, unclear if elements of intervention and control conditions cross over.	Control condition contains elements of the intervention condition

Domain	Low risk of Bias	Unclear risk of bias	High risk of bias
Treatment Fidelity and Validity	Treatment fidelity explicitly assessed and found to be sufficient. Treatment protocol clearly described. Intervention delivered by either a sufficiently qualified professional OR sufficient training described.	Treatment fidelity undertaken but not described/evaluated. Protocol not clearly described. Therapists qualifications not described OR training not described.	No mention of treatment fidelity tests or processes used to ensure fidelity. No protocol described. Facilitators clearly not qualified to deliver intervention OR inadequate training was provided.
Detection Bias	Outcome assessors were blinded to allocation. Reliable/valid measure used.	No reporting of whether outcome assessors were blind to allocation. Unclear validity/reliability. Measure created for the study and reliability/validity not reported.	No blinding of outcome assessors. Poor reliability/validity of measures used.
Attrition Bias	Missing data has been handled appropriately e.g. using intent-to-treat analysis.	Unclear reporting and handling of attrition. Reasons for missing data not provided	Reason for attrition is likely to be related to true outcome. OR attrition is

Domain	Low risk of Bias	Unclear risk of bias	High risk of bias
	<p>OR No or low attrition</p> <p>OR Reasons for attrition unlikely to be related to true outcome (e.g. sickness, moved house).</p> <p>OR Attrition is balanced across both groups with similar reasons.</p>	<p>OR reasons stated to be unknown.</p>	<p>imbalanced across groups with dissimilar reasons.</p> <p>OR Completer analysis used with a substantial reduction (greater than 25% attrition).</p>
Reporting Bias	<p>Reported results of measures as outlined in the method.</p>	<p>Not all descriptive and/or summary statistics are presented.</p>	<p>Not reported full outcome measures as stated in the method section/ reported only a subsample of results/only significant results. Subscale reported when full scale has been administered. One or more outcomes reported incompletely.</p>

Domain	Low risk of Bias	Unclear risk of bias	High risk of bias
Generalisability	Sufficient sample for generalisation and representation of target population (>20 per group). Demographics reported and are representative with no areas of bias.	Sufficient sample for generalisation but with either one or two idiosyncratic features (> 20 per group). OR Demographics not reported.	Small sample (<20 per group). OR more than two idiosyncratic features and issues with overall demographics.

Results of Quality Appraisal Tool

The quality appraisal judgements are summarised below by domain. Unless otherwise stated all effect sizes taken from a study were given the same rating and are described by study. Difference in ratings within a study is seen in the domain of detection bias due to the differing psychometric properties of the outcome measures used. A visual summary of the quality ratings is presented in Figure 2 for each effect size. A limitation of this quality appraisal tool is that a study could meet several criteria across more than one level of risk within a domain of bias. Where this was the case a judgement had to be made by the researcher. This judgement was made on an individual, study by study basis (or where applicable effect size by effect size basis). If there was uncertainty regarding a study's level of risk for a particular domain of bias the researcher's judgement was cautious, and a higher level of risk was

allocated. For example, if a study met both low and unclear risk it would be allocated a rating of unclear risk of bias.

Study name	Selection Bias	Performance Bias	Contamination Bias	Treatment Fidelity	Detection Bias	Attrition Bias	Reporting Bias	Generalisability	Quality Index
Barrowclough et al., 2014 ST, a	Yellow	Yellow	Red	Green	Green	Green	Green	Green	86%
Barrowclough et al., 2014 ST, b	Yellow	Yellow	Red	Green	Green	Green	Green	Green	86%
Barrowclough et al., 2014 LT, a	Yellow	Yellow	Red	Green	Green	Green	Green	Green	86%
Barrowclough et al., 2014 LT, b	Yellow	Yellow	Red	Green	Green	Green	Green	Green	86%
Edwards et al., 2006	Green	Red	Red	Red	Red	Green	Green	Green	57%
Fowler et al., 2009 a	Yellow	Yellow	Yellow	Red	Green	Yellow	Green	Yellow	64%
Fowler et al., 2009 b	Yellow	Yellow	Yellow	Red	Green	Yellow	Green	Yellow	64%
Fowler et al., 2009 c	Yellow	Yellow	Yellow	Red	Red	Yellow	Green	Yellow	50%
Gleeson et al., 2009	Green	Yellow	Red	Yellow	Green	Green	Green	Green	86%
Jackson, McGorry et al., 1998 a	Red	Red	Red	Red	Red	Yellow	Green	Green	36%
Jackson, McGorry et al., 1998 b	Red	Red	Red	Red	Green	Yellow	Green	Green	50%
Jackson, McGorry et al., 2005 a	Yellow	Red	Red	Red	Red	Green	Green	Green	50%
Jackson, McGorry et al., 2005 b	Yellow	Red	Red	Red	Red	Green	Green	Green	64%
Jackson, Trower et al., 2009 a	Green	Yellow	Yellow	Green	Green	Green	Red	Green	86%
Jackson, Trower et al., 2009 b	Green	Yellow	Yellow	Green	Green	Green	Red	Green	86%
Jackson, Trower et al., 2009 c	Green	Yellow	Yellow	Green	Green	Green	Red	Green	86%
Kemp et al., 2007	Red	Red	Red	Red	Red	Red	Green	Red	14%
Lecomte et al., 2008	Yellow	Red	Yellow	Green	Green	Green	Green	Green	86%
Morrison et al., 2018 a	Yellow	Red	Red	Yellow	Green	Green	Green	Green	71%
Morrison et al., 2018 b	Yellow	Red	Red	Yellow	Green	Green	Green	Green	71%
Penn et al., 2011	Yellow	Yellow	Red	Green	Green	Green	Green	Red	71%
Power et al., 2003	Green	Yellow	Red	Red	Green	Yellow	Red	Green	57%
Uzenoff et al., 2008	Green	Yellow	Yellow	Yellow	Green	Yellow	Green	Red	71%
Madigan et al., 2013	Yellow	Yellow	Red	Yellow	Green	Red	Green	Green	64%

Figure 2. Summary of quality criteria applied to each effect size. Red indicates high risk of bias, amber an unclear risk of bias and green a low risk of bias.

Note: a, b, c versions of each study refers to different effect sizes extracted from the same study as described in the 'Reporting multiple outcomes from a primary study' section.

Note: Quality index is calculated by allocating low, unclear or high risk of bias as 0, 1 or 2 points respectively for each domain. Percentage is then calculated by dividing the total points obtained by the total number available and multiplying by 100.

Selection bias. Overall selection bias was mixed with five studies rated as low risk, seven as unclear risk and two as high risk. The low risk studies used true randomisation and had no significant differences in demographics at baseline (Edwards et al., 2006; Gleeson et al., 2009; Jackson, Trower et al., 2009; Power et al., 2003; & Uzenoff et al., 2008).

Seven studies were rated as unclear risk due to a mixture of randomisation method (pseudo/non-randomisation) and unclear or no significant differences between groups at baseline. One study (Jackson, McGorry et al., 2005) was non-randomised; the researchers allocated participants to groups. Two studies were judged to be at high risk of bias due to differences at baseline between the groups on the outcomes of treatment effect and to influential demographic differences such as educational attainment and diagnosis (Jackson, McGorry et al., 1998) or problematic alcohol abuse (Kemp et al., 2007).

Performance bias. Overall this domain had the second largest risk of bias across studies. No studies had low risk of bias in this domain. The majority of studies (eight of the fourteen) had unclear risk of bias (Barrowclough et al., 2014; Fowler et al., 2009; Gleeson et al., 2009; Jackson, Trower et al., 2009; Penn et al., 2011; Power et al., 2003; Uzenoff et al., 2008; & Madigan et al., 2013). These eight studies did not report on concealment of group allocation from participants. Six studies had a high risk of bias where allocation was not concealed from the participant (Edwards et al., 2006; Jackson, McGorry et al., 1998; Jackson, McGorry et al., 2005; Kemp et al., 2007; Lecomte et al., 2008; & Morrison., 2018). None of the studies reported on social desirability.

Contamination bias. This domain contained the highest risk of bias. It should be noted that the majority of studies (ten of the fourteen) (Barrowclough et al., 2014; Edwards et al., 2006; Gleeson et al., 2009; Jackson, McGorry et al., 1998; Jackson, McGorry et al., 2005; Kemp et al., 2007; Morrison et al., 2018; Penn et al., 2011; Power et al., 2003; Madigan et al., 2013) had a design problem due to being carried out in the context of specialised early psychosis services. In these services TAU (which was provided to both groups) included access to psychosocial interventions including cognitive behavioural techniques from specialised care coordinators, family therapy and social groups. This TAU introduces contamination of cognitive behavioural approaches across the groups and the confounding variables of family therapy, social groups and specialist knowledge of case managers. Whilst these options of support and therapy are available to both intervention and control conditions the uptake of these is not reported on in either condition. The remaining four studies were carried out in either secondary care mental health services where TAU was described as medication with case management (Fowler et al., 2009; & Jackson, Trower et al., 2009) or outpatient clinic where TAU was described as either medication with supportive therapy (Uzenoff et al., 2008) or medication alone (Lecomte et al., 2008).

Treatment fidelity. The distribution of risk across the studies was fairly balanced with six studies at a high risk of bias, four studies at an unclear risk of bias, and four studies at a low risk of bias. Threats to treatment fidelity tended to come from a lack of formal measures of treatment fidelity being reported on (Edwards et al., 2006; Fowler et al., 2009; Jackson, McGorry et al., 1998; Jackson, McGorry et al., 2005; Kemp et al., 2008; Morrison et al., 2018; Power et al., 2003; & Madigan et al.,

2013) and/or a variety of differently qualified and trained mental health practitioners delivering the intervention (Fowler et al, 2009; Gleeson et al, 2009; Jackson, McGorry et al, 1998, 2005; Kemp et al, 2008; Morrison et al, 2018; Uzenoff et al, 2008) . In some studies, such as Penn et al., (2011) the mixture of practitioners: social workers and clinical psychologists, was mitigated for by training, good fidelity reporting, and detailed supervision. As such, this study was judged to be low risk.

Detection bias. This domain showed different risk of bias within studies depending on the outcome measure used. As such it is summarised by effect sizes rather than by study. Of the five effect sizes rated as high risk of bias four were due to the use of the BDI which has poor validity in the target population (Edwards et al, 2006; Fowler et al c, 2009; Jackson, McGorry et al., a, 1998; & Jackson, McGorry et al., a, 2005). The remaining study at high risk (Kemp et al, 2008) did not blind assessors to allocation. The remaining 19 effect sizes were judged to be at low risk of detection bias.

Attrition bias. Two studies were at high risk of bias. Kemp et al., (2008) used completer analysis and had unbalanced attrition with more participants dropping out of the control group, likely because they had not been randomised to the intervention. Madigan et al., (2013) reported completer data and had attrition greater than 25% which was unbalanced across groups. Overall attrition rates were variable. However, the studies were generally consistent at providing reasons for drop-outs and providing adequate controls for this, including intention-to-treat analyses and reporting differences between completers and non-completers.

Selective reporting bias. Generally, studies fully reported their measures and risk of reporting bias was mostly low. However, two studies were at high risk of bias: Jackson, Trower et al., (2009) & Power et al., (2003). These two studies did not report some of the outcome measures they described in the methodologies.

Generalisability. Risk of bias was mixed in this domain. Three studies had a high risk of bias due to generalisability (Kemp et al., 2008; Penn et al., 2011; & Uzenoff et al., 2008). All three of these studies had a small sample of less than 20 participants. Kemp et al., (2008) and Uzenoff et al., (2008) also used samples with an idiosyncratic feature. In the former participants had to accept that they had problematic substance use. As such this is likely to represent a more insightful and change ready population. In the later, participants were excluded if they had a substance dependence, something that is common amongst the target population (Lechner, Dahne, Chen, Pickover, Richards, Daughters, & Lejuez, 2013).

One study had unclear risk (Fowler et al, 2009) due to one idiosyncratic feature of their inclusion criteria: Participants had to have a formal diagnosis such as schizophrenia, schizo-affective disorder, bipolar disorder or psychotic depression and were excluded if they had the more diagnostically uncertain first episode psychosis. However, examination of the participant characterises revealed participants to be young people (mean age of 29 years) with a mean duration of onset of psychosis to be less than five years. Thus, fitting within the 'critical period' (Birchwood, Todd & Jackson, 1998) and meeting the criteria for treatment to be offered by UK early intervention services within the first 3-5 years of psychosis developing (National Institute for Mental Health in England, 2008). Whilst this sample can be argued to meet the current meta-analysis inclusion criteria, if applied liberally, it is somewhat

unclear if the participants are 'typical' of the FEP population and therefore this study has been rated to have an unclear risk of bias for generalisability.

Summary. Overall the risk of bias was mixed across the studies. Two studies did not report high risk of bias in any domains (Barrowclough et al., 2014; & Gleeson et al., 2009). There was notably high risk in the four domains of: Contamination bias and performance bias where no studies had low risk; In treatment fidelity six studies had high risk; Finally, in Detection bias five studies had high risk and the remainder low risk. These four domains question the validity of the study designs to accurately measure the specific impact of the intervention. The included studies are representative of the research literature in this area at the time of writing and therefore are included despite high and unclear risks of bias.

Characteristics and Summary of Meta-Analysed Studies.

The construct of distress measured and the number of participants for each extracted effect size is summarised in Table 4. As can be seen from Table 4 a variety of self-report distress measures were reported. However, distress as a direct result of psychotic symptoms (e.g. as measured by PSYRATS) was not reported in the literature. A subgroup analysis will be completed to better understand the sensitivity of the subcategories of distress to cognitive behavioural approaches. The details of the primary studies and the participant demographics for each primary study included in this review are shown in Tables 5 and 6 respectively. This review aimed to explore the impact of CBA on distress in first or early episode psychosis. The emphasis of the research question is focused on distress and the specific early psychosis population

therefore no limitation was placed on the target of the intervention. The number of eligible studies identified was relatively small, consequently adding additional limiters may have been overly specific and could have resulted in an unreviewable number of studies. Furthermore, this wide range of intervention targets is representative of the literature at the current time and follows the precedent set by Morrison (2009).

An important consideration of the reviewed studies is that the service context in which they were conducted resulted in an inherent confounding variable. Namely, that EIP services provide treatment as usual that includes access to active therapy (family therapy), social support groups and, specialised psychosis case management that includes cognitive behavioural techniques. Whilst attempts were made to control for this in the primary studies via the presence of the control condition the access to the different support was not reported on and therefore could not be properly controlled for. The impact of the service context will therefore be investigated through a subgroup analysis.

Table 4*Measure of Treatment Effect Reported for each Extracted Outcome Measure*

Study Name	Outcome measure	Construct of distress	Participant n	Distress Treatment effect (Cohen's d)
Barrowclough et al., 2014 ST, a	CDS	Depression	51	0.48
Barrowclough et al., 2014 ST, b	BAI	Anxiety	52	-0.13
Barrowclough et al., 2014 LT, a	CDS	Depression	47	0.00
Barrowclough et al., 2014 LT, b	BAI	Anxiety	45	-0.05
Edwards et al., 2006	BDI-SF	Depression	47	-0.23
Fowler et al., 2009 a	BHS	Hopelessness	71	-0.28
Fowler et al., 2009 b	BAI	Anxiety	71	-0.02
Fowler et al., 2009 c	BDI	Depression	71	-0.07
Gleeson et al., 2009	MADRS	Depression	81	-0.24
Jackson, McGorry et al., 1998 a	BDI-SF	Depression	65	0.81
Jackson, McGorry et al., 1998 b	SCL90-R (GSI)	Distress	65	0.56
Jackson, McGorry et al., 2005 a	BDI-SF	Depression	91	0.10
Jackson, McGorry et al., 2005 b	SCL90-R (GSI)	Distress	91	0.04
Jackson, Trower et al., 2009 a	IES	Trauma	66	-0.35
Jackson, Trower et al., 2009 b	CDS	Depression	66	-0.29
Jackson, Trower et al., 2009 c	RSEQ	Self-esteem	66	-0.02

Kemp et al., 2007	DASS	Negative affect	16	0.00
Lecomte et al., 2008	SERS-SF	Self-esteem	75	-0.40
Morrison et al., 2018 a	HADS- Anx	Anxiety	49	-0.70
Morrison et al., 2018 b	HADS- Dep	Depression	49	-0.49
Penn et al., 2011	CDS	Depression	46	-0.07
Power et al., 2003	BHS	Hopelessness	42	-0.69
Uzenoff et al., 2008	CDS	Depression	24	-0.53
Madigan et al., 2013	CDS	Depression	87	0.02

Note: A negative effect size represents a reduction in distress and favours the intervention

CDS: Calgary Depression Scale. BAI: Beck Anxiety Inventory. BDI-SF: Beck Depression Inventory- Short Form. BHS: Beck Hopelessness Scale. BDI: Beck Depression Inventory. MADRS: Montgomery-Åsberg Depression Rating Scale. SCL90-R: Symptom Checklist 90 Revised GSI: Global Severity Index. IES: Impact of Events Scale. RSEQ: Rosenberg Self Esteem Questionnaire. DASS: Depression Anxiety Stress Scale. SERS-SF: Self Esteem Rating Scale- Short Form. HADS-Anx: Hospital Anxiety and Depression Scale- Anxiety: HADS-Dep: Hospital Anxiety and Depression Scale- Depression

Table 5

Study details presented by study

Study Name	Study information					
	Target	Description	Control condition	Delivery method	Mean Number of sessions	Mean length (weeks)
Barrowclough et al., 2014	Substance use	Short term integrated MI-CBT	EIP TAU	1:1	12	19.5
		Long term integrated MI-CBT with additional CBT modules	EIP TAU		24	39.1
Edwards et al., 2006	Substance use	Cannabis and psychosis therapy. A <i>cognitive-behavioural harm minimization approach to cannabis use</i>	Psycho-education of Psychosis + EIP TAU (EPPIC)	1:1	10	13
Fowler et al., 2009	social recovery	Social recovery cognitive behavioural therapy	Medication + Case management	1:1	12	39.1
Gleeson et al., 2009	Relapse prevention	CBT for relapse prevention	EIP TAU	1:1 therapy & family therapy	11.84	30.4

Jackson, McGorry et al., 1998	Psychosis	Cognitively orientated psychotherapy for early psychosis (COPE)	EIP TAU (EPPIC)	1:1	18	unable to rate
Jackson, McGorry et al., 2005	Psychosis	Cognitively orientated psychotherapy for early psychosis (COPE)	EIP TAU (EPPIC)	1:1	52	52
Jackson, Trower et al., 2009	trauma	Cognitive recovery Intervention. <i>cognitive therapy to reduce post psychotic trauma symptoms</i>	Medication + Case management	1:1	11	26.1
Kemp et al., 2007	Substance use	Brief CBT "Stop using stuff" <i>MI & CB practices working towards harm reduction.</i>	EIP TAU (PEIRS)	1:1	5	26.1
Lecomte et al., 2008	Psychosis	Group CBT for psychosis	Medication	Group	24	13
Morrison et al., 2018	Psychosis	CBT	Medication	1:1	14.39	26.1
Penn et al., 2011	functional recovery	Graduated recovery intervention program for FEP. <i>CBT</i>	EIP TAU (OASIS)	1:1	26	unable to rate

		<i>program to facilitate functional recovery</i>				
Power et al., 2003	suicidality	LifeSPAN therapy <i>Draws on COPE and specific suicide prevention cognitive therapy manuals</i>	EIP TAU (EPPIC)	1:1	10	10
Uzenoff et al., 2008	Treatment adherence	*Adherence coping education. <i>manual-based psychotherapy consistent with traditional cognitive-behavioural psychotherapies</i>	*Outpatient TAU + Supportive therapy	unable to rate	14	26.1
Madigan et al., 2013	Substance use	MI & CBT	Medication + Case management	Group	12	12

*Note: All intervention conditions also contained the control condition (TAU) with the exception of Uzenoff et al., (2008) which is marked with a *. This study intervention contained outpatient treatment as usual whilst the control condition contained outpatient TAU + supportive therapy.*

Table 6*Participant details presented by study*

Study Name	Participant information					
	% male	Mean age (years)	Ethnicity (% White)	DUP in months Mean (Unless otherwise stated)	Duration of psychosis Mean (unless otherwise stated)	Reported diagnoses (%)
Barrowclough et al., 2014 ST	90% male	24.1	93% white	<4months:40% >4months:59%	Range: 1.4-62.8 months	Schizophrenia: 49% Schizophreniform: 8% Schizo-affective: 12% Delusional disorder: 8% Substance induced psychosis: 5% PDNOS: 17%
Edwards et al., 2006	72% male	20.9	Not reported	Not reported	Not reported	Schizophrenia/Schizophreniform: 72% Affective psychoses: 10.9% NOS/delusional disorder/other: 17%
Fowler et al., 2009	71.% male	29	91% White	Not reported	Mean: 57.6 months	Non affective psychoses: 65%

Gleeson et al., 2009	63% male	20	Not reported	Mean: 13 months (a)	Not reported	Schizophrenia: 33% Schizophreniform: 11% Schizoaffective disorder: 6.2% PDNOS: 30% Bipolar: 4.9% Substance induced psychotic disorder: 4% MDE with psychotic features: 6% Delusional disorder: 1%
Jackson, McGorry et al., 1998	62% male	21	Not reported	Mean: 8 months	Not reported	Schizophrenia: 42% Schizophreniform: 20% Schizoaffective: 8% Bipolar: 8% Depressive: 11% Delusions: 5% PDNOS: 8%
Jackson, McGorry et al., 2005	77% male	23	Not reported	Not reported	5 months	Schizophrenia: 30% Schizophreniform: 12%% Schizoaffective: 16% Bipolar/Depressive: 32%

						Delusional/PDNOS : 8%
Jackson, Trower et al., 2009	74% male	23	71% white	5 months	Not reported	Not reported (PANSS reported)
Kemp et al., 2007	Int=70% TAU=100%	21	Not reported	Not reported	Not reported	Not reported
Lecomte et al., 2008	Int =65% Control = 83%	24	Int =71% white Control =53%	Not reported	Not reported	Schizophrenia spectrum: Int= 54% Control =54% Mood disorder with psychotic features: Int =21% Control= 17% PDNOS: Int= 25% Control =29%
Morrison et al., 2018	55% male	24	Not reported	9 months	Not reported	FEP: 100% Other diagnosis not reported (PANSS reported)
Penn et al., 2011	30% male **	22	63% white **	4 months	Not reported	Not reported
Power et al., 2003	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
Uzenoff et al., 2008	60% male	Not reported	75% white	Not reported	Not reported	Not reported (PANSS reported)
Madigan et al., 2013	78% male	28	Not reported	13 months	Not Reported	Schizophrenia: 22% Schizophreniform disorder: 10% Bipolar Disorder: 16%

						Schizoaffective disorder: 1% Delusional disorder: 6% Brief psychotic disorder: 7% Major depressive disorder: 7% Substance-induced psychosis: 6% PNOS: 5%
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**PDNOS: psychotic disorder not otherwise specified*

**NOS: Not otherwise specified.*

(a): DUP estimated between reported onset of symptoms and entry to service.

***converted to % from mean.*

Analytic Strategy

The Omnibus Test

The summary effect size and 95% confidence intervals (CI) were calculated using the random effects (RE) model. The RE model accounts for variation between studies as a result of idiosyncrasies in the methodologies of the primary studies, as is commonly seen in psychological research (Borenstein, Hedges & Rothstein, 2007). The inverse variance RE model was calculated using the DerSimonian and Laird (1986) method.

Cohen's d has been shown to systematically overestimate the absolute value of the standard mean difference in small samples (Borenstein, Hedges, Higgins 2009). Accordingly, all calculations were performed on a transformation of Cohens d (i.e., Hedges g) which controls for this slight overestimation. For the sake of clarity all figures and tables are back transformed into Cohen d .

The Quality Effects Model

The quality effects (QE) model (Doi, Barendregt, Khan, Thalib & Williams, 2015a) is a meta-analytic model that extends the random effects model. The QE model includes the rating of methodological quality for each study. In this review the QE model was calculated using the total score from the risk of bias scores as rated by the author and reported in the section 'Results of quality appraisal tool'. The QE model controls for methodological bias and can be interpreted as the meta-analytic synthesis that would have been obtained if all the studies had been of the same methodological quality as the best study in the review.

Handling Problematic Variance

An effect is considered heterogeneous if it presents with variation from the meta-analytic effect size that cannot be attributed to true variation in treatment outcome. Heterogeneity can result from methodological variation in the studies, measurement error or uncontrolled individual difference factors within the reviewed literature. Higgins I^2 is a commonly used measure of heterogeneity, with greater values of I^2 indicating variation in effect that cannot be attributed to true variation in the treatment effect. Heterogeneity of over 50% is considered substantial by the Cochrane collaboration (Higgins & Green, 2011). As such, for the purpose of this review problematic heterogeneity was defined as a Higgins I^2 of over 50%.

If problematic heterogeneity is observed three subsequent analyses will be completed to investigate causes of this heterogeneity. These will be:

- 1) A 'leave-one-out' analysis: To examine whether any particular study or studies are exerting a disproportionately high influence on the overall meta-analytic effect by sequentially omitting effect sizes from the meta-analysis. Any effect size that exerted a disproportionately influential effect on the meta-analytic synthesis will be reviewed for possibility of exclusion due to the risk of bias it introduces.
- 2) A subgroup analysis: To evaluate the variance in different subgroup mean effect size around the grand meta-analytic effect size. Studies will be grouped for subgroup analysis by service context, and by distress construct (as outlined in the section 'Characteristics and summary of meta-analysed studies.').

- 3) Meta regression will be used to attempt to identify whether uncontrolled continuous variables such as year of publication or participant demographics influenced the size of the intervention effect.

If heterogeneity is found to be low, these analyses are not essential.

Publication Bias and Small Study Effects

A funnel plot will be used to assess the spread of treatment effects around the meta analytic synthesis in relation to standard error. Publication bias and small study effects will be identified through visual and statistical inspection of the funnel plot.

In the absence of publication bias, it is assumed that studies with high precision will be plotted near the average (i.e., the meta analytic synthesis), and studies with low precision will be spread evenly on both sides of the average, creating a roughly funnel-shaped distribution where the distance from the average is inversely proportionate to the precision of the study. A symmetric inverted funnel shape arises from a 'well-behaved' data set, in which publication bias is unlikely. Deviation from this shape can indicate publication bias especially if there is an absence of studies in the region associated with small samples sizes and non-significant effects.

If publication bias is identified, then a trim and fill procedure (Duval & Tweedle, 2000a; Duval & Tweedle, 2000b) will be undertaken to yield an unbiased estimate of the effect size. In addition, the fail-safe N will also be calculated (Rosenthal, 1979). The fail-safe N is an estimation of the number of missing studies (often known as 'file drawer' studies) that would need to be retrieved for the effect to be no longer significant. If this number is large (relative to the number of primary studies in the

meta-analysis) then the omnibus test can be considered robust to the effects of publication bias.

Results of Data Analysis

Main Effect

The treatment effects of the primary studies are reported in Table 4. There were 14 studies reporting a total of 24 effect sizes (multiple effect sizes from the same study are denoted by a, b, c etc) and 1434 participants.

A random effects models was calculated using the generic inverse variance method. The random effects model showed a non-significant omnibus effect of $d = -0.09$ ($z = -1.34$, $p = 0.18$) and a 95% confidence interval of between -0.23 to 0.04 (studies = 14, participants = 1434). The results can be seen in the forest plot in Figure 3. This suggests that there is a small but statistically non-significant effect favouring the CB intervention.

Heterogeneity of variance attributed to non-effect factors as measured by Higgins I^2 was low, $I^2 = 40\%$. This was deemed not problematic. Given the nonsignificant effect without problematic variance further analysis of heterogeneity is not required. Nevertheless, in the interest of probing the literature we will examine attenuation due to methodological quality and the treatment effect in specific subgroups.

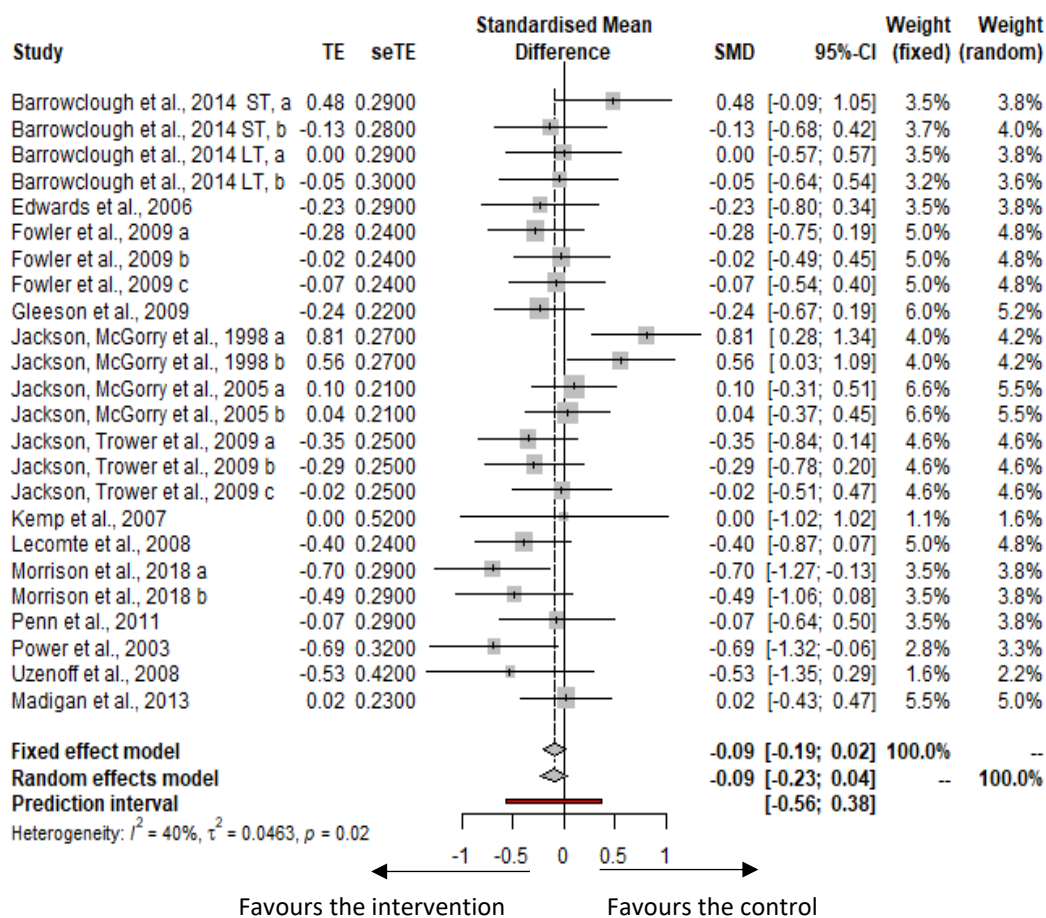


Figure 3. Forest plot of main meta-analytic effect

Impact of Methodological Variance

The QE model was used to assess the impact of methodological bias within the reviewed literature upon the treatment effect. The QE model reported a synthesis of $d = -0.14$ ($z = -1.85$, $p = 0.06$) and a 95% confidence interval of between -0.28 to 0.01 (studies = 14, participants = 1434). Thus, the meta analytic treatment effect remains non-significant. The results can be seen in the forest plot for the QE model in Figure 4 below.

The quality effects model evidences an approximately 55% increase in the treatment effect size relative to the RE model estimate. This new effect size is still negligible as d is less than a 0.2 (Cohen, 1988). Accordingly, when the synthesis includes information about the methodological quality of the studies there is no important change in the conclusions.

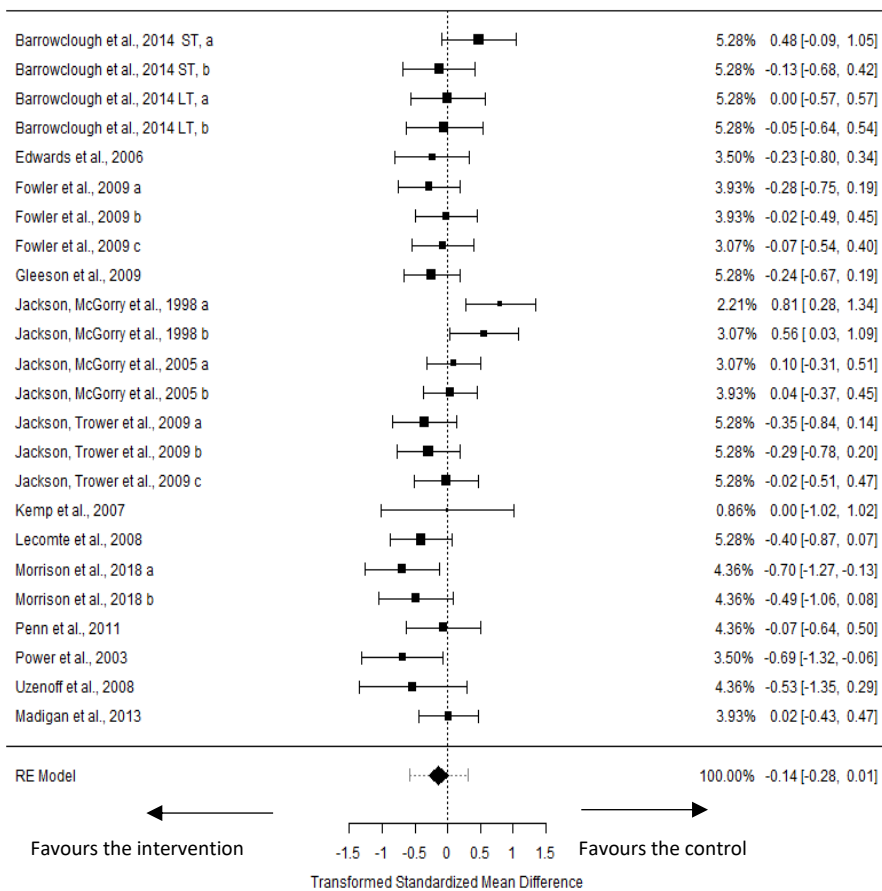


Figure 4. Forest plot depicting the quality effects model.

Identifying influential studies. The impact of disproportionately influential studies was assessed using a “leave-one-out” analysis. The figure showing the relevant forest plot can be seen in Appendix A along with a brief description of the results. Overall, no study exerted an excessive influence on the meta analytic treatment effect.

Publication Bias and Small Study Effects

The funnel plot of the correlation between the treatment effect and the standard error, and the results of Egger’s test (Egger, Smith, Schneider, & Minder, 1997) are shown in Appendix B. These tests reveal no evidence of substantial publication bias.

Planned Subgroup Analysis.

Studies were grouped by service context and distress construct for two planned subgroup analyses. Table 7 summaries the findings.

Table 7
Subgroup analyses

Sub-group						Test statistic	Significance value
	Non-specialised	Specialised				Q	p
Service context	SMD= -0.21, 95% CI -0.5 to -0.04. Studies = 4 Participants =510	SMD= 0.05, 95% CI -0.15 to 0.26. Studies =10 Participants = 739	n/a	n/a	n/a	3.91	0.04*
	Anxiety	Depression	Hopelessness	Self-esteem	Trauma	Q	p
Distress construct	SMD= -0.21, 95% CI -0.52 to 0.10. Effect sizes = 4 Participants = 217	SMD= -0.03, 95% CI -0.23 to 0.18. Effect sizes = 12 Participants =725	SMD= -0.43, 95% CI -0.82 to -0.04. Effect sizes = 2 Participants = 113	SMD= -0.22, 95% CI -0.59 to 0.16 . Effect sizes =2 Participants = 141	SMD= -0.13, 95% CI -0.28 to 0.01. Effect sizes = 1 Participants =66	4.36	0.36

*Significant at p<0.05

1. Service context.

The reviewed studies can be broadly divided into specialised EIP services and non-specialised services. The specialised services were described to be aimed solely to work with service users experiencing first episode/early psychosis. As such they provided all participants in both control and intervention conditions with access to psychosocial interventions including cognitive behavioural techniques from care coordinators, family therapy and social groups as TAU. The non-specialised services were reported in the literature as either secondary care mental health services or out-patient services. These provided TAU in the form of medication or medication plus traditional case management.

As can be seen from the forest plot in Figure 5 and the data in Table 7 a small significant treatment effect on distress, favouring the intervention was seen in non-specialised services. In specialised services no significant treatment effect was seen; however, there was a slight trend in favour of TAU.

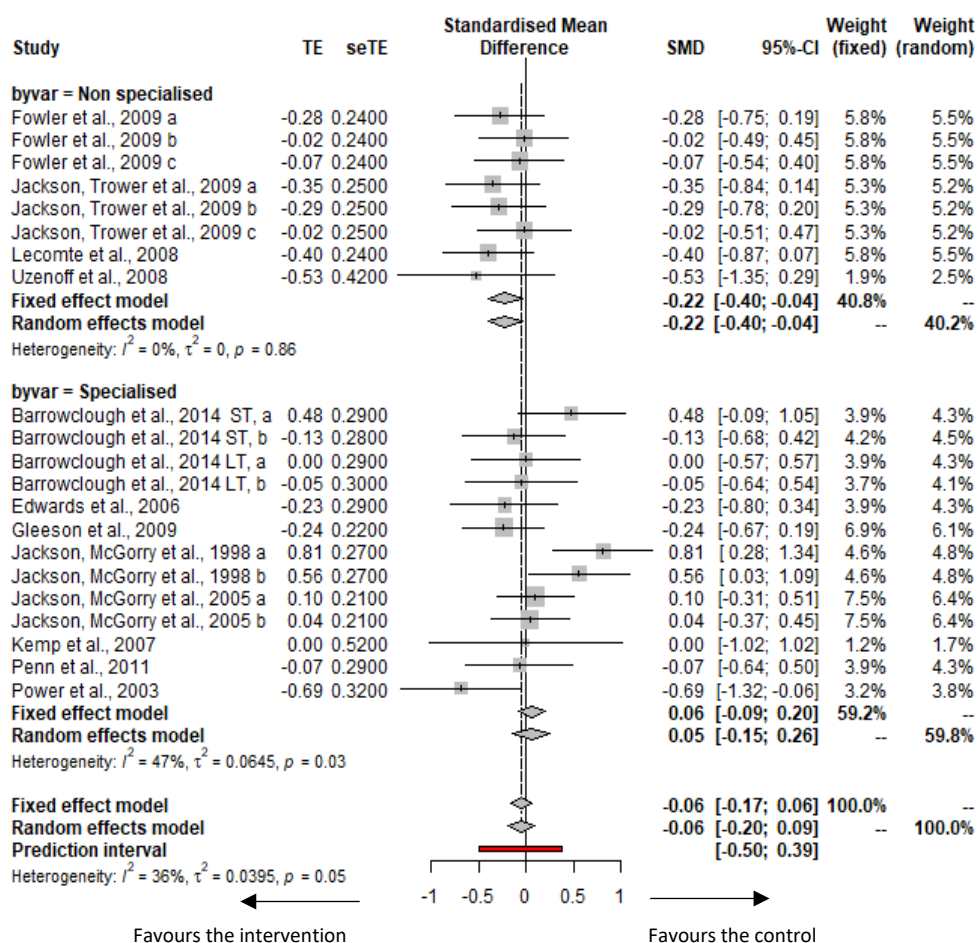


Figure 5. Forest plot depicting the subgroup analysis of service context

Note: Morrison et al., (2018) and Madigan et al., (2013) studies were omitted as they were carried out in the mixed context of specialised and non-specialised services

2. Distress construct.

The measures of distress used in the reviewed literature can be broken down into different psychological constructs of distress. As can be seen from the forest plot in Figure 6 and data in Table 7 only hopelessness was significantly impacted by the

intervention, above that of TAU. The effect size was small-moderate (SMD = -0.43) and the confidence intervals incorporate the grand meta analytic effect size. The subgroup analysis for hopelessness was only contributed to by two effect sizes. No other significant effects were found for specific psychological construct of distress.

Three effect sizes were omitted from this subgroup analysis as the outcome measures reported do not measure a specific aspect of distress. Specifically, these were the GSI of the SCL90-R (Jackson, McGorry et al, 1998 b; 2005 b) and the Depression Anxiety Stress Scale (DASS) (Kemp et al, 2007). As such they do not fit well the subgroup analysis.

It should be noted that due to the variation in types of distress measured there were very few effect sizes in each subgroup analysis.

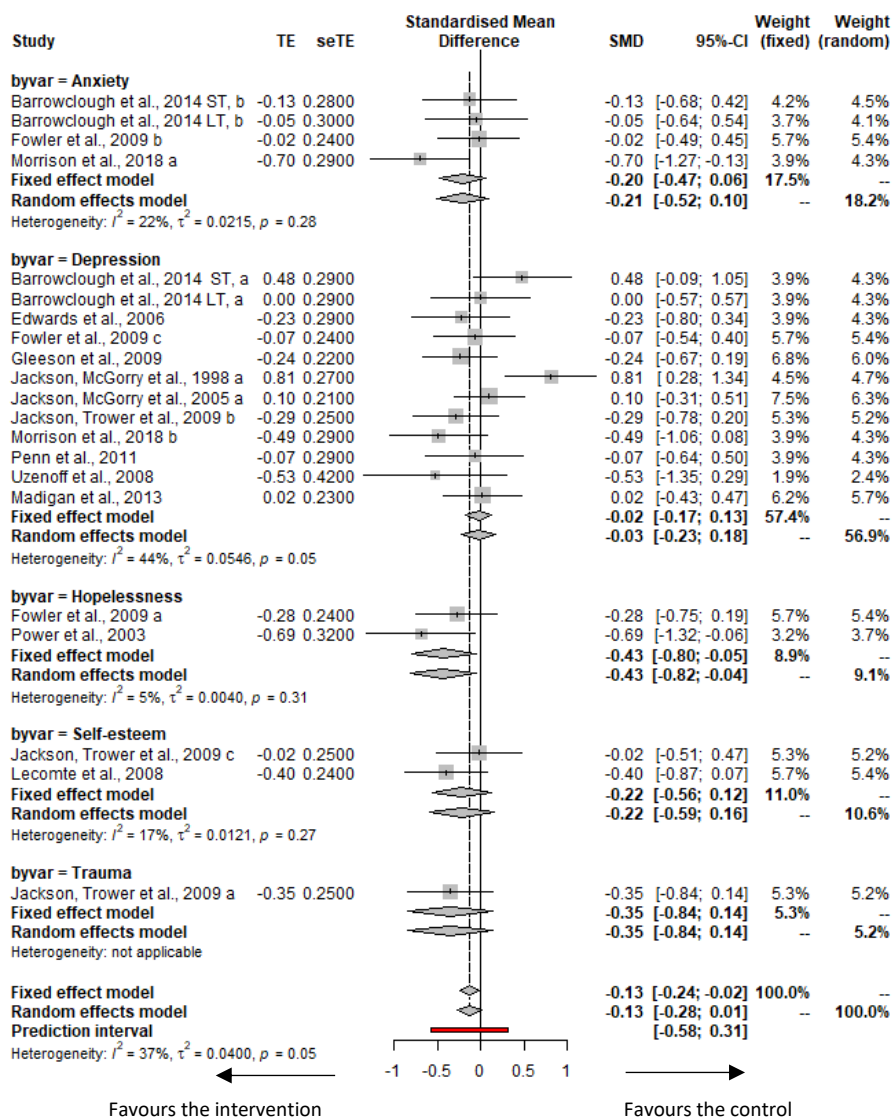


Figure 6. Forest plot depicting the subgroup analysis of distress context.

Note: Jackson, McGorry et al, 1998 b; Jackson, McGorry et al, 2005 b) and Kemp et al, 2007 effect sizes were omitted as they did not measure a specific aspect of distress.

Discussion

Findings

This review aimed to answer the question: Do cognitive behavioural approaches to first episode psychosis change an individual's experience of distress beyond that of TAU?

To answer this question the relative impact of cognitive behavioural approaches compared to TAU on self-report outcome measures of psychological distress was examined. Fourteen primary studies were identified which were designed and reported data in such a way that they could provide a useful contribution to answer this question.

Main effect. The main effect analysis showed no significant effect of CB approaches on distress above that seen in TAU across the 14 studies. The trend, although very slight, was in favour of the intervention. The preponderance of poor-quality studies have likely contributed to an underestimation of the treatment effect size in the literature. This can be seen in the application of the quality effects model to the data whereby, if all the studies were of a better quality (i.e. as good as the best study in the review) the effect size would increase by approximately 55%. Whilst this is interesting, and argues the need for future studies to be of better quality to accurately identify the magnitude of the treatment effect, the estimated effect size is still negligible ($d=-0.14$) and non-significant.

This lack of significant main effect aligns with recent Cochrane reviews of CBT for schizophrenia. It seems CBT in the broader field of psychosis offers little

convincing benefit over standard care (Jones, Hacker, Xia et al., 2018). This may be due to a lack of true effect or to a lack of adequately designed, good quality research.

Distress construct. The subgroup analysis of distress construct revealed that the intervention reduced hopelessness (as measured by the BHS) significantly more than TAU did. The effect size (-0.43) was at the high end of a to medium effect size, as interpreted by Cohen where 0.2=small, 0.5= medium and 0.8=large (Cohen, 1998). The contributing effect sizes came from studies conducted in both specialised (Power et al., 2003) and non-specialised (Fowler et al., 2009) services which suggests this effect may be seen across service context. This effect seems to suggest that hopelessness is perhaps more responsive to CB approaches than other aspects of distress. However, it is important not to give too much weight to this finding as only two effect sizes contributed towards this.

Service context. The subgroup analysis of service context revealed that CB approaches had a significantly greater impact on distress than TAU (SMD= -0.22; a small effect size), but only when provided in the context of non-specialised services. In the context of specialised services this effect disappears. In fact, such is the impact of specialised services that the remaining trend is reversed so that TAU seems to have a greater impact on distress than the intervention. It seems that the EIP services which provide care within a service model that was developed specifically to meet the needs of people within the critical developmental period of early psychosis has an impact on a person's experience of distress that, in the current literature cannot be surpassed by adding therapy informed by cognitive behavioural approaches.

Limitations of the Literature

There are a number of limitations to the existing literature which make it difficult to draw a firm conclusion. These are namely: problems with design, the definition of terms and the measurement of distress.

Design. The design of the studies is such that the absolute effectiveness of CB approaches in the FEP population cannot be addressed. It is likely that this question will not be able to be addressed without the significant ethical implications of preventing access to EIP services. This design difficulty is further compounded by the integration of cognitive behavioural principles such as graded exposure, thinking errors, thought challenging and activity scheduling into TAU in EIP services. This integration introduces contamination bias which makes even the question of effectiveness relative to TAU difficult to answer.

A further difficulty is that the primary outcome of most of the included studies was symptom reduction. Consequently, the literature may underestimate the effect on distress as the studies may not have been designed to target, or be adequately powered for, the secondary outcome measures of distress (Andrade, 2015; Lincoln & Peters, 2019).

Definition of terms.

Distress. Problems within the literature regarding the definition of distress presents a significant limitation, and the literature would benefit from more nuanced, better defined concept of distress that could be measured accordingly.

Distress is a broad concept that describes overwhelming unpleasant emotional experiences alongside a perceived inability to cope with these experiences

(Ridner, 2004). Within the wider psychosis literature, the concept of distress is theorised to include distress caused by psychotic symptoms; such as voice related distress (Birchwood et al., 2014), paranoia distress and delusion distress (Lincoln and Peters, 2019). Additionally, distress experienced by individuals with psychosis may include anxiety, hopelessness, depression and other similar experiences (Bernard et al., 2015). This is perhaps unsurprising given that research suggests people who experience psychosis also experience a range of other mental health difficulties (Braga, Reynolds, & Siris, 2013; Uptegrove et al., 2010).

The recognition that early psychosis represents a distinct and critical period (Reading & Birchwood, 2005) gives space for the hypothesis that the experience of distress within the early period of psychosis may be distinct with its own complexities. Complexities particular to early psychosis may come from: The novelty of the psychotic experiences and attempts to develop an explanatory narrative (Carter, Read, Pyle & Morrison, 2018); the psychological and social changes that occur during this early period of psychosis (Birchwood, Todd & Jackson, 1998); and the developmental changes during the adolescent period in which psychosis onsets. These developmental changes can in themselves can be distressing, and when disrupted by the onset of psychosis can be a further source of distress (Harrop & Trower, 2001).

Distress within early psychosis therefore seems to be complex and multifactorial. This was captured by Griffiths et al. (2019) whose meta-synthesis emphasised the complexity of distress in early psychosis and identified that distress arises from a diverse range of factors and occurs across two broad domains of intrapersonal distress and interpersonal distress. Intrapersonal distress captured a

variety of internal experiences such as distress caused by psychotic symptoms, experiences of states such as depression and anxiety, problems resolving conflicts, difficulty maintaining a sense of identity, feeling unable to work towards valued goals and concerns about physical health. Interpersonal distress encompassed distress arising out of past traumatic and abusive experiences, personal relationships, contact with health professionals, and fears of stigmatization.

It is evident that distress in early psychosis is a complex and multifaceted concept. The development of a robust definition that encompassed this complexity might allow for a clearer and more nuanced understanding of effectiveness in terms of distress reduction.

Measurement and reporting of distress. Building on the difficulties identified with the definition of distress, the measurement and reporting of distress in this literature is problematic. There is currently no quantifiable method of measuring the interpersonal distress reported by Griffiths et al., (2019).

Where quantifiable measures of distress are available these are limited to a few facets of intrapersonal distress and there is no consensus on which are used. For example, the BDI is used when CDS would provide a more psychometrically sound measure of depression. Other aspects of intrapersonal distress identified by Griffiths et al. (2019), such as difficulties maintaining a satisfactory sense of identity and feeling unable to work toward valued goals are not quantifiably represented within the literature.

The style of reporting in the literature means that information is lost; the author came across no study where the distress scores of the PSYRATS were reported, or

where they could be calculated. This poor measurement and reporting of the existing quantitative measures of distress is rectifiable. Its existence as a limitation may represent a delay in the shift from CBT as a “quasi-neuroleptic” to a process of supporting insight and relief from distress.

First Episode Psychosis. As described in the introduction the literature struggles with an unclear definition of FEP. This is likely to result in variation within the population sampled. Such variation can be problematic as there may be meaningful differences within the participants who may respond differently to the intervention (Field, 2009)

Whilst these limitations of design and definition of terms, particularly the definition of FEP, are important to acknowledge, they are reflective of clinical practice. Consequently, these could be considered to hold an intrinsic benefit as they capture the defining characteristics of current service provision. This ecological validity makes the review relevant to clinical practice.

Limitations of the Review

There are several limitations of this review that warrant consideration. Perhaps most notable is the resampling of participants in order to capture various elements of distress. This has resulted in the artificial inflation of sample size which can result in a problematic over-estimation of effect size (Moeyaert, Ugille, Beretvas, Ferron, Bunuan, & Van den Noortgate, 2017). However, resampling is necessary due to the use of multiple distress measures in primary studies which were not designed to assess the

impact on a specific aspect of distress. Abstaining from re-sampling would result in large amounts of data and participant experience being omitted from the review.

The current review assessed changes in distress. However, due to the primary outcome of many studies being symptom reduction, and distress being a somewhat nebulously defined concept (as is described above) it was not possible to include distress as a meaningful search term. Consequently, the review may be limited as it relied on the judgement of the researcher to identify studies which met the criteria set out in the section titled systematic search method.

Finally, the review did not consider process variables that might be expected to mediate the experience of distress, such as beliefs about voices (Chadwick, Lees & Birchwood, 2000). Such analyses may be helpful to identify aspects of therapy that have the most impact on distress and isolate therapeutic change mechanisms.

Future research

In light of the limitations described above, future research would benefit from design which targets distress as a primary outcome. Moreover, the distress scales of the PSYRATS should be reported and the CDS used in preference to less valid measures of depression such as the BDI. Furthermore, future research may benefit from considering the mechanism of change, in addition to distress as an outcome measure, as was done in the COMMAND trial (Birchwood et al., 2014).

In line with Morison's (2009) review of the effectiveness of CBT for FEP, the current meta-analysis recommends that future research may benefit from the consideration of therapies designed to target specific elements of distress. Such

elements of distress may include hopelessness, given the significant treatment effect that was seen in this meta-analysis.

Perhaps, given the difficulties isolating CB intervention from TAU, the literature may benefit from development and acceptance of study designs other than RCT which may more comprehensively assess the effects of therapy in this population. RCTs are best used with symptom focused approaches for uncomplicated diagnoses (Shean, 2014) which neither talking therapies nor psychosis are. A marrying of quantitative and qualitative approaches within primary studies could provide a realistic alternative, such as the pragmatic RCT used by Fonagy et al. (2015) which utilised quantitative outcome measure, qualitative semi structured interviews and clinical components. Psychosis is known to be related to attachment difficulties, family dynamics and to impact markedly on identity (Gergel & Iacoponi, 2017; Korver-Nieberg, Berry, Meijer, & de Haan, 2014; Koutra, Vgontzas, Lionis, & Triliva, 2014). Therapeutic models with a stronger focus on the concept of self and relationships such as psychodynamic, systemic or existential therapies warrant further, thoughtful investigation and it is possible that a change in focus of the preferred research design may allow clearer evidence regarding effectiveness to emerge for both CB and other models of therapy above TAU.

Clinical Implications

Given the limitations of the literature and of this review some tentative clinical implications are proposed:

- EIP services should continue to incorporate the CB model in its understanding and care of those with early psychosis. Services should not be led, under the

current climate of austerity and service pressure, to return to a more traditional service design where the CB model is left solely to the therapists.

- Clinicians should consider carefully the nature of their clients' distress to inform who is likely to benefit from a more formal CB based therapy. It may be that those with high levels of hopelessness have the most to gain from CB based therapy in addition to treatment as usual in specialised EIP services.

Conclusion

This meta-analysis is the first to review the impact of CB approaches to therapy in the FEP population. The quality of the literature in this area is poor, as all included studies contained elements of unclear and high risk. Consequently, whilst there appears to be no significant impact of CB approaches on distress above that of TAU the literature does not allow for firm conclusions to be drawn. A key consideration of the literature is that the nature of specialised services for FEP make research into the absolute effectiveness of CB approaches in this population a difficult task. The literature is still relatively early in its shift away from CBT as a "quasi-neuroleptic". This is reflected in the small number of studies using distress as a treatment outcome.

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Note: * Studies included in this meta-analysis are denoted by an asterisk (*)

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Making Sense of the Experience of Visual Hallucinations in Psychosis: An Interpretative Phenomenological Analysis.

Abstract

Introduction: The literature regarding visual hallucinations within the context of psychosis is sparse and our understanding of how individuals experience and make sense of visual hallucinatory experiences is lacking, especially when compared to the understanding of auditory hallucinations.

Method: Interpretative phenomenological analysis was selected to provide the opportunity for a detailed ideographic understanding of participants' experiences. Semi-structured interviews were completed with each participant, with support from their psychologist where needed.

Participants: Six participants with experiences of visual hallucinations within the context of a schizophrenia spectrum diagnosis were recruited through psychologists in their care team. Participants were under the care of a range of services including Early Intervention, Community Teams, Assertive Outreach and Inpatient Rehabilitation.

Analysis: Five superordinate themes were identified: 'It's not only a visual experience', 'Agency', 'Role of others', 'Coming to know the experience' and 'Creating a narrative'. Emotional experience was interwoven within each superordinate theme.

Discussion: Links are drawn between the superordinate themes and existing literature regarding visual hallucinations, hallucinations in general and psychosis.

Clinical Implications: It was identified that the term “visual hallucinations” is a poor descriptor for the experiences participants described and therefore clinical work may be better focused on exploring the relationship between sensemaking and experience with psychosis more broadly, than on visual hallucinations in particular. The importance of listening and valuing an individual’s experience of visual hallucinations was emphasised and supporting individuals to engage with their experiences with the aim of psychological growth and recovery is recommended.

Future research: A more detailed definition and phenomenologically grounded description of visual hallucinations is required to support the development of future research efforts.

Introduction

Visual Hallucinations and Psychosis

Psychosis is a term that transcends diagnostic categories, which have been criticised for being an arbitrary categorisation of distress (Wong, 2014). In this thesis the term psychosis is used interchangeably with schizophrenia to reflect the work of the authors cited and to provide clearer clinical implications. Precedent for this is seen by the British Psychological Society (BPS) who described persistent psychosis as synonymous with schizophrenia (BPS, 2000).

Hallucinations have been defined as “a sensory perception that has the compelling sense of reality of a true perception, but that occurs without external stimulation of the relevant sensory organ” (American Psychiatric Association, 2000, p. 767). Hallucinations can occur in any sensory modality; visual hallucinations are the second most commonly occurring modality (after auditory) and they affect around 27% of those with schizophrenia (Waters et al., 2014).

Phenomenological Understanding of Psychosis

Phenomenological considerations of psychosis have a long history (Bürgy, 2008). This section comprises a brief overview to provide context for phenomenological understandings of visual hallucinations.

Laing (1960) emphasises the importance of entering the world of the person with psychosis and trusting that their experiences are meaningful. He theorised that psychosis is rooted in ontological insecurity (loss of a secure sense of being or existing), which in its less extreme form is proposed as common to all humans (van Deurzen, 1998). Spinelli (2001) hypothesised that this ontological insecurity could

promote meaningful reflection and facilitate resolution of persistent life problems.

Alternatively, Spinelli (2001) also suggested that psychotic experiences such as fixed beliefs can provide a newfound ontological certainty, thus providing a sense of comfort for the person.

Qualitative research has attempted to unpack the lived experience of psychosis. In a meta-synthesis, McCarthy-Jones et al. (2013) identified four overarching themes to the experience of psychosis: loss, identifying a need for and seeking help, rebuilding and re-forging life, and finally, better than new: gifts from psychosis. These themes were understood in the context of a sense of fear, confusion and hope. It is important to note that many of the reviewed studies lacked methodological rigour and none of the reviewed studies considered visual hallucinations specifically or explicitly. Therefore, it is impossible to know how much these themes describe the experience of individuals with visual hallucinations.

Auditory hallucinations are better researched than visual and have been examined using Interpretative Phenomenological Analysis (IPA). Some prominent findings are that there is a sense of enmeshment and a battle for power and control between the voice and the voice hearer (Chin, Hayward & Drinnan, 2009; Mawson, Berry, Murray & Hayward, 2011). The experience is reported to change over time, with the person developing an understanding of their voices, and the voices having a reciprocal relationship with emotional state (Milligan, McCarthy-Jones, Winthrop & Dudley, 2013). These studies provide a level of insight and understanding that is not yet present for visual hallucinations.

Current Understanding of Visual Hallucinations

The content and features of visual hallucinations in psychosis are summarised in Waters et al's. (2014) review to: be perceived as real and present; have the physical properties of real perceptions; include people, supernatural aspects, animals, objects and events; be brief; and to induce a varied emotional response from fear and hopelessness to happiness and reassurance. Within the broader field of mental health, it has been identified that visual hallucinations can be appraised in different ways and that negative appraisals are predictors of distress, regardless of the amount of perceived control a person might feel over their hallucinations (Gauntlett-Gilbert & Kuipers, 2005).

Visual hallucinations as part of schizophrenia are associated with a greater level of distress, functional impairment, and a poorer prognosis compared to those who experience schizophrenia without visual hallucinations (Clark, Waters, Vatskalis & Jablensky, 2017; Oorschot, Lataster, Thewissen, Wichers & Myin-Germeys, 2012). Despite the prevalence and poorer associated outcomes, the study of visual hallucinations and their meaning to individuals is sparse, and consequently successful intervention is limited (McCarthy-Jones et al., 2013; Waters et al., 2014). There is a call for a greater understanding of hallucinations to improve interventions (McCarthy-Jones et al., 2016), perhaps by "asking service users about their visual hallucination experiences to explore much more in-depth questions about their experiences, including what they see, [and] what leads to their distress" (Dudley, Collerton, Nicholson & Mosimann, 2013, p132). The current study aims to reduce the gap in the literature by moving towards an understanding of the experience and sense making of visual hallucinations.

Research Question

To contribute to the embryonic literature in this area the current study will explore:

How do people experience and make sense of visual hallucinations in psychosis?

Method

Design and Theoretical Rationale for IPA

Qualitative approaches and IPA in particular are well suited to address the research question. The phenomenological aspect of IPA is concerned with exploring in detail an experience in its own terms rather than through the lens of a predefined concept. The interpretative aspect is concerned with layers of meaning of the ideographic experience and utilises the double hermeneutic with the “researcher making sense of the participant who is making sense of [their experience]” (Smith, Flowers & Larkin, 2009, p. 35) resulting in an iterative analysis of a person’s experience. These two aspects combined with the methodological rigour of IPA (Biggerstaff & Thompson, 2008) will allow a rich understanding of the complexity of the lived experience of visual hallucinations in schizophrenia from the individual’s perspective.

Reflexivity. Within the double hermeneutic, IPA recognises that the researcher’s presuppositions can hinder or enhance the interpretation of another’s lived experience. The following summaries the author’s position:

Throughout the interviews I was working within an early intervention for psychosis (EIP) service. Previous work within EIP sparked my interest in psychosis

as an area in which psychiatric thinking was, I thought, overly-privileged above the psychological. My work in EIP gave me a better understanding of the often-debated idea that schizophrenia does not exist as an entity. My work with clients emphasised the importance of distress and the attempts of the psyche to function in, and understand, difficult or traumatic circumstances. My own epistemology and ontology are best described as critical realist where the existence of a reality is assumed but this reality cannot be known with certainty.

Ethics and Sampling

The research was approved and sponsored by the University of Birmingham, granted ethical approval by NHS ethics committee (IRAS: 228510, REC: 18/WM/0089) (see Appendices A and B for approval letters) and was approved by the relevant Trust research department.

Participants were recruited using purposive sampling to enable access to individuals with a particular experience (visual hallucinations) within a particular context (schizophrenia spectrum disorder). Participants who met the inclusion/exclusion criteria (see Table 1) were identified by their psychologist in their care team. Recruitment is detailed further in Table 2.

Table 1*Inclusion and Exclusion Criteria*

Inclusion	Exclusion	Rationale
Experience of visual hallucinations as a part of a schizophrenia spectrum diagnoses. Specifically: Schizophrenia, Schizo-affective disorder, Schizophreniform disorder, schizotypal personality disorder.	A primary diagnosis of PTSD or bi-polar disorder. Hallucination induced by neurodegenerative disorders, optical disorders or substance abuse	For ease of identification of participants by a multidisciplinary care team the diagnostic umbrella of schizophrenia spectrum was used. It was hoped that these diagnostic exclusion and inclusion categories would provide a homogenous group who have experienced visual hallucinations and therefore will have greater similarity of experience and sense making.
Capacity to consent and over 18 years of age		This is necessary to provide a homogenous group with ability to consent autonomously.
Ability to verbally communicate their experiences articulately.		This is necessary for the participants to be able to partake in the semi structured interview.
	Requirement of the use of a translator to converse in English	This is necessary as one of the key aspects of IPA is that the researcher makes interpretations of the participant's report of their experience. The distancing of the researcher from the participant's experience

		through a translator will erode the validity of the method and any conclusions that may be drawn.
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Procedure

The procedure for the study is shown in Table 2:

Table 2

Study Procedure

Stage	Description
1.Awareness of study raised for recruitment	<ul style="list-style-type: none"> Information about the study was disseminated to all relevant care teams within the trust via the researcher speaking at team meetings, meeting with relevant consultant psychiatrists and via email to all relevant psychologists within the Trust
2.Identification of participants	<ul style="list-style-type: none"> Individuals who met the inclusion and exclusion criteria were identified by a member of their care team. For all participants this was their psychologist. Participants were provided with a verbal summary of the research and a participant information leaflet (see Appendix D). If the participant expressed interest in taking part in the study the clinician obtained their consent to pass contact details to the researcher
3.Interview arranged	<ul style="list-style-type: none"> Date for interview was arranged with the potential participant

4.Consent obtained, and interview completed	<ul style="list-style-type: none"> • At the meeting consent was obtained from the participant (see Appendix E for consent form). • The interview was completed using the semi structured interview schedule and lasted for approximately one hour. • The interview was audio recorded
5.Transcription and analysis	<ul style="list-style-type: none"> • The interview was transcribed verbatim. • Interpretative phenomenological analysis completed

Participants

Seven participants were identified as suitable to participate. Six participants gave informed consent and took part in the research, one participant did not give informed consent and so did not participate. The six participants are summarised in Table 3 and the text below.

Table 3

Participant Summary

Participant Pseudonym	Care Team	Diagnosis given
Darren	Assertive Outreach Team (AOT)	Schizophrenia
Jess	Early Intervention for Psychosis (EIP)	Schizophrenia
Kathryn	Inpatient rehabilitation Service (IPS)	Schizophrenia
Rashid	Community Mental Health Team (CMHT)	Schizo-affective disorder
John	Assertive Outreach Team (AOT)	Schizophrenia

Sally	Assertive Outreach Team (AOT)	Schizophrenia
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Note: All participants were working directly with a psychologist.

John and Sally's psychologist sat in on and took part in the interview. His speech in the transcript is identified as 'Psych'

The demographics of participants are broadly summarised to maintain the participants anonymity. As can be seen in Table 3 five participants had a diagnosis of schizophrenia, one had a diagnosis of schizo-affective disorder. Two participants identified as Asian- British, one as Mixed- Caribbean and White British, and three as White- British. Ages ranged from 37 years to 59 years old with a mean of 45 years old. Chronicity of mental health difficulties was requested from care coordinators, this was available for half of participants and was measured via number of years since first known contact with services, this ranged from 34 years to four years. All participants were working with a psychologist who identified them as eligible for the study.

Interview schedule

IPA utilises semi-structured interview to ensure key topics are covered whilst allowing exploration of idiosyncratic elements of the individual's experience. The interview schedule was developed in collaboration with a service user consultant with experience of visual hallucinations in the context of schizophrenia (See Appendix C).

Analytic Method

Analysis followed the recommendations of Smith et al. (2009).

Individual Level

After transcription, analysis was completed on each transcript in turn following the steps in Table 4. A reflective diary was kept noting the researcher's thoughts and observations about the analysis to enable these to be bracketed (Smith et al., 2009).

Table 4

Steps of the Individual Transcript Analysis

Step	Name	Details
1	Reading	The transcript was read to allow the researcher to become familiar with the transcript and immerse themselves in the narrative
2	Initial noting	Initial noting of salient points of the participant's experience on right-hand side of the transcript (see Appendix F for example)
3	Phenomenological coding	A close, detailed coding of the participant's experience, their claims and concerns of this experience and their understanding of this experience. These codes were considered through the frame of descriptive, linguistic and conceptual codes (Smith et al., 2009). These codes were annotated onto text and the left-hand side of the transcript using a different coloured pen to the initial noting (see Appendix G for example).
4	Emergent themes developed	Codes were reviewed and organised into clusters to form emergent themes in a separate document (see Appendix H for example).
5	Themes and subthemes developed	Emergent themes were grouped and organised into themes and subthemes according to principles of abstraction, subsumption, polarization, and contextual features (Smith et al., 2009) (see Appendix I for example)
6	Early transcripts reviewed	Transcripts 1-5 were reviewed in turn to identify any overlooked codes and themes that had been identified in later transcripts

Group Level

Superordinate themes across all participants were identified: Each participant's themes were written on pieces of paper and arranged to form a new set of cross-participant superordinate themes with subthemes (see Appendix J). This final stage aims to reflect the key experiential claims and concerns across participants.

Validity

Triangulation was used to safeguard the validity of the analysis: The analysis was discussed and reviewed at regular supervision meetings and the researcher joined an IPA working group where the organisation of themes was reviewed. Although the researcher's fore-structures were attempted to be bracketed it is likely the analysis would have different nuances if completed by a different researcher. As such it should be considered within the context of the reflexivity statement.

Analysis

Five superordinate themes (SOTs) are presented. These are summarised with their subthemes and participant contribution in Table 5. (See Appendix K for table of cross-participant themes and quotes)

Table 5

Table of Themes Across all Participants

Superordinate theme	Subthemes	Participants contributing
1. It's not only a visual experience	1.1. It's a complex and multifaceted experience	All
	1.2. It's just like everything else, sometimes.	Darren, John, Sally, Jess, Rashid
2. Agency	2.1. Sense of agency	All
	2.2. The role of agency in the emotional experience	All
	2.3. The role of agency in the sense of real-ness	All
3. Role of others	3.1. Shared experience or understanding	Jess, Kathryn, John
	3.2. They can't/won't understand	All
4. Coming to know the experience	4.1. Hard to make sense of: wrestling with reality	Darren, Jess, Sally
	4.2. Importance of reality	Kathryn, Rashid, John
5. Creating a narrative	5.1. Incorporating the experiences into pre-existing ideas	All
	5.1.1. Spiritual side	Kathryn, Darren, Jess
	5.1.2. Link to previous trauma	Jess, Sally, John
	5.1.3. Medical/biological explanation	Jess, Rashid, Darren

	5.2. Loop of experience and sense making	All
	5.3. This new way of thinking about myself and the world has changed things	All

1. It's Not Only a Visual Experience

This SOT captures the idea that the concept of visual hallucinations does not fully describe the participants' experiences: they are more complex and occur across sensory and extra-sensory modalities. Furthermore, for Darren, John and Sally the term hallucination suggested a degree of difference to non-hallucinatory experiences that they did not relate to their experiences.

1.1. It's a complex and multifaceted experience. This theme featured strongly across all participants. Overall, participants described their experiences as complex and multifaceted occurring across three of the main sensory modalities namely: "*seeing*", "*hearing*" and "*felt*". The tactile experiences incorporated both temperature changes and an interaction between the hallucinatory experience and the person:

It's this: I was rushed into hospital, it started there like. The room went freezing cold and smoke came down outside [Darren]

And later:

It sort of went in me a bit like. Y'know 'cus I was swelled up and lying on the bed and it sort of went inside my head [Darren]

Here the hallucinatory experience interacted with Darren by crossing the physical boundary of his body and entering inside him. Darren also describes how he had the

visual experience of seeing his body swell up as a consequence of the interaction. At times these different sensory modalities were mixed-up together:

it felt, it sounded (pause) well it didn't sound it felt like some invisible hand around my throat [Kathryn]

Here Kathryn was asked to describe her visual hallucinations and her response suggests confusion or cross-over between the visual, auditory and tactile senses.

This seems to demonstrate that the different sensory modalities are interlinked and difficult to tease apart.

In addition to the different sensory aspects of the experience participants sometimes experienced seeing someone through an inference. John provides an example of this:

J: The girl's peeping through the fence, she must have been because that's what they've been doing.

Psych: did, did you see her?

J: No I just heard her, but I presumed that she was at the back of the fence over there and see me sit down on the other side. So then just she said: 'he's there', with great delight and it, her boyfriend said 'where is he'. He's on the other end and I'm on the other side. I see them everyday. [John]

Here John initially describes seeing a girl, but then clarifies that he is presuming that she was there watching him because he heard her voice. It is not clear if this inferred seeing of “*the girl*” contributes to “*them*” he sees “*everyday*”.

Further to the multi-sensory way of experiencing the hallucination, there seemed at times to be an inherent communicatory aspect to the experience:

D: I had three words going in my head, that it was actually telling me like. Authority, love and care.

I: Authority, love and care?

D: Of myself. [Darren]

In the above quote Darren describes that one feature of his hallucinatory experience was a direct communication, a transfer of three words “*authority, love and care*” from the hallucinated other straight to his own mind. Darren explains that implicit in these three words was an almost paternal instruction to take care of himself. Jess described a different way in which she received a communication:

it [the cloud] formed a cross and I could see Jesus on this cross in the sky. I cried. Because I really thought I was seeing this: This is a calling for me. [Jess]

Here Jess infers that what she has seen must have some meaning; she interprets it as a communication in the form of a calling. The certainty she used when speaking of this communication: “*This is*” suggests a strong conviction that what she has seen is a communication.

For some participants the complex way of experiencing their reality included a form of extra sensory perception:

I've actually seen people, actually spirit people, and sensing and hearing things what aren't there.

I: Sensing things that aren't there?

D: Yeah.

I: tell me a bit more about that?

...

D: I experienced a ghost just outside my ear, just outside my ear to the

back.

I: and when you were hearing that, did you see anything?

D: No, I was sensing things at the time [Darren]

Here Darren describes how he has sensed and experienced things. He explains that this is different to hearing and seeing when he corrects the interviewer's question to emphasise that he was "*sensing things*" not hearing or seeing.

1.2. It's just like everything else, sometimes. Participants' descriptions of their experiences as complex, multifaceted phenomena described above in the subtheme 1.1 fits with a non-psychotic experience of the world: we do not just see a person, we feel their presence, hear their voice and have an idea of their internal world (i.e. their intention, emotions and thoughts). All whilst feeling the force of the environment on our own bodies: the feel of the seat of a chair, the temperature of the room, along with our internal bodily sensations (i.e. temperature changes, awareness of various bodily parts). To take away these elements would be to lose the richness and reality of the experience of existing. It is therefore perhaps unsurprising that participants described their multifaceted experiences with a degree of normalcy that suggests that they're all just experiences of the world.

John described this by emphasising the normalcy of seeing and hearing the things he has been told are not real:

J: Just like I'm with you now, I see you now I see these visions these people and hear these voices just the same.

I: so they seem exactly the same they feel the same?

J: (nodding) quite physical [John]

John underscores the physicality of hallucinatory experiences; he describes that they are indistinguishable from his other experiences. For John this way of experiencing

seems to be important for his sense making of the experiences as definitely real. In a similar vein Darren struggles to articulate what the experience is like, it seems this is because of the ordinary nature of them:

I don't know I was just hearing things like. [Darren]

Darren furthers this to explain that all his experiences of the world, including those that involve the “*spiritual side*” are just variations of the same category of thing, that is they are all “*just experiences*”:

D: I've actually seen people, actually spirit people, and sensing and hearing things what aren't there.

...

I: tell me a bit more about that?

D: I don't know. They're just experiences while I've been in hospital.

[Darren]

The simplicity and ordinary nature of the experiences, and of how they are seen is captured in an exchange between the researcher and Sally:

S: I was just getting some milk out the fridge because I was making a drink, and someone was standing behind the door dressed in black and with a black coat

...

I: Ok so you were sort of getting milk out the fridge and how did you notice the person in black?

S: I just seen him. [Sally]

Here Sally seems to be explaining that there is no special process of seeing the figure. She uses “*just*” giving emphasis to the normality of the experience of sight, regardless of whether she is seeing things she has been told are hallucinations or not.

Alongside this ordinary-ness, participants described a contrasting sense of something odd about their experiences:

I: I guess what I'm wondering is, you said that you feel things that weren't there. How did you know that they weren't there?

D: Well there's things about it, it sort of went in me a bit like. Y'know 'cus I was swelled up and lying on the bed and it sort of went inside my head. [Darren]

Here Darren describes how the experiences do not behave as he has come to expect the things within the world to behave. Sally describes a similar oddness about the perception:

I: so you said that you see people with knives and chainsaws and is that something, do they feel or look as real as I do or is there something different about them?

S: they're not, they're just like faint, I don't really (trails off) [Sally]

This concurrent and contrasting experience of hallucinatory perceptions as both normal and odd was seen both within and across participants.

This SOT summaries that the concept of a visual hallucination did not seem to capture the participants' experiences very well. The experiences they described are more complex and confusing than the term suggests.

2. Agency

This SOT captures the experience of participants having a varying sense of agency over their hallucinatory experiences. Two main areas in which the role of agency seemed to feature in the experience of visual hallucinations is in the emotional experience and in the experience of 'real-ness'

2.1. Sense of agency. Across participants there was a variation in the amount of control over, or extent to which the participant played a role in the generation of their visual hallucinations. All participants at some points in their interview talked about their experiences as being external to the self with no sense of agency:

I see him pass the door today, the one that was saying last night 'where is he'. [John]

Here John talks about seeing a person, the implication being that the person was physically there to be seen and exists as separate entity to John with its own agency. In contrast to this, there were times when all participants (except John) moved towards describing their experiences as internally generated or had a sense of agency over them:

Thinking that people are being killed, watching people be killed, actually seeing it with your eyes. [Jess]

In Jess' extract there is a hint to the role of her mind in the experience when she says "thinking that people are being killed" which she then moves away from to emphasise the external nature of the experience and the reality of it: "actually seeing it with your eyes". A more explicit example of agency can be seen in Darren's transcript:

D: There was two veins sticking out where they operated like. When I was looking at that (gestures to surgical scar on his wrist) when I was in hospital it was like it was being cured like.

I: Ok

D: the healing of the wound like

I: So what did you see?

...

D: I had a cut on my wrist from where the doctors had done the

operation and I was visualising that it had been cured. Like a hallucination towards the wound like. [Darren]

Here Darren use the terms “*visualising*” and “*hallucination*” to describe his experiences, suggesting that he is creating the visual experience. This type of language, specifically: “*picturing*”, “*imagining*”, “*dreaming*” and “*hallucinating*” was used by Rashid, Sally and Jess suggesting a sense of agency in the production of their experiences.

Kathryn differed slightly in her use of agency. She didn’t express a feeling that she was producing them but that she played an active role in them and had control over them:

I: do they come in the day time?

K: When I communicate with spirit. When I meditate.

I: So now it’s more of a errr, choice?

K: Yes I’m in control. [Kathryn]

For Kathryn agency comes in the form of meditation which she uses to invite and allow her experiences.

The mixed use of agency in the participants’ descriptions was not simply assigned to different experiences: Words denoting a sense of agency were used interchangeably with those descriptions suggesting no agency such as “*it actually happened*” and “*I saw*”. This is well demonstrated by Sally and Rashid:

S: I just picture them there and just like ermm picture knives and things like that and I can see them cutting my throat at the back of me and stuff.

I: so you said you can picture and you can see them. Is that two

different sorts of experiences or is it the same?

S: the same [Sally]

R: I just see water, you know the sea. I imagine myself on a ship, a battle ship and a boat is going through the waves. I'm on the boat and then the water comes.

I: and when you say you're on the boat are you imagining that?

R: No, I can see the boat, going through the water. I'm on a boat myself but I can see the other boat from where I am. I never thought about seeing or imagining y'know I don't know the difference. [Rashid]

In the above extracts Sally and Rashid explain that there isn't a difference, or at least not a difference that they can glean between seeing and picturing/imaging. However, they show ambivalence over this as later in their transcripts. Sally distinguishes that the experiences she "pictures" are "[her]self" and are different to those hallucinations that are "actually here". Similar to Sally, Rashid describes a difference between the two:

R: Yeah, it's when I'm looking at the ceiling. Y'know I just imagine, I wander off.

I: So is it something that you see in your mind, like in your imagination or is it something that you see out in front of you?

R: Both. Yes.

I: and what's the difference between those two?

R: difference is, y'know in your imagination you can imagine just about anything. But then with the visionary hallucinations I want them to stop sometimes. When they get too strong, they get too violent, too violent, and with imagination, a lot I can imagine nice things and sometimes being in your mind on holiday, nice hot place.

I: But that's not true of the hallucinations?

R: No. [Rashid]

Rashid describes that like Sally he is generating the “*imagination*” experiences and that he can control their content and duration. However, unlike in his earlier extract he recognises a difference and describes that the opposite seems to be true of the experiences he is describing here as hallucinatory.

The movement towards and away from the sense of agency, and the interchangeable language suggests that sense of agency is not experienced as a discrete distinction, instead it seems to be more of a continuum along which participants' experiences and sense-making of their experiences varies.

2.2. The role of agency in the emotional experience. When discussing her experience of “*picturing*” Sally describes that:

S: when I was at home, I'd just be there thinking about my mum and just picture them and stuff.

I: and do you see them here like you would see this chair or is it a bit different?

S: Erm, bit different

I: can you tell me how its different?

S: doesn't bother me, I just think it's myself sometimes so it doesn't bother me.

I: what do you mean, you think it's yourself?

S: probably that I'm imagining things myself [Sally]

Here Sally explains that experiences which have a strong sense of agency don't “*bother*” her because they are internally generated, the implication being those that don't have a strong sense of agency are experienced differently and do bother her. It is assumed that Sally uses “*bother me*” to describe an unpleasant emotional

experience. Similarly, John, who does not experience a sense of agency over his experiences finds them completely terrifying:

J: Just like I'm with you now, I see you now I see these visions, these people and hear these voices just the same.

I: so they seem exactly the same the feel the same

J: quite physical

I: can you describe that to me, what that's like?

J: What that's like, let me see. Traumatizing. Disturbing. Upsetting. Nerve wrecking. Shocking. Nightmare. Horrific. Horrendous and the likes. Why don't they leave me alone? They're not giving up, they're not letting it go, I know that much, I've heard them say that. [John]

It seems that in John's case the intention to harm that he ascribes to the hallucinations, combined with the absence of a sense of agency make the experience of them particularly frightening. In contrast to this, Darren's experiences with no sense of agency seem to bring a sense of being cared for:

I: So tell me more about the spiritual feeling

D: I dunno, it's just the spiritual side like.

I: What is, was there a particular quality about it?

D: There was just a warm feeling in the room like. Sort of [pause] I had three words going in my head, that it was actually telling me like.

Authority, love and care.

I: Authority, love and care?

D: of myself. Erm it was when I sort of thought I was experiencing God in the hospital. That's how I explain it. [Darren]

The extracts from Darren and John suggest that how the experience is understood seems to play an important part in the relationship between agency and emotional experience. For Darren spirituality may contribute to the positive emotional

experience while for John the intent to harm may contribute to the terror. This is explored in more detail in SOT five 'Creating a narrative'.

Kathryn's sense of agency is slightly different, she does not describe that the experiences are internally generated but that she can influence them:

K: I told this medium, an international medium what was happening to me and he said: 'tell the spirit when they visit you at night that they're disturbing my rest and that I will work with them in the day time'. And I did and I don't get any spirit visitation at night now.

I: OK that's better, so you can rest now?

K: Yes

....

K: Yes I'm in control.

I: How does that feel?

K: Good [Kathryn]

Kathryn explains that the support of others has facilitated her gaining a sense of agency through control over the initiation of the experience. This provided her with a sense of relief and allowed her to better meet her fundamental need of sleep.

2.3 The role of agency in the real-ness of the experience. There is a hint of a relationship between sense of agency and the feeling of real-ness an experience had, but again this is not simple: One might expect there to be an indirectly proportional relationship where a strong sense of agency equates to a weak feeling of real-ness. However, this does not seem to be the case. For Jess, the agency of interacting with a hallucination seems to make it more real:

I remember sitting at the porch and the door, the front door being opened because I pushed it, the door was open and I pushed it ajar. Up until then my hallucinations were visual hallucinations, were only visual

*I weren't, I wasn't interacting with them but this time I was.
... But I know, I feel it was so real sitting on the porch step, the door
was open, it was definitely open [Jess]*

Here we see that for Jess the active role she takes to change the environment by pushing open a door that she describes as part of her hallucination makes the experience feel more real.

However, Sally seems less concerned by experiences she has agency over, she discusses the difference between experiences with different senses of agency:

*S: I just think it's myself sometimes so it doesn't bother me.
I: what do you mean, you think it's yourself?
S: probably that I'm imaging things myself and but the, when that, when
someone was in the kitchen and tried to hit me in the face that wasn't
myself.
I: that was different?
S: that was different.
I: what was different about that?
S: because it was actually there. [Sally]*

The experience she has no agency over “*when someone was in the kitchen...that wasn't myself*” seems to be different and more real: it was “*actually there*”, than her experiences that seem internally generated.

This SOT of agency summaries the continuum of sense of agency all participants experienced. The use of language like ‘picturing’ or ‘seeing’ was important in identifying where participants were at a given moment on that continuum. The sense of agency seems to relate in a complex way to the emotional experience and the felt sense of real-ness.

3. Role of Others

Participants talked about other people in their lives, both professionals and non-professionals as contributing to how they understood their experiences, which in turn seemed to relate to the experiences they had. The role of others appeared to be experienced in two main ways: it either helped and felt positive to the participants or it felt negative: alienating and angering them.

3.1. Shared experience or understanding. Jess, Kathryn and John described positive aspects of sharing their experiences with other people that understood their experiences, or their understanding of their experiences.

Considering Jess and Kathryn's experiences:

I: I guess I'm wondering, the people who haven't had visual hallucinations, but have had other sorts of hallucinations. How did they respond to you?

Jess: Alright, strangely. And that puts you at ease as well. But alright. [they] knew that I wasn't talking y'know a load of bullshit. It was real. And they understand that. And that makes me feel better within myself.
[Jess]

K: I'm in an environment where I go to psychic meetings, I'm with other psychics who have had similar experiences to me and people who I can relate to.

I: and what's that like?

K: It feels comforting. I feel errrm, right where I am. I feel great that I can actually talk about my experiences to people who have had similar experiences. [Kathryn]

In both examples we see that sharing experiences with others seems to contribute to a validation of their experiences as real, feeling understood and gaining a sense of

calmness about their experiences. The importance of this is underlined by Jess later in her transcript when she says:

I feel more normal when I come to drop in [informal social group within EIP] than I do anywhere else.

This suggests that Jess otherwise lives with some degree of feeling abnormal.

Another experience of helpful others is demonstrated by John who focuses on his care team, something other participants shared, and which Kathryn got from her psychic circle. Although John struggles to trust his team he does find that working with them gives him hope for his future:

*J: A clearer horizon, that's what I'm hoping for. A whole new horizon
I: So that's what you're hoping for the future?*

*J: Mmm that's what I'm hoping to get out of the likes of this and
cooperating with the team I've been in the service for a good 35 years
and I'm a volunteer and I was helping.*

...

Psych: So we have voluntary and involuntary patients here

J: For the doctor to try and help me, and me to help myself. [John]

These moments of hope and kindred experiences punctuated the transcripts and provided relief from the struggles and more difficult emotions that were otherwise focused on, giving the impression that they provided a sense of grounding and psychological safety.

3.2. They can't/won't understand. In contrast to the previous subtheme, other people provided a source of pain and alienation, which was rooted in a general feeling that others couldn't understand because they hadn't lived through psychosis or, that they refused to attempt to understand the experience. All participants

articulated this experience to a greater or lesser degree. An example of this is seen in Sally's description of attempting to talk to her mother, which she generalises:

S: I did tell my mum about it but she thought I was silly. Mmm. People think I was going crazy they didn't, um they think that I'm pathetic probably and things like that.

I: Ok, so quite, yeah negative things. Is that something they've said to you?

S: (nods)

I: yeah. Erm so it sounds like sharing what you've experienced has been, what, I don't know quite hard maybe?

S: I know deep down my mum and dad did care, but people around me didn't. [Sally]

Here Sally conveys a sense of being othered, dismissed as crazy and feeling that other people don't care about her. In line with this, participants showed an awareness of the stigma associated with visual hallucinations which Jess describes:

the look on people's faces when you tell them that [you] hear and see things that they don't hear and see, there's a look of fear [Jess]

In the previous subtheme John identified his care team as a source of hope. But his ambivalence about his team is seen as he describes how his relationship with them is also framed by his sense of mistrust:

J: I'm convinced they're real and I'm thinking that the team work in collaboration and hoping I just to go along with it

I: the team are in collaboration with?

J: with the voices and the hallucinations because they're not taking their time when they say it's not real.

...

J: I'm seeing people, stalking me and plotting to harm me. Let's see, I go to the team, explain to the team, the team say they don't exist

they're not real, only heaven exists. Mmmm? So where does that leave me? [John]

Here John describes how he sought help from his team but that he experienced them as not considering that his experiences were real, or at least real to him. This seems to push John closer to his explanation that people are out to harm him. Similarly, Kathryn describes that she experienced her team as unwilling to consider her explanation of her experiences as spiritual which seems to create distance between them and generate anger:

K: Yes, yes. Now I know I'm dealing with professional people, but they've wrongly diagnosed me and they don't know anything about the spiritualism. As far as they're concerned it's schizophrenia and it's not. I: and that's, it makes you very angry?

K: It does yes, I'm dealing with ignorant people. People that don't know anything about spiritualism. [Kathryn]

This SOT describes the importance of other people and their responses to participants' experiences and sense making. The two subthemes reflect how these responses can be polarised and consequently seem to generate different emotional responses in the participants.

4. Coming to Know the Experience

It emerged across participants that they had been and were still working through a process of coming to know what was real and what wasn't. The importance of this reality varied across participants. This process of coming to know seemed quite emotionally fraught and has strong links with the understanding participants developed which is discussed in SOT five "Creating a narrative".

4.1. Hard to make sense of: wrestling with reality. Talking about the visual experiences was marked by a wrestling back and forth about what was real and what wasn't. This process of wrestling with reality was demonstrated by Jess:

J : Now this must be a hallucination, because I can't, because it was so real. I remember sitting at the porch and the door, the front door being opened because I pushed it, the door was open and I pushed it ajar... I could hear my nan and my dad saying 'just shoot her, get rid of her, everything will be normal again' I remember them saying that. I could hear them saying that. But I mean, I'm not in contact with them to be able to speak to them. But I know, I feel it was so real sitting on the porch step, the door was open, it was definitely open, but it couldn't have been it must have been a hallucination.

I: What makes you say it must have been a hallucination?

J: Because, err, because, I don't think they really had a gun. And, but I still don't, it was so real, pushing that door that door was open and those voices I heard it. But now I know, well, well I don't actually. [Jess]

Here Jess is engaging with a 'wrestling' process, giving us a taste of the confusion and anguish involved. This idea links with SOT two where agency has a relationship to real-ness and SOT one where visual hallucinations are not simply seen. The varied nature of the experience is as Jess would expect 'reality' to be, and her actions impact on this experience just as she would expect to happen in 'reality'. She is pushed back and forth between viewing her experiences as real and not real.

To try to ascertain what is real and what is not, Jess and Sally spoke about checking out their experiences with other people. At some points this seemed helpful to Jess and allowed her to settle on one side of her dilemma of reality which brought her some clarity and peace:

J: I thought people could see what I was seeing because it was that real.

I: and when you say it was a bit weird, tell me about that

J: Bit weird?

I: Yeah

J: Then you know you've got problems don't you. So that's what I meant by weird. That erm, coming to terms and accepting what I'm experiencing is a visual hallucination, that it's not something that everybody's seen. [Jess]

Here Jess explains that having spoken to her ex-partner's sister she realised that she is not seeing what everyone else is seeing. Jess describes this knowledge as allowing her to accept her experiences as hallucinations.

Both Jess and Sally seem closely tied to the idea that reality is a shared experience, as demonstrated above where Jess explains that seeing things that other people can't see is "weird" and problematic. We can see that in Darren's case a helpful idea to resolve this problem has been that the experiences are "real to [him]"

D: I just looked behind me and he was gone like. He was there and then he wasn't. I think I can see things but I don't know if it's my mind playing tricks or what.

I: So did you have a question in your mind as to whether it was real or not?

D: yeah, whether it's real.

I: Can you tell me a bit more about that questioning?

D: [My psychologist] said it feels real to me like so, it must be happening. It's real to me, like I say

I: And at the time did you have a question, a wondering if it was real or not?

D: erm. No, it was what I saw and feel. It was real to me what happened [Darren]

This idea of his reality seems to allow Darren to hold two seemingly conflicting ideas that what happened was both real and the possibility that it wasn't real whilst acknowledging the importance of the feeling of reality.

4.2. The importance of reality. The question of whether it is important that experiences are real or not varied across participants. John and Kathryn made it clear that it was very important that their experiences were real, and it seemed important for them to communicate this in their interviews. Kathryn started the interview by making it clear her experiences are not hallucinations but are very real spiritual experiences:

I: First off I guess I want to ask, have you experienced what people might term visual hallucinations?

K: They're not hallucinations they're visions.

I: They're visions OK.

K: erm, I've had premonitions, visions and I've had spirit visitations. I'm a psychic.

I: And visions is what you prefer to call them?

K: Yes

I: Ok, that's good to know because people have different ways they like to talk about it.

K: Spiritualism has been around for donkeys' years. And if you haven't had experience of spiritualism you're a bit kind of ignorant to the fact that spirit communication with actual spirits is what I've been doing.

[Kathryn]

This extract demonstrates that Kathryn seems to have found it undermining for her experiences to be classed as hallucinations. Similarly, John seemed to find it insulting to not be taken at his word that his experiences were real:

I know what's there. I'm not daft, I might be daft but I'm not stupid. It's not a dream. [John]

At the other end of the spectrum was Rashid who addressed the question of importance of reality with some ambivalence. On the one hand it seems very important that the question of reality is unimportant to him:

I: and has that [professionals' explanation of his experiences as visual hallucinations] changed your understanding of what you see?

R: not really no, because I think I'd always get them I think. There's no way I'd ever stop them. No way. Never stop them. So I don't want it to have a big impact on me, so that's why I don't make a great deal out of it. I don't really wanna act on them. I think so long as they're managed or you're in control of them then it's not too bad. [Rashid]

It seems that for him knowing that they aren't real makes no difference as to whether they continue to occur. Instead his focus is on his response to the experiences which he views as unrelated to the question of reality. On the other hand, Rashid demonstrates ambivalence over reality:

I don't want to believe they're real, see. I don't think, no I've never thought they're real... because y'know if I start believing that they're real then I'd really think to myself that I'm not y'know like sane. I'd think that I'm mentally unwell [Rashid]

Followed later by:

They were just like people, they felt real. It wasn't like it was a picture or a video on a screen. It was like y'know reality. Real. [Rashid]

Here Rashid seems to suggest the question of reality is in fact important to him and to how he views himself. It seems that his denial of the importance of reality is rooted in a fear that it will mean he is “*mentally unwell*” and the ambivalence over whether

his experiences are 'real' or not seems to be associated with a fear of being labelled as "*mentally unwell*".

The remaining three participants: Sally, Jess and Darren, as discussed in subtheme 4.1, do wrestle with what is reality and what is not reality. However, they did not focus so explicitly on this in their interview, suggesting that whilst it is important to them, it is perhaps less important to them to communicate their position to other people.

This SOT reflects an ongoing process of participants knowing their experience. The process of struggling with understanding what it means for an experience to be real, how one can ascertain that, and whether or not reality is an important aspect to be concerned with has been described, and variation across participants acknowledged.

5. Creating a Narrative

Across all participants there was a theme of creating a narrative to explain their experiences. Multiple narratives were considered, and these are described in turn. The relationship of participants' explanations of their experiences to the experiences themselves is considered.

5.1. Incorporating the experiences into pre-existing ideas. All participants seemed to use knowledge or experience they already had to make sense of their hallucinatory experiences. This fell into three main categories: a spiritual explanation, a link to previous trauma and a medical/biological explanation. The ideas of spirituality and medical/biological are ones that existed within the participants' culture, while the link to previous trauma is a link to previous experiences rather than knowledge.

5.1.1. The spiritual side. The idea of a spiritual side to life is largely culturally acceptable, as is evidenced in the existence of religion, spirituality and psychics. Spirituality or religion was important to Darren, Jess and Kathryn:

D: well it sort of tells you there's something there anyway. I mean I hadn't believed in anything like that but it shows you that there's something there

I: when you say that there's something there, what do you mean by that?

D: Well it's a spiritual side, I've experienced ghosts and stuff y'know it's like there, after death or something. Y'know it's real. [Darren]

Here Darren acknowledges that he was aware of the concept of a spiritual side.

However, for him it was only when he experiences his visual hallucinations that he recognises the existence of it. Kathryn relates her experiences to this spiritual side in a similar way, although she holds more strongly to this explanation and it becomes a part of her identity:

I've had premonitions, visions and I've had spirit visitations. I'm a psychic. [Kathryn]

Both Darren and Kathryn have lost close family members, which they link to their explanation of the existence of a spiritual side:

I don't know, I don't really why it was happening anyway. I think it's all to do with my mum dying and stuff, my mum and brother. I mean it happens on her birthday two years after she died. [Darren]

Whilst Darren and Kathryn make a link between their bereavements and their experiences neither of them explicitly offers an explanation of how or why they are linked. However, it seems that a sense connection to their deceased family may play a role:

I: what about your parents?

K: They died, they're both dead. Passed over.

I: and do they communicate with you at all?

K: My father does.

I: And what's that like?

K: It's very emotional, I mean if your parents communicated with you you'd feel emotional. I miss him, I love him, y'know. [Kathryn]

Here Kathryn describes how her experiences give her an ongoing connection with her father. This link between bereavements and a spiritual explanation may explain the importance of this explanation.

The religious aspect of spirituality is more relevant to Jess:

I could see it ... and I remember thinking maybe, maybe this is a calling ... I questioned all of my beliefs and what, y'know I'm seeing Jesus Christ on a cross here! What the, what is it time for me to change or is it a sign for me [Jess]

Jess had a pre-existing knowledge of a variety of religions and was brought up Buddhist. Jess' faith and understanding of religions is something she described as helpful and that gave her "strength".

5.1.2. Link to previous trauma. The explanation of the visual experiences linking to previous traumatic experiences was explicit in Jess and Sally's interviews:

I had, I'd gone to the police station to report [a family member], he erm. He erm he sexually abused me ... And the auditory hallucinations and the visual hallucinations were all based around the fact that I'd gone to the police. That there were people that didn't believe me, that thought I'd ruined their lives by going to the police and telling them this, and how I'd affected them. [Jess]

Psych: before the voices and that, and do you make a link between that the experiences with these girls that were kind of bullying or, because I just know that you've had some quite difficult or traumatic experiences with, erm, do you think that they are related to the voices in anyway?

S: (nods)

I: how do you think they were related

S: I think they used to know each other.

I: so you think the voices used to know these girls?

S: (nods)

I: and what about the people that you see? did they used to know the girls as well or?

S: (nods) [Sally]

Here Jess and Sally explain their experiences using links to previous trauma. For Jess this explanation seemed more of an acknowledgement of the psychological impact of her trauma whereas Sally made a direct link that the people she sees now knew the people who previously traumatically bullied her.

John repeated that his “*face doesn't fit*” and that the people he sees are intent on harming him. John does not explicitly link this to any events in his life, but his psychologist did explain that John had been the victim of racial attacks. It seems that John may have interpreted his visual hallucinations as threatening because of his previous experiences of being assaulted due to his race.

5.1.3. Medical/biological explanation. This medical/biological explanation is widely asserted in the participants' culture and seems to have been emphasised through their contact with medical professionals:

D: [My psychologist] said it was because I wasn't well at the time which is probably right yeah.

I: It was because you weren't well at the time?

D: I probably wasn't well at the time. [Darren]

Here we can see that Darren considers the explanation but maintains some distance from it through his use of the word “*probably*”. Jess considers an explanation of some kind of biological problem in her brain, which she described as predating her contact with services:

I knew that something was going on in my brain, I just didn't know what. I could hear and see things that other people weren't hearing and seeing. [Jess]

Here Jess explains something that is also featured in Rashid's interview; that the hallucinatory experiences are abnormal and are a manifestation of a physical problem with the health of the brain or mind.

Across participants there was variation in their conviction in the explanations. It seems that for some only one explanation can be considered and is held on to tightly (Kathryn, Rashid, Sally and John) whereas Darren and Jess seem to tolerate and move between different explanations.

5.2. The loop of experience and sense making. There was evidence across all participants that their experiences (during psychosis or prior to it) were used to help make sense of their visual hallucinations, and that this understanding of the hallucinatory experiences then seems to have a relationship with their subsequent experiences. It is not clear at what point in the cycle this process starts, but it seems evident that experience and sense making were relating to each other as if in a loop.

The different explanations considered in the subtheme above (5.1) tended to have different relationships with the hallucinatory experience. Darren provides a good example of the relationship between sensemaking and experience:

D: I was sensing things at the time, that was while I was in (old asylum), my mum and brother had died [pause]

...

I: OK, and you were sensing and feeling things?

Darren: It's this: I was rushed into hospital, it started there like. The room went freezing cold and smoke came down outside, I felt like a ghost in the room [Darren]

Here we see that Darren's spiritual explanation of his experiences seems to be associated with him identifying changes in temperature and seeing smoke as being a ghost. For Kathryn, Darren and Jess the experiences that they explained as spiritual tended to be made sense of as more benevolent, especially for Kathryn and Darren:

K: they're my guides and they make sure that I'm safe and I ground myself and I talk to spirit.

I: and they're quite positive then?

K: yes they are yes. [Kathryn]

When reflecting on how difficult his experiences have been Darren explains that despite it all, he has experienced them as a good thing. He seems to suggest that it is the spiritual nature of this experience that makes it good:

probably It's a good thing though, got to be, it's got to be spiritual.

[Darren]

For Jess, Sally and John, the understanding of their experiences as a result of trauma seems to leave them interpreting the presence of visual hallucinations as threatening:

J: They're quite normal people, quite normal individuals

Psych: so so you're not able to differentiate whether they are like a visual hallucination or an actual person is that right?

J: I know it's an actual person

Psych: you know

J: I'm convinced

Psych: Yeah but you know that they want to harm you, you believe that they want to harm you

J: Indeed, indeed, indeed. [John]

Here we see an exchange between John and his psychologist. John explains that there is nothing different between what he has been told are hallucinations and all the “*normal people*” he sees. His psychologist clarifies with John that he can tell the difference, because of the visual hallucination’s intention to harm him, which John strongly confirms “*Indeed, indeed, indeed*”.

Similarly, Sally describes that she experiences the people she sees as threatening, most likely due to her sense making that they know her previous bullies:

S: Its like as if, someone's got a grudge against me or something and I've not, I've done, I haven't hurt no one. I know I haven't.

I: but you feel like someone must have a grudge against you, what makes you say that?

S: Erm, I don't know, because, they [visual hallucinations] think like because I'm a good person and that they take the piss and thinking that, erm they think that they can do anything they like to me and stuff.”

[Sally]

Jess explains explicitly that how a person understands the experience of visual hallucinations is important:

J: it [visual hallucinations] could be quite dangerous.

I: quite dangerous?

Jess: Yeah, yeah I think so.

I: dangerous in what way?

J: How you interpret your hallucinations. Or if you're even able to tell that you're having a hallucination, because at first I didn't know they were hallucinations. [Jess]

Here Jess explains that the sense made of a hallucinatory experience can make it dangerous and scary, particularly when they are experienced as real. She later elaborates on one of the ways she experienced this danger:

J: The hallucination at the time, it was, I remember seeing my brother walking towards my flat because he wanted to speak to me because of what I'd done, because I'd gone to the police station and because he'd come into contact with me that's why he was shot. That's what I thought was going on, in my brain. Seeing my brother shot. And then shortly after that I erm I think I went a bit crazy actually after that.

I: Do you remember what happened?

J: I ran out into the street, without any shoes on erm, I thought that, the message that, what I was experiencing at the time was telling me that I had to martyr myself in order to save the rest of family because they too would be affected and maybe killed. So I ran in front of a lorry. Because I thought that was going to be able to save everyone. [Jess]

Here Jess demonstrates the loop of experience and sense making: the visual hallucination she saw of her brother being shot and which she experienced as scary was made sense of as being a consequence of her actions linked to her previous trauma:

because of what I'd done, because I'd gone to the police station and because he'd come into contact with me that's why he was shot. That's what I thought was going on

Following this sense making, Jess then experienced her hallucination as giving her a message:

the message that, what I was experiencing at the time was telling me that I had to martyr myself in order to save the rest of family

Within which the sensemaking seems to suggest that because of her previous understanding that she had been the cause of her brother being harmed, she had to resolve this threat to her family by killing herself to save them.

This loop of sense making and experience is not limited to just the visual hallucinations. John articulates that his experience of the people he sees is:

J: Traumatising. Disturbing. Upsetting. Nerve wrecking. Shocking. Nightmare. Horrific. Horrendous and the likes. Why don't they leave me alone? [John]

This scary experience and his sense making that they intend to harm him seems to colour all John's experiences in his life with mistrust:

*J: I ask her am I in trouble? The lady [CPN] turn round and tell me no. Now that's a weight off my shoulders.
I: so you thought you might have been in trouble?
J: Indeed, big trouble. [John]*

Including fearing getting in trouble with his care team, or fearing they are collaborating with the people he sees.

5.3. This new way of thinking about myself and the world has changed things. Participants explained that their experiences have altered their understanding of themselves and of the world. Darren explains:

I've heard people have had visits of spirits, when they've lost members of their family y'know. And I wouldn't believe them if it didn't happen to me like. It's changed my perspective of things anyway. [Darren]

Darren is describing how his experiences have made him more open minded and have altered his perspective of life and what is available to be experienced. Jess explains that the way she sees the world has changed and that she has become a kinder and more open-minded person because of her experiences:

J: strangely despite everything that's happened I'm actually a better person now.

I: Better how, in what way?

J: The way that I look at things, the way that I perceive things. I try and be a nicer person now towards people. [Jess]

Kathryn also described that her experiences have “*opened me up to the spirit world*” and are enriching her life:

I: imagine, you'd not had these experiences, you'd not seen the visons how would your life be different?

K: well it would just be boring to be quite honest. I'd just be plodding along getting through various experiences. This is going to change my life. [Kathryn]

However, there was a split in the participants with Rashid, John and Sally describing their experiences with a sense of loss:

R: And I think these thoughts the hallucinations they, in my experience they make me very negative. You know before was positive. You know

the positive and the love and the affection towards people is replaced by negativity, anger, hatred.

I: so its changed the way you feel about other people?

R: and life, life in general, and you know society, the world [Rashid]

Here Rashid describes how his experiences have robbed him of joy and made him view the world in a negative way.

Sally and John similarly describe that:

I was pinned to the sofa (with fear) ... and I've never been right since.
[John]

I: is there anything that we've not talked about that you feel is important?

S: No I think you've asked lots about what I've seen, I think it's really important because I just want it all to stop really. I mean what has happened and that, its like as if (voice starts to break) my whole life has been taken away (deep breath) [Sally]

The loss in Sally's and John's extract is palpable and their experience of visual hallucinations has had a detrimental effect on their lives. It seems that their sense making through the lens of previous trauma has been key to how they experienced their visual hallucinations.

This SOT summarises participants' process of understanding their experiences and the relationship of this understanding to the experience itself, and to the understanding of the self and the world.

Discussion

This study aimed to understand how visual hallucinations are experienced and made sense of in the context of psychosis. Five SOTs were presented encompassing the nature of the experience as not just visual, that there is a varied sense of agency in the experience, a questioning of the reality as participants engage with a process of trying to know more about their experiences and finally creating a narrative whereby participants engaged in a process of trying to explain and understand their experiences.

It's Not Only a Visual Experience

This superordinate theme suggests that the term 'visual' hallucinations is an oversimplification of a complex and multi-faceted experience and may lose essential aspects of the experience. The false distinction between modalities may make it difficult to gather prevalence rates or make meaningful inferences about prognosis. Clinically this underlines the importance of hearing the participant's experience, in its own terms rather than through the context of psychiatric terminology.

Existing literature suggests that the experience of hallucinations as usual perceptions is early in the developmental process and occurs prior to an explanatory model being formed (Carter, Read, Pyle & Morrison, 2018). However, the findings of the current study do not wholly support this view as participants described generating explanatory models for their experiences prior to contact with services and experiencing hallucinations as usual perceptions concurrently with noticing odd things about them, throughout their experience of psychosis.

Role of Others

This SOT emphasised the importance of feeling heard and understood and the impact this can have on self-esteem, particularly when sharing experiences with other individuals who have experience of psychosis, as has previously been identified (Perry, Taylor, & Shaw, 2007). This is likely to be particularly important given the reduced social networks and support observed with psychosis (Gayer-Anderson, & Morgan, 2013). The response of both family/friends and professionals was at times experienced by participants as a refusal or inability to understand. This resonates with literature linking stigma from others to lowered self-esteem and an ongoing struggle for acceptance (Knight, Wykes & Hayward, 2003)

The response of professionals seems to link to the medical/biological explanation, especially for Kathryn. Existing literature links this explanation to stigmatization (Read, Haslam, Sayce & Davies, 2006) which can impede recovery (Beresford, Nettle & Perring, 2010). Furthermore, the explanation and responses of a clinician can play an important role in the client's development of their beliefs (Carter et al., 2018) which emphasises the need for a considered response from professionals.

Agency

Movement along the continuum of sense of agency over experiences may link to the sense of enmeshment and jostling for power that is reported in voice hearing (Chin et al., 2009; Mawson et al., 2011) and to the loss of sense of self in psychosis (McCarthy-Jones et al., 2013). This dissipated sense of self may explain why hallucinations were at times perceived as being both externally or internally generated, or experienced with varying degrees of control: If the sense of self has

dissipated the boundary of the self is no longer clear, and it is hard to identify where phenomena are generated. As such the self may encompass stimuli within the environment typically seen to be outside of the self; perhaps such as the door in Jess' hallucination. Alternatively, the self could exclude stimuli that the mind has generated such as one's own thoughts, as may be possible in the case of Darren who described three words "authority, love and care" being implanted to his mind by God. This exclusion fits with evidence that hallucinations may be a result of an externalising bias in the misattribution of cognitive events (Brookwell, Bentall & Varese, 2013).

The theme of sense of agency had a varying relationship with the emotional experience and the sense of real-ness of the experience, irrespective of where the hallucinatory experience was perceived to be generated. Furthermore, it was seen that control or interaction with the experience could strengthen the sense of reality. This finding can be considered in cognitive terms through the ideas of Trower and Chadwick (1995) who suggested that the self is continuously constructed and never secure: The self is proposed as made up of the subjective self (which has the power of agency and awareness of self), and the objective self (the self presented in relation to another person) which is reified by awareness from the subjective self (Chadwick, Birchwood & Trower, 1996). As such, the sense of agency and its relationship to felt sense of reality and emotional experience that participants described may be linked to varying degrees of strength or weakness in this subjective self and could originate in the disruptions of typical adolescent developments of the self and agency that is seen in schizophrenia (Harrop & Trower, 2001).

Creating a Narrative

To understand their experiences participants linked their experiences to their frames of reference. Although these explanations were characterised by some jumps of logic, they did not seem to be wholly unreasonable. Indeed, the link to previous trauma fits well with established literature regarding the association of hallucinations with traumatic life events (Bentall, Wickham, Shevlin & Varese, 2012; Janssen et al., 2004). The findings concur with Bentall et al.'s (2012) results that childhood sexual abuse is a predictor of visual-auditory hallucinations and that the experience of being victimised is a predictor of paranoia and visual-auditory hallucinations. However, the current study furthers the model proposed by Bentall et al. (2012) by providing a phenomenological understanding of this association, particularly through the loop of experience and understanding. This loop, whereby previous life experiences colour how a person encounters and makes sense of experiences, which then impacts on subsequent experiences, goes beyond existing literature that suggests that differing appraisals of visual hallucinations are made and that these appraisal impact on distress (Gauntlett-Gilbert & Kuipers, 2005). The loop suggests an explanation for how the appraisals might be generated, how distress might be maintained and how these appraisals might affect the generation of hallucinations and the experience of the world.

Coming to Know the Experience

SOT five: 'Creating a Narrative' links with SOT four: 'Coming to Know the Experience' which was characterised by a difficult and fraught process of trying to understand what it means for an experience to be real. Within the subtheme 4.1 of

wrestling with reality, the idea that reality is a shared experience was identified; this concurs with McCarthy-Jones et al.'s (2013) theme that psychosis is characterised by a loss of consensual reality.

It seems that what the participants think about their experiences (how they experience and make sense of them) becomes their reality and forms 'The loop of experience and sense making' (subtheme 5.2). This fits with the idea that reality "mean[s] something approximate to 'what is thought about things in general'... rather than 'how things really are when thought is removed'" (Larkin, Watts & Clifton, 2006, p105). As such, the wrestling of trying to distinguish between the reality of their thoughts and cognitive experiences, and the reality of their experience of physical objects in the world is a difficult and perhaps impossible task.

The participants' ontology and epistemology seemed changed, or at least shaken by their experiences. Given these ontological and epistemological changes it is perhaps unsurprising that participants' views of the world are altered. For some this loss of the security of the self in the world was an opportunity for meaningful personal growth, for others this was terrifying, and for others still it gave newfound certainty and meaning. This fits well with existing phenomenological understandings (Laing, 1967; Spinelli, 2001) and has some links to the overarching themes of loss, rebuilding and re-forging life, and gifts from psychosis identified in McCarthy-Jones et al., (2013) meta synthesis on psychosis.

Strengths and Limitations

IPA methodology. The criteria for good quality, valid IPA described by Smith (2011) and Yardley (2000, 2008) are set out in Table 6.

Table 6

Criteria for good IPA

Smith (2011)	Yardley (2000, 2008)
Subscribes to the theoretical principles of IPA: is Phenomenological, Hermeneutic and idiographic	Sensitivity to context
Transparent	Transparency and coherence
Coherent, plausible and interesting analysis	Impact and importance
Sufficient sampling	Commitment and rigour

This study subscribes with commitment, rigour and transparency to the theoretical principles of IPA: The interview schedule was created from a phenomenological position to capture ideographic experience with the help of an expert by experience to promote sensitivity to context; Analysis was completed participant by participant to allow ideographic meaning to emerge (see Appendices F-I); The author's context and fore-structures are acknowledged; and the double hermeneutic can be seen in the analysis. Sufficient sampling of n=6 was reached (Smith et al., 2009) and at least three participants contributed to each theme (Smith, 2011). Triangulation through supervision and working groups strengthen the validity of the themes. The analysis links with existing psychosis literature both phenomenological and otherwise, suggesting that it is a plausible analysis. Given the scant literature on the subject it is hoped this study provides an important contribution.

Sample characteristics. Participants were sampled from a range of care teams spanning from EIP, to CMHT, AOT and IPS. This broad range allows a view of the experience across different levels of need. Two participants (John and Sally)

requested that their psychologist was present in their interviews, and whilst present, he also contributed to the interviews. The presence of the psychologist enabled these participants to take part in the interviews and have their experiences heard. However, it may have introduced issues of power dynamics to the interviews. Two of these power dynamics are: Firstly, the balance of professionals to service users was uneven with the service user outnumbered two to one. Furthermore, the participants would be aware that in AOT their liberty and the type of care they receive depends upon how mentally well they are. This context combined with the presence of their psychologist may have resulted in participants feeling somewhat disempowered, unable to speak freely or share all of their experiences.

A second power dynamic is that although the researcher (the trainee clinical psychologist completing their first IPA study) remained the lead interviewer and all questions on the interview schedule were addressed a sense of being observed and appraised by the qualified psychologist was felt by the researcher. This power dynamic may have influenced both the researcher and the qualified psychologist. It is possible that this dynamic facilitated the qualified psychologist to actively participate in the interviews whilst simultaneously impeding the researcher from asking the qualified psychologist to refrain from participating in the interviews. This participation somewhat altered the pace and direction of the interviews towards the style and interests of the qualified psychologist which may have biased the findings.

The main recruitment criterion was that participants had experience of visual hallucinations. However, as identified in SOT one 'It's not only a visual experience' this may be an unsuitable way to identify a sub-group of individuals with homogenous

experience. A more meaningful way to group participants may be by considering the psychological flexibility with which they understand their experiences.

Clinical Implications

The experience of visual hallucinations as 'not only visual' suggests they are not a discrete experience and interventions aimed specifically at visual hallucinations may only address part of the experience and distress. Instead, considering the role these hallucinations play in the understanding of previous life experiences and attending to the loop of experience and sense making with the individual might be a more holistic focus for therapy, as is described in Hulme (1999) and Spinelli (2007).

Working within the client's framework of understanding to support them develop a sense of agency and control over their visual hallucinations, as was seen in Kathryn's experience within her psychic circle, may be a beneficial way to develop coping strategies, as is done with voices (Farhall, Greenwood & Jackson, 2007). This may be furthered by embedding these strategies with the more holistic focus of therapy and supporting the development of the disrupted self (Harrop & Trower, 2001).

The importance of coming alongside the person, listening to and engaging with their experiences of their reality was identified in SOTs one and three ('It's not just a visual experience' and 'The role of others'). This process of engagement can be transformative, facilitating change and psychological growth (Laing, 1967) as was identified in SOT five ('Creating a narrative'). Supporting an individual along this journey links well with recovery principles (Amphlett, 2015) and is something clinicians are well placed to do.

Future Research

This study is, to the author's knowledge, the first of its kind. As such, there is much work to be done. Points of particular interest are:

- How to best describe and conceptualise the experience of 'visual hallucinations' given that they are not experienced in the unidimensional way this term suggests.
- Understanding the experience from different groupings of participants, such as the amount of psychological flexibility with which individuals understand their experience. This may be a more meaningful grouping of individuals and this could be measured by the Acceptance and Action Questionnaire-II (Bond et al., 2011).
- Further qualitative explorations of the sense of agency experienced in and over the hallucinatory experience, particularly the relationship of this with emotional distress and contributing factors to this relationship.

Conclusion

Superordinate themes of 'It's not only a visual experience', 'Agency', 'Role of others', 'Coming to know the experience' and 'Creating a narrative' were identified. Across participants a sense of confusion, at times of curiosity and an earnest need to try to understand the experiences was conveyed; these understandings were held with varying degrees of psychological flexibility and could contribute to feelings of terror and hope. See Appendix L for author's concluding note on reflexivity.

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Press Release

Literature review: Do Cognitive Behavioural Approaches to First Episode Psychosis Change an Individual's Experience of Distress Beyond that of Treatment as Usual? A Systematic Review and Meta-Analysis of the Literature.

Introduction. Cognitive behavioural therapy for psychosis (CBTp) is recommended for those struggling with a first episode of psychosis (National Institute for health and Care Excellence (NICE), (2014). However, there has been debate in the literature regarding the best way to measure the effectiveness of CBTp. Primarily the debate has concerned whether outcome is best captured as symptom reduction or as changes in emotional experience, such as a reduction in distress: “The primacy of distress is a core principle of CBT, but CBT for psychosis has not always followed this, given its primary emphasis on psychosis outcomes.” (Birchwood & Trower, 2006 pp. 107). Promisingly the impact on distress has started to be considered and a recent review of the literature (Lincoln & Peters, 2019) looked at the impact of cognitive behavioural approaches (CBA) to delusions and hallucinations; this review identified twelve studies, most of which utilised a measure of distress.

The current review focuses on those experiencing a first episode of psychosis and included only studies that used psychometrically valid and reliable psychological measures of distress that the literature identifies as important in the psychosis population. The review aimed to answer the question: What impact do cognitive behavioural approaches have on the distress felt by people during their first/early episode of psychosis, above that of treatment as usual (TAU)?

Method. Systematic searches yielded 14 studies to be meta-analysed. Search terms were guided by those used in a similar review (Lincoln & Peters, 2019). The main criteria were any controlled intervention study where the intervention utilised cognitive and/or behavioural approaches with people who meet the criteria for a first episode/early psychosis. Data was extracted to calculate the effectiveness of CBA at reducing distress. The studies were allocated a quality rating using a quality rating tool adapted from the Cochrane Collaboration's tool for assessing risk of bias in randomised trials (Higgins et al., 2011) and the Risk of Bias Assessment Tool for Non-randomised Studies (Kim et al., 2013).

Analysis. The main effect analysis showed no significant effect of CBA on distress above that seen in TAU across the 14 studies. There was a slight trend in favour of the intervention. The quality of studies was poor and this may have contributed to an underestimation of the treatment effect size. This can be seen in the application of the quality effects model to the data whereby, if all the studies were of a better quality (i.e. as good as the best study in the review) the effect size would increase by approximately 55%. Whilst this is interesting and argues the need for future studies to be better quality to accurately identify the magnitude of the treatment effect, the estimated effect size is still negligible and non-significant.

A subgroup analysis comparing the effect in the context of specialised early psychosis services, compared to non-specialised services revealed that CBA had a significantly greater impact on distress than TAU, when provided in the context of non-specialised services. In the context of specialised services this effect disappears. It seems that the specialised services which provide care within a service model that was developed specifically to meet the needs of people with early psychosis has an

impact on a person's experience of distress that, in the current literature, cannot be surpassed by adding therapy informed by cognitive behavioural approaches.

A second subgroup analysis of the different measures of distress revealed that the intervention reduced hopelessness significantly more than TAU did in both specialised and non-specialised services. This effect seems to suggest that hopelessness is perhaps more responsive to CB approaches than other aspects of distress. However, it is important not to give too much weight to this finding as only two effect sizes contributed towards this.

Limitations. Study outcomes suffered as they were not designed to measure distress or assess the impact of a specific therapy. Furthermore, the lack of a main effect may be due to the use of both non-specialised and specialised early psychosis services as TAU.

Future research. Future studies would benefit from using distress measures as a primary outcome. Therapies other than CBA would benefit from investigation to consider the unique contribution they could make to service users' care.

Clinical implications. The selection of services users for CBA should be carefully considered to weigh up the return for the service user beyond that which they would get from routine care offered by specialised early psychosis services.

Empirical paper: Making Sense of the Experience of Visual Hallucinations In Psychosis: An Interpretative Phenomenological Analysis.

Introduction. Hallucinations can occur in any sensory modality; visual hallucinations in psychosis are the second most commonly occurring modality (after auditory) and they affect around 27% of those with psychosis (Waters et al., 2014).

A review of the qualitative literature identified four overarching themes to the experience of psychosis: loss, identifying a need for and seeking help, rebuilding and re-forging life, and finally, better than new: gifts from psychosis (McCarthy-Jones, Marriott, Knowles, Rowse, & Thompson, 2013). It is important to note that none of the reviewed studies considered visual hallucinations specifically or explicitly. Therefore, it is impossible to know how much these themes describe the experience of individuals with visual hallucinations.

Visual hallucinations as part of schizophrenia are associated with a greater level of distress and a poorer prognosis compared to those who experience schizophrenia without visual hallucinations (Clark, Waters, Vatskalis & Jablensky, 2017; Oorschot, Lataster, Thewissen, Wichers & Myin-Germeys, 2012). The study of visual hallucinations and their meaning to individuals is sparse, and consequently successful intervention is limited (McCarthy-Jones et al., 2013; Waters et al., 2014). There is a call for research to provide a greater understanding of visual hallucinations (Dudley, Collerton, Nicholson & Mosimann, 2013).

Aims and Method. The study aimed to understand how people with psychosis experience and make sense of visual hallucinations. Six participants with

experiences of visual hallucinations within the context of a schizophrenia spectrum diagnosis were interviewed. The interviews were analysed using the qualitative method of interpretative phenomenological analysis which allows a detailed ideographic understanding of participants' experiences to be gained (Smith, Flowers & Larkin, 2009).

Analysis. Five superordinate themes were identified: 'It's not only a visual experience', 'Agency', 'Role of others', 'Coming to know the experience' and 'Creating a narrative'. Emotional experience was interwoven within each superordinate theme. The themes are summarised in Table 1 below:

Table 1

Table of Themes Across all Participants

Themes	Description
<p>1. It's not only a visual experience</p> <p>1.1. It's a complex and multifaceted experience</p> <p>1.2. It's just like everything else, sometimes.</p>	<p>The experiences did not just occur in the visual sensory modality. Multiple senses and interactions with the experience were described and extra senses were involved such as sensed, felt or experienced. Participants also described receiving a communication or message from the hallucinatory experience.</p> <p>Participants described their experiences as perceived just like everything else and as different to normal, with an odd quality about the experience.</p>
<p>2. Agency</p> <p>2.1. Sense of agency</p> <p>2.2. The role of agency in the emotional experience</p> <p>2.3. The role of agency in the sense of real-ness</p>	<p>There was a variation in the amount of control or extent to which participants felt they played a role in the initiation of their visual hallucinations. All participants at some points in their interview talked about their experiences as being external to the self with no sense of agency.</p>
<p>3. Role of others</p> <p>3.1. Shared experience or understanding</p> <p>3.2. They can't/won't understand</p>	<p>Participants talked about other people in their lives, both professionals and non-professionals as contributing to how they understood their experiences. These other people were at times experienced by some participants to be helpful, whilst at other times were experienced as negative and dismissive.</p>
<p>4. Coming to know the experience</p> <p>4.1. Hard to make sense of: wrestling with reality</p> <p>4.2. Importance of reality</p>	<p>Some participants described that they had been and were still working through a process of coming to know what was real and what wasn't. Participants described that their hallucinatory experiences were difficult to make sense of and talk about.</p>

<p>5. Creating a narrative</p> <p>5.1. Incorporating the experiences into pre-existing ideas</p> <p>5.2. Loop of experience and sense making</p> <p>5.3. This new way of thinking about myself and the world has changed things</p>	<p>All participants seemed to use knowledge or experience they already had to make sense of their hallucinatory experiences. This fell into three main categories: 1) a spiritual explanation, 2) a link to previous trauma, 3) a medical/biological explanation. It seemed that experiences of the hallucination and sense making of it were relating to each other as if in a loop.</p>
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Conclusions. The term ‘visual hallucinations’ seems to be on oversimplification of the experiences the participants described. The importance of how professionals respond to an individual’s description of their experiences is important. Furthermore, if clinicians can support individuals to psychologically engage with their psychotic experiences there is opportunity for psychological growth. The varying sense of agency can be linked to established literature regarding changes in the sense of self that can occur in psychosis (McCarthy-Jones et al., 2013; Trower & Chadwick, 1995). The loop of experience and sense making provides an explanation of how individuals might appraise their experiences. Further research is needed to provide a more detailed definition of ‘visual hallucinations’ and to better understand the role of agency in the experience.

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Appendices

Literature Review Appendices.

Appendix A: Identifying studies with excessive influence

As can be seen from the forest plot in Figure 1 if Jackson, McGorry et al., (1998 a) is omitted then the meta-analytic effect becomes significant. The modified treatment effect size is $d = -0.13$ [-0.25; -0.01] $p < 0.05$ ($p = 0.03$) which remains negligible and is marginally significant. However, the confidence intervals do include the synthesised treatment effect value ($d = -0.09$) and as such, this study is not considered to be exerting excessive influence on the outcome.

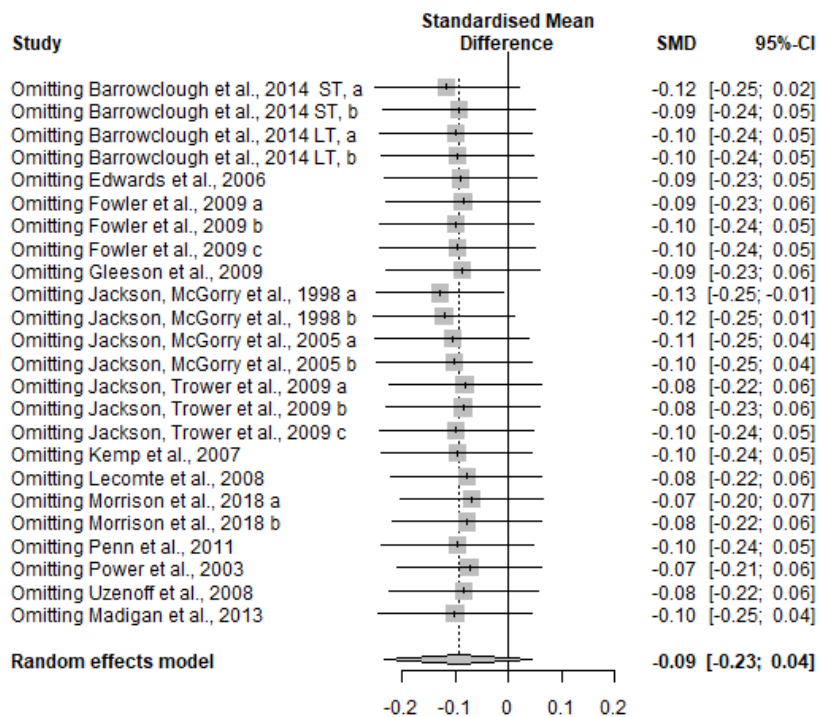


Figure 1. Forest plot depicting leave one out analysis.

Appendix B: Publication bias and small study effects.

a. Funnel plot

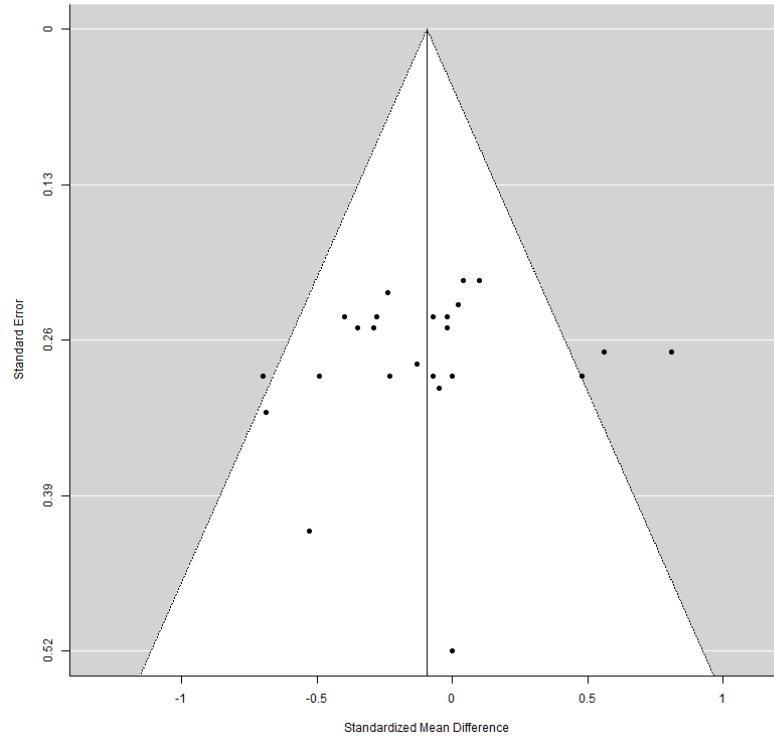


Figure 2. Funnel plot of publication bias and small study effects.

b. Eggers's test (Egger et al., 1997)

$t = -0.64$ (95% CI = -0.99 to 1.54) $p = 0.53$ (not significant).

Empirical Paper Appendices.

Appendix A: NHS Ethics Approval from the Health Research Authority



Miss Charlotte Denton
School of Psychology
Edgbaston
Birmingham
B15 2TT

Email: [REDACTED]

12 April 2018

Dear Miss Denton

Letter of HRA Approval

Study title: The experience of visual hallucinations for individuals with a schizophrenia spectrum diagnosis: An Interpretative Phenomenological Analysis.

IRAS project ID: 228510

Protocol number: RG_17-219

REC reference: 18/WM/0089

Sponsor: University of Birmingham

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further from the HRA.

How should I continue to work with participating NHS organisations in England?
You should now provide a copy of this letter to all participating NHS organisations in England, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "summary of HRA assessment" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland, Scotland and Wales?
HRA Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland, Scotland and Wales.

If you indicated in your IRAS form that you do have participating organisations in one or more devolved administration, the HRA has sent the final document set and the study wide governance report (including this letter) to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with Northern Ireland, Scotland and Wales.

How should I work with participating non-NHS organisations?

HRA Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

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

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

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

I am a participating NHS organisation in England. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Mr Sean Jennings

[Redacted contact information]

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 228510. Please quote this on all correspondence.

Yours sincerely

[Redacted signature]

Email:

[Redacted email address]

Copy to: Mr S [REDACTED] t
Ms [REDACTED] Foundation Trust,
Lead [REDACTED] [REDACTED]

Appendix B: University of Birmingham Approval and Sponsorship



UNIVERSITY OF
BIRMINGHAM

FINANCE OFFICE

Miss Charlotte Denton
School of Psychology
University of Birmingham

Wednesday, 28 February 2018

Dear Miss Denton

Project Title: The experience of visual hallucinations for individuals with a schizophrenia spectrum diagnosis: An Interpretative Phenomenological Analysis.
Sponsor Reference: RG_17-219
ERN reference: ERN_17-1467

Under the requirements of Department of Health Research Governance Framework for Health and Community Care, the University of Birmingham agrees to act as Sponsor for this project. Sponsorship is subject to you obtaining a favourable ethical opinion and NHS R&D management approval where appropriate.

As Chief Investigator, you must ensure that local study recruitment does not commence until all applicable approvals have been obtained. Where a study is or becomes multi-site you are responsible for ensuring that recruitment at external sites does not commence until local approvals have been obtained.

Following receipt of all relevant approvals, you should ensure that any subsequent amendments are notified to the Sponsor, REC and relevant NHS R&D Office(s), and that an annual progress report is submitted to the Sponsor, REC and NHS R&D departments where requested.

Please ensure you are familiar with the University of Birmingham Code of Practice for Research (<http://www.birmingham.ac.uk/Documents/university/legal/research.pdf>) and any appropriate College or School guidelines.

Finally please contact [REDACTED] should you have any queries.

You may show this letter to external organisations.

Yours sincerely

[REDACTED]
Dr Sean Jennings
Head of Research Governance and Ethics
Research Support Group

cc Dr Andrew Fox

University of Birmingham Edgbaston Birmingham B15 2TT United Kingdom
w: www.finance.bham.ac.uk

Appendix C: Semi Structured Interview Schedule

Questions & topic areas for semi-structured interviews

Presence and form

- Do/have you experienced visual hallucinations?
 - How would you like to refer to these experiences?
- Could you tell me more about these [use of participants preferred term for VH].. ?
 - Triggers? Setting?
 - What do you see? -description
 - What other, if any, sense are involved? |
- When you see these, how do they impact on you?
 - What do you do? -try to test them?
 - How do you feel?
- How do your [use of participants preferred term for VH].. compare to known experiences of reality?

Understanding and meaning

- When did you first experience [use of participants preferred term for VH]?
 - How did you feel?
 - How did you understand it?
 - Has your understanding of [use of participants preferred term for VH].. changed over time?
- Did you try to talk to other people about your experience?

Relationship with, and relating to VHs

- Is there anything in particular you like, or see as positive about your [use of participants preferred term for VH]..?
- Is there anything in particular you don't like, or see as negative about your [use of participants preferred term for VH]..?
- How would you describe your relationship with your... [use of participants preferred term for VH]?

Impact on identity and view of self/world

- Have your [use of participants preferred term for VH].. altered the way you see the world?
- Have your [use of participants preferred term for VH].. altered your personality and sense of self?
- What would it mean to you, to never have had [use of participants preferred term for VH]..?
 - how would things be different?

Version 1.0 Dated: 18th December 2017

Appendix D: Participant Information Sheet



UNIVERSITY OF
BIRMINGHAM

IRAS ID: 228510

Participant Information Sheet

The experience of visual hallucinations for individuals with a schizophrenia spectrum diagnosis: An Interpretative Phenomenological Analysis.

You are being invited to take part in a research study. Before you decide whether to take part or not it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully.

Please ask if there is anything that is not clear or, if you would like more information.

Take time to decide whether or not you wish to take part.

- **What is the purpose of this research?**

This study forms part of the research thesis for a doctoral student in clinical psychology (Charlotte Denton).

The study aims to find out what it is like to experience visual hallucinations. People who have a diagnosis of schizophrenia can sometimes experience these. It is hoped that our research will help clinicians working with people with visual hallucinations to have a better understanding of them. Additionally, it is hoped that in the future this understanding will help to develop more effective talking therapies for people with visual hallucinations.

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

You have been invited to take part because your clinician has identified that you have experienced visual hallucinations and that you are able to talk about these.

- **What happens if I agree to take part?**

If you agree to take part a member of the team providing your care will pass your contact details to the Chief Investigator (Charlotte Denton). Charlotte will then contact you to arrange a face to face meeting.

At this meeting, Charlotte will check that you understand what is involved in the study, give you another copy of this information sheet and will ask you to sign the consent form. You will be able to keep a copy of this information sheet and the signed consent form.

Charlotte will then complete an interview with you. The interview will focus on your experience of visual hallucinations. There will be some predetermined questions, but you will also be free to talk about your own specific experience of visual hallucinations. There will be a break about half way through the interview. After the interview there will be some time to reflect on the experience of talking about the visual hallucinations and ask any questions you might have. In total, it is expected that this meeting will last around 90 minutes, and not more than two hours.

The interview with Charlotte will be audio recorded and then typed up by Charlotte into a word document, this is known as a transcript. Information that directly identifies you (such as your name) will be removed. As soon as the transcript is completed the audio recording will be deleted.

If you would like to, you can provide feedback on the analysis of the interviews. If you give your consent to provide feedback you will be sent a summary of the analysis in the post and asked to comment on how this relates to your experience of visual hallucinations. This may be several months after you have given your interview. A stamped, addressed envelope will be included for you to return your feedback within two weeks.

- **What are the risks of taking part?**

The risks of taking part in this research are low.

Some people may find that it is upsetting to talk about their experience of visual hallucinations. Others may not. The person you will be talking with (Charlotte) is training as a Clinical Psychologist, and so is skilled at talking with people if they become upset.

- **What are the benefits of taking part?**

Whilst there are no clear clinical benefits to taking part in the study people often find talking about their hallucinations helpful when trying to understand them.

- **What will happen if I do not want to carry on with the study?**

Taking part in this research is completely voluntary. If you do decide to take part you are still free to withdraw during the interview without giving a reason. Whether you decide to take part or not, or withdraw at a later date, your care will not be affected.

After the completion of the interview you have two weeks during which time you can change your mind and withdraw from the study. If you do change your mind you should contact Charlotte Denton who will remove your interview from the study.

If you withdraw from the study during this two week period, your interview transcript will be destroyed but your consent form must be kept for proof of

withdrawal. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your data please contact Dr Andrew Fox (Clinical Psychologist) at a.p.fox@bham.ac.uk.

If you have not made contact after this two week period Charlotte will assume that you wish to continue to be involved in the study. Whether or not you decide to take part in the research your care will not be affected in anyway.

- **Expenses and payments**

You will need to visit a trust site on one occasion to give your consent to take part and complete the interview. This will be arranged between you and Charlotte at a suitable date and time. You will be reimbursed for the cost of, up to £20.

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

The interviews from this study will be analysed and the results of this analysis may be published in an academic journal. This study forms part of a doctoral thesis and this thesis will be held by the University of Birmingham Library. Portions of the research may be used in training and presentations. If you would like, you can be sent a summary of the results to keep.

- **Will my information be kept confidential?**

Your information will be anonymous: your transcript and any quotes from it will not include any information that will identify you personally. At the meeting with Charlotte you will be assigned a pseudonym (a different name to your own), this is the name that you will be referred to in the written report of the research to maintain your anonymity

To help the analysis of the interviews some relevant quotations from some participants will be used. In the full thesis an example of part of a transcript may be included.

The analysis of your anonymous interview transcript will be supervised by two Clinical Psychologists (Dr Andrew Fox and Dr Catherine Amphlett). In addition to this the analysis of your anonymous interview transcript may be shared with academic doctorate researchers. This is to help ensure the analysis is a fair and true representation of your anonymous interview transcript.

If you suggest that you or someone else is at risk of harm, or if the process of talking about your visual hallucinations has been very upsetting for you this may be shared with your NHS care team. If this is the case a member of your care team will be told so they can ensure that you and all relevant individuals are safe and well. Charlotte will always try to let you know first if she thinks she needs to do this.

To ensure that the research is being conducted in line with its submitted procedure and the relevant guidelines an audit may take place. In which case, the regulatory bodies and the sponsor (The University of Birmingham) may request to view the anonymous transcript.

- **How will my information be stored?**

Your consent form will be transported from the interview site to a secure Birmingham and Solihull Mental Health Foundation Trust location where it will be stored securely. The audio recording of your interview will be stored on an NHS encrypted memory stick until it is transcribed and then it will be deleted. Upon the completion of the research the consent forms and anonymous electronic transcripts will be moved to the University of Birmingham where they will be securely stored under the Supervision of Charlotte Denton's supervisor: Dr Andrew Fox (BSMHFT employee

and Clinical Psychologist) until ten years has passed, after which they will be securely destroyed.

The University of Birmingham is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

- **How is this research funded?**

The research is organised and funded by the University of Birmingham

- **Who has reviewed this study?**

This study was given a favourable ethical opinion for conduct in the NHS by West Midlands, Black Country Research Ethics Committee.

- **What happens if I have any further concerns?**

If there are any problems or you have any concerns during the course of the study you can discuss them with Charlotte on the contact number below. She will do her best to answer your questions. If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure.

Researchers:

Charlotte Denton: Clinical Psychologist in Training

[Redacted]
[Redacted]

Birmingham and Solihull Mental Health Foundation Trust complaints:

[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]

If you would like to discuss any aspect of this research please contact:

Charlotte Denton

[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]

Appendix E: Consent form



NHS
Birmingham and Solihull
Mental Health
NHS Foundation Trust

UNIVERSITY OF
BIRMINGHAM

INFORMED CONSENT FORM

Research site: Birmingham and Solihull Mental Health NHS Foundation Trust

Study Number: RG_17-219.

IRAS ID: 228510

Study Title: The experience of visual hallucinations for individuals with a schizophrenia spectrum diagnosis: An Interpretative Phenomenological Analysis.

Researcher: Charlotte Denton

Please initial box

1. I confirm that I have understood the participant information sheet dated 10th July 2018 (version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

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

3. I understand that the research interview will be audio-recorded

4. I understand that following the research interview I will have a two-week period for reflection. During this two week period I understand that I can contact the

researcher to withdraw my consent, without giving any reason, without my medical/social care or legal rights being affected.

5. I understand that the data collected during this study may be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data.

6. I understand that parts of the data may be made available to the NHS team responsible for me but **only if** any previously undisclosed issues of risk to me or another person's safety are disclosed. I also understand that in the case of audit the regulatory authorities and sponsor (University of Birmingham) may request to view the research data.

7. I confirm that I have understood the process for storage and transport of my data as set out in the participant information sheet dated 10th July 2018 (version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

8. I understand that direct quotes from my interview may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments.

9. I would like to provide feedback on the analysis of the interviews.
Please provide your postal address below.

10. I would like to receive a copy of the completed study.
Please provide your postal address below.

Postal Address:
.....
.....

.....
.....

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

.....

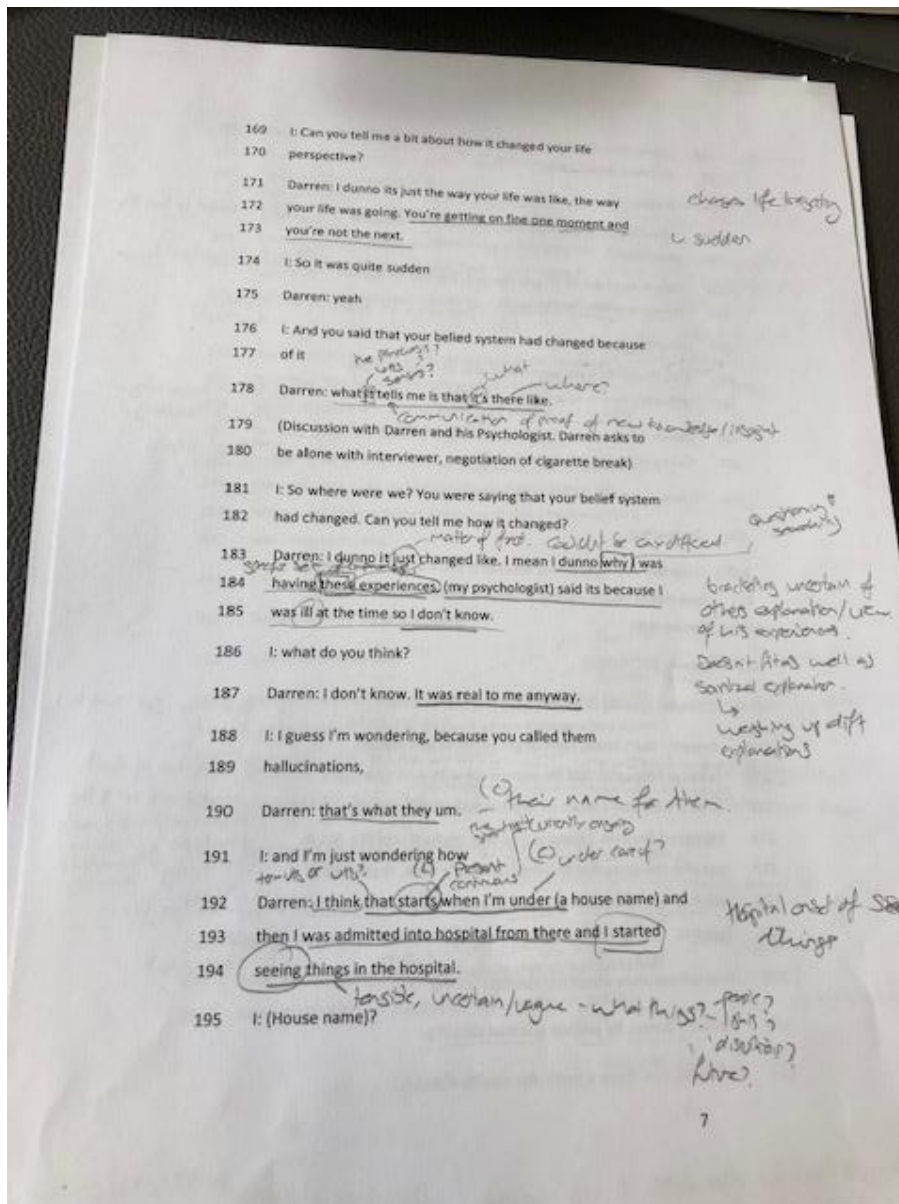
Name of participant	Date	Signature
---------------------	------	-----------

.....

Name of researcher	Date	Signature
--------------------	------	-----------

Two copies of the completed document are to be made.
The original will be stored in the study site file. One copy will be stored in participant's clinical notes, and one copy will be given to the participant to keep.

Appendix F: Example of Initial Noting



Appendix G: Example of Coding

169 I: Can you tell me a bit about how it changed your life
 170 perspective?

171 Darren: I dunno its just the way your life was like, the way *changes life trajectory*
 172 your life was going. You're getting on fine one moment and *↳ sudden*
 173 you're not the next.

174 I: So it was quite sudden

175 Darren: yeah

176 I: And you said that your belief system had changed because
 177 of it *he means? what was it? what where?*

178 Darren: what it tells me is that it's there like *communication of proof of new knowledge/insight*

179 [Discussion with Darren and his Psychologist. Darren asks to
 180 be alone with interviewer, negotiation of cigarette break)

181 I: So where were we? You were saying that your belief system
 182 had changed. Can you tell me how it changed? *anything?*

183 Darren: I dunno it just changed like. I mean I dunno why I was *material prob. could be avoided*
 184 having these experiences (my psychologist) said its because I *bracketing certain of*
 185 was ill at the time so I don't know. *others explanation/ view of his experience*
 186 I: what do you think? *Doesn't fit as well as*
 187 Darren: I don't know. It was real to me anyway. *social explanation*
 188 I: I guess I'm wondering, because you called them *↳ weighing up diff*
 189 hallucinations, *explanations*

190 Darren: that's what they um. *(O) their name for them*

191 I: and I'm just wondering how *↳ what's the origin*
 192 Darren: I think that starts when I'm under (a house name) and *(O) under care?*

193 then I was admitted into hospital from there and I started *hospital out of story*
 194 seeing things in the hospital. *change*

195 I: (House name)? *↳ possible, uncertain/ vague - what this? - poor? this is 'discovery' here?*

sudden negative change
Alters trajectory of life
The experience gave new knowledge about the world
The experience
Change of belief system not strictly matter of fact - it's obvious
Interpretation: what is it about me that led to these experiences
experiences not be caused by illness
uncertain of cause
illness would be not real but they were real for me
experience of seeing things starts in hospital

Appendix H: Extract of Emergent Themes for One Participant

Table 1

Participant 1 (Darren): Extract of emergent themes

Theme	LINE NUMBER(S)	QUOTES	COMMENTS
Sight/sound/temperature	Sight: 9-10, 27-28, 53, 70, 117-118, 124-125, 140, 194, 234, 244, 258-260 Sound: 10, 64, 147, 155-156 Touch: 27, 40, 99, 225, 255	I've actually seen people, actually spirt people, and sensing and hearing things what aren't there. : it's this. I was rushed into hospital, it started there like. The room went freezing cold and smoke came down outside, i felt like a ghost in the room. I saw, i thought i saw my double on the other side of the room, i didn't know what was happening.	People, smoke, voice, temperature (external to self)
Interaction with the self: mind and body	34-36, 40-41, 97-99, 234-240, 242, 244-246, 256, 262-263, 291-293	Well there's things about it, it sort of went in me a bit like. Y'know 'cus i was swelled up and lying on the bed and it sort of went inside my head. I sort of experienced the room went freezing cold and it went in me,	Internal to self/crosses boundary of self
Things are experienced, just like everything else	14, 18, 40, 56, 80-81, 216,	Darren: i've actually seen people, actually spirt people, and sensing and hearing things what aren't there. I: sensing things that aren't there? Darren: yeah. I: tell me a bit more about that?	

		<p>Darren: i don't know. They're just experiences while i've been in hospital like.</p>	
<p>Experienced: spiritual</p>		<p>I've actually seen people, actually spirit people, and sensing and hearing things what aren't there.</p> <p>I sort of experienced the room went freezing cold and it went in me, so i don't know</p> <p>I: someone that looked that same as you? Your double? Darren: yeah it was like i was experiencing things in there.</p> <p>Well it's a spiritual side, i've experienced ghosts and stuff y'know its like there, after death or something. Y'know its real.</p> <p>I sort of thought i was experiencing god in the hospital. That's how i explain it.</p> <p>I sort of got better in (old asylum) because i thought i had the experience with god. Like that's what it was, that's how i err understood what's actually happened like erm. I thought god was spiritual side like. But it was also like an authority thing like.</p>	

		That's what, that's what was feeling in the room	
--	--	---	--

Appendix I: Extract of Themes and Subthemes for One Participant

Table 2

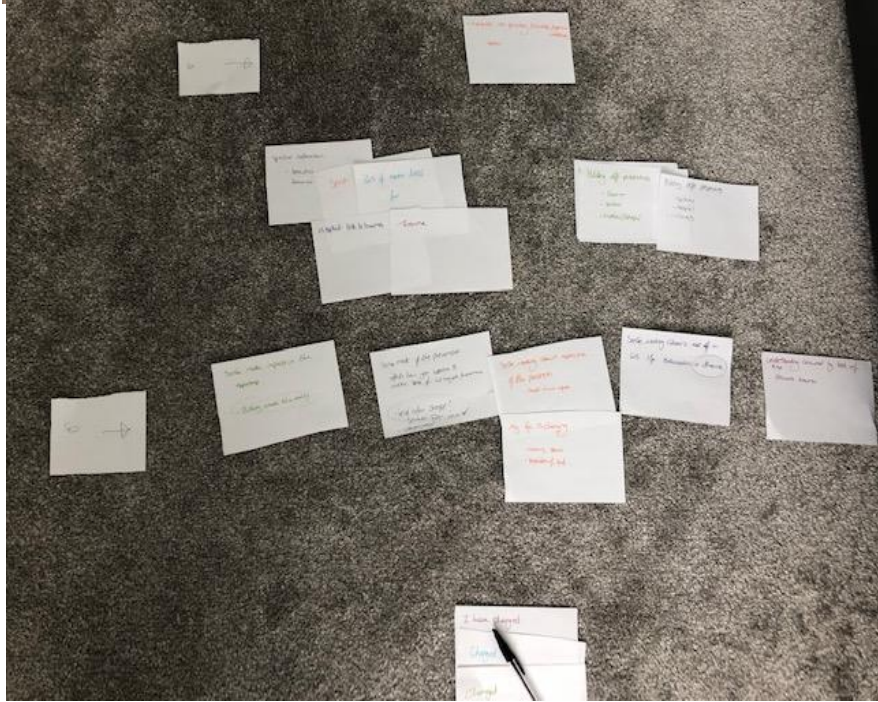
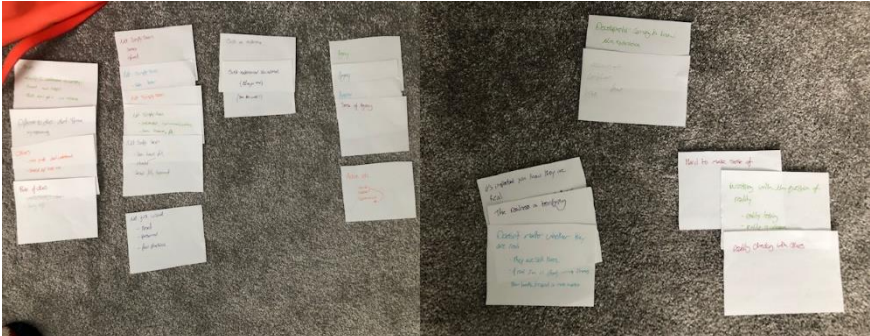
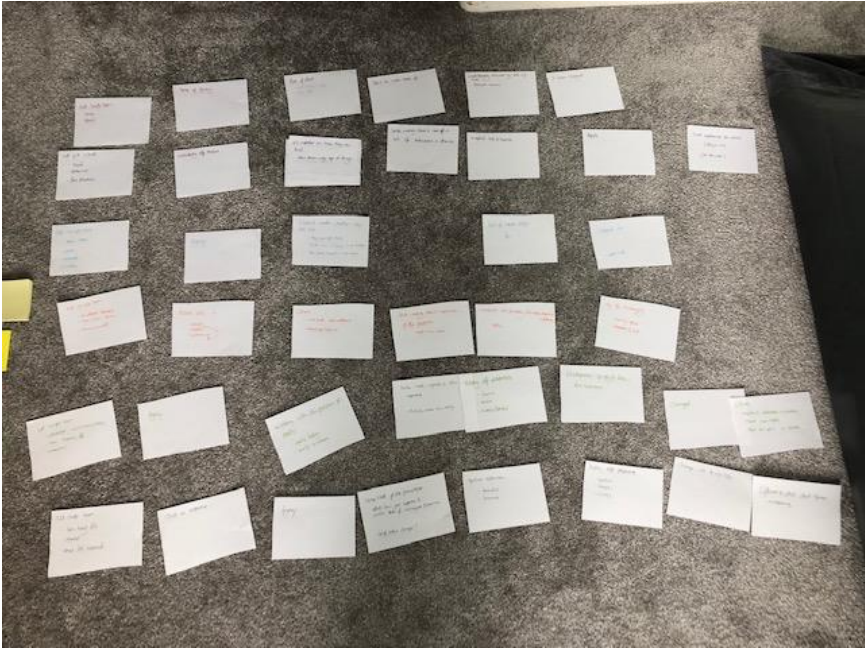
Participant 1 (Darren): Extract of Themes and Subthemes

THEME NUMBER	THEME	QUOTES
1	Things are not simply seen	<p>Darren: I've actually seen people, actually spirt people, and sensing and hearing things what aren't there.</p> <p>I: Sensing things that aren't there?</p> <p>Darren: Yeah.</p> <p>I: tell me a bit more about that?</p> <p>Darren: I don't know. They're just experiences while I've been in hospital like. I don't know why that makes them come on like.</p> <p>I: What sort of things did you...</p> <p>Darren: I experienced a ghost just outside my ear, just outside my ear to the back.</p> <p>I: and when you were hearing that, did you see anything?</p> <p>Darren: No, I was sensing things at the time,</p>
1.1	Seen	<p>I've actually seen people, actually spirt people, and sensing and hearing things what aren't there.</p> <p>saw a girl, a woman. I was on the phone to someone and she just appeared, she just appeared right in front of me. I was on the phone to her and she just turned up.</p>
1.2	Heard	<p>I was just hearing things like.</p> <p>I: you were hearing thing, you said you sensed things too, in your body?</p> <p>Darren: yeah</p> <p>I: and you saw some one that looked the same as you, your double?</p> <p>Darren: I saw, them when I was in hospital like on my own.</p>
1.3	Felt	<p>it's this. I was rushed into hospital, it started there like. The room went freezing cold and smoke came down outside, I felt like a ghost in the room.</p>
1.3.1	Interacted with my body and mind	<p>Well there's things about it, it sort of went in me a bit like. Y'know 'cus I was swelled up and lying on the bed and it sort of went inside my head</p> <p>Darren: There was just a warm feeling in the room like. Sort of... I had three words going in my head, that it was actually telling me like. Authority, love and care</p> <p>I: Authority, love and care?</p>

Darren: of myself. Erm it was when I sort of thought I was experiencing God in the hospital. That's how I explain it.

Darren: I don't know its probably spiritual, probably comes from God. 'Cus I was hallucinating when I had my operations on my arm (gestures to what looks like a surgical scar on wrist for duration of this speech). And it was like I was sensing what was going on with the actual cut what I had in hospital, erm there was two veins sticking out where they operated like. When I was looking at that when I was in hospital it was like it was being cured like.

Appendix J: Developing Cross Participant Themes



Appendix K: Master Table of Cross Participant Themes and Quotes

Table 9

Master Table of Cross Participant Themes and Quotes

<u>Superordinate theme 1:</u>	<u>It's not only a visual experience</u>
Description	Hallucinations were not bound by the visual sensory modality and were perceived as both normal and different to normal.
Subtheme 1.1	It's a complex and multifaceted experience
Description	The experiences did not just occur in the visual sensory modality. Multiple senses and interactions with the experience were described and extra senses were involved such as sensed, felt or experienced. Participants also described receiving a communication or message from the hallucinatory experience.
Participants contributing	All
Darren	<p>"it sort of went in me a bit like. Y'know 'cus I was swelled up and lying on the bed and it sort of went inside my head"</p> <p>"D: There was just a warm feeling in the room like. Sort of (trails off), I had three words going in my head, that it was actually telling me like. Authority, love and care. I: Authority, love and care? D: Of myself. Erm it was when I sort of thought I was experiencing God in the hospital. That's how I explain it"</p>

	<p>“I’ve actually seen people, actually spirt people, and sensing and hearing things what aren’t there. I: Sensing things that aren’t there? D: Yeah. I: tell me a bit more about that? ... D: I experienced a ghost just outside my ear, just outside my ear to the back. I: and when you were hearing that, did you see anything? D: No, I was sensing things at the time “</p> <p>“I: I guess what I’m wondering is, you said that you feel and sense things that weren’t there. How did you know that they weren’t there? Darren: Well there’s things about it, it sort of went in me a bit like. Y’know ‘cus I was swelled up and lying on the bed and it sort of went inside my head.”</p>
Jess	<p>“it [the cloud] formed a cross and I could see Jesus on this cross in the sky. I cried. Because I really thought I was seeing this: This is a calling for me”</p> <p>“I remember sitting at the porch and the door, the front door being opened because I pushed it the door was open and I pushed it ajar. Up until then my hallucinations were visual hallucinations were only visual I weren’t... I wasn’t interacting with them but this time I was and I could hear my nan and my dad saying ‘just shoot her, get rid of her, everything will be normal again’ I remember them saying that. I could hear them saying that. But I mean I’m not in contact with them to be able to speak to them. But I know, I feel it was so real sitting on the porch step, the door was open, it was definitely open”</p> <p>“I remember sitting in the caravan and looking up to the sky and gradually the clouds were forming this picture that I could see, but forming the shape of a cross and I can remember thinking at the time Is this really happening? Is this really going on? And it did yeah, it formed a cross and I could see Jesus on this cross in the sky. I cried. Because I really thought I was seeing this: This is a calling for me.”</p>

Kathryn	<p>“All of a sudden I saw this tunnel, it was black and I was travelling down this tunnel faster than the speed of light. Flashing lights going off either side it was white and yellow lights and I was catapulted down this tunnel and my hair was blowing behind me but there was no wind!”</p> <p>“it felt, it sounded (pause) well it didn’t sound it felt like some invisible hand around my throat”</p>
Rashid	<p>“No, it’s not like a scene or a picture it’s like alive. Y’know movement. Charlotte it’s never ever a picture, it’s like its going on around me y’know it’s like active”</p> <p>“I: the things that you see, you said that see a jungle war fare, and its moving in front of you? R: yes I: does it feel separate to you or? R: No, it feels like I’m involved”</p>
John	<p>“J: The girl’s peeping through the fence, she must have been because that’s what they’ve been doing. Psych: did, did you see her? J: No I just heard her, but I presumed that she was at the back of the fence over there and see me sit down on the other side. So then just she said: ‘he’s there’, with great delight and it, her boyfriend said ‘where is he’. He’s on the other end and I’m on the other side. I see them everyday”</p>
Sally	<p>“S: I was just getting some milk out the fridge because I was making a drink, and someone was standing behind the door dressed in black and with a black coat and he was hitting me in the face.”</p> <p>“S: yeah! And they couldn’t see it, only I could see it! I: and it was right there and you were there and this guy with the chain saw. And you asked your sister, what did you say? S: she couldn’t see it Psych: and was it a guy with a chainsaw or was it just a chainsaw? S: it was just the chainsaw, it was as if I couldn’t see him. I: so was it, floating? S: nods”</p>

Subtheme 1.2	It's just like everything else, sometimes
Description	This subtheme was polarised. Participants described their experiences as not special and perceived just like everything else. Or as different to normal, with an odd quality about the experience and perception.
Participants contributing	Darren, John, Sally, Jess, Rashid
Darren	<p>"I don't know I was just hearing things like."</p> <p>"I dunno its just the spiritual side like."</p> <p>"Darren: I've actually seen people, actually spirt people, and sensing and hearing things what aren't there.</p> <p>...</p> <p>I: tell me a bit more about that?</p> <p>D: I don't know. They're just experiences while I've been in hospital like."</p> <p>"I: I guess what I'm wondering is, you said that you feel things that weren't there. How did you know that they weren't there?</p> <p>D: Well there's things about it, it sort of went in me a bit like. Y'know 'cus I was swelled up and lying on the bed and it sort of went inside my head."</p>
John	<p>"J: Just like I'm with you now, I see you now I see these visions these people and hear these voices just the same.</p> <p>I: so they seem exactly the same they feel the same?</p> <p>J: (nodding) quite physical"</p>

	<p>“well I see, if I’m seeing things I’ve got two eyes. I’ve got two ears. Just like everybody else. I’ve got very sensitive ears I can hear a pin drop”.</p>
Sally	<p>“S: I was just getting some milk out the fridge because I was making a drink, and someone was standing behind the door dressed in black and with a black coat</p> <p>...</p> <p>I: Ok so you were sort of getting milk out the fridge and how did you notice the person in black? S: I just seen him.”</p> <p>“I: so you said that you see people with knives and chainsaws and is that something, do they feel or look as real as I do or is there something different about them? S: they’re not, they’re just like faint, I don’t really (trails off)”</p> <p>“S: ...I just lie, I’m lying down and I just see them and I just go to sleep just like. I: So you lie in bed at night and you just go to sleep, and do you see them when you’re falling asleep, or? S: I just ignore them and just go to sleep. I just do that. I don’t really like put, erm and there’s times that I’ve heard voices and stuff.”</p>
Jess	<p>J: I think, I hope, I’m able to recognize what’s real and what’s hallucination. I: Has that become quite a big part of your life now? J: Yeah, yeah, absolutely. I: how often would you say you think about whether things are real or not? J: Everyday.</p>
Rashid	<p>“they [visual hallucinations] were normal, life size. They were just like people, they felt real.”</p>

<u>Superordinate Theme 2</u>	<u>Agency</u>
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Description	The SOT of agency captures the experience of participants having a varying sense of agency over their hallucinatory experiences. The relationship between the sense of agency and how the visual hallucination is experienced varied. Two main areas in which the role of agency seemed to feature is in the emotional experience and in the experience of 'real-ness'
Subtheme 2.1	Sense of agency
Description	There was a variation in the amount of control or extent to which they played a role in the initiation of their visual hallucinations. All participants at some points in their interview talked about their experiences as being external to the self with no sense of agency.
Participants contributing	All
Darren	<p>"D: There was two veins sticking out where they operated like. When I was looking at that (gestures to surgical scar on his wrist) when I was in hospital it was like it was being cured like. I: Ok D: the healing of the wound like I: So what did you see? ... D: I had a cut on my wrist from where the doctors had done the operation and I was visualising that it had been cured. Like a hallucination towards the wound like."</p> <p>"D: I don't know, I just looked behind me and he was gone like. He was there and then he wasn't. I think I can see things but I don't know if it's my mind playing tricks or what."</p>
Jess	<p>"Thinking that people are being killed, watching people be killed, actually seeing it with your eyes."</p> <p>"I'm seeing a monk in the garden that's not moving. It's time for bed! (laughs) quite scary. I: So that 'it's time for bed' that sounds like you were quite dismissive about it, initially? Jess: Yeah, my mind's playing tricks on me, that's what I thought."</p>

	<p>"I remember sitting at the porch and the door, the front door being opened because I pushed it the door was open and I pushed it ajar"</p> <p>"I'm seeing Jesus Christ on a cross here... Visual Hallucinations didn't come into my mind at that point"</p> <p>"Thinking that people are being killed, watching people be killed, actually seeing it with your eyes"</p>
Kathryn	<p>"I: do they come in the day time? K: When I communicate with spirit. When I meditate. I: So now it's more of a errr, choice? K: Yes I'm in control. I: How does that feel? K: Good."</p> <p>"I'm at the moment going to a psychic development circle every week and they're teaching us how to communicate with spirits."</p> <p>"I've got to meditate every day. And when I meditate spirit comes to me and shows me things in my mind."</p>
Rashid	<p>"R: I just see water, you know the sea. I imagine myself on a ship, a battle ship and a boat is going through the waves. I'm on the boat and then the water comes. I: and when you say you're on the boat are you imagining that? R: No, I can see the boat, going through the water. I'm on a boat myself but I can see the other boat from where I am. I never thought about seeing or imagining y'know I don't know the difference."</p> <p>"R: Yeah, it's when I'm looking at the ceiling. Y'know I just imagine, I wander off. I: So is it something that you see in your mind, like in your imagination or is it something that you see out in front of you? R: Both. Yes."</p>

	<p>I: and what's the difference between those two? R: difference is, y'know in your imagination you can imagine just about anything. But then with the visionary hallucinations I want them to stop sometimes. When they get too strong, they get too violent, too violent, and with imagination, a lot I can imagine nice things and sometimes being in your mind on holiday, nice hot place. I: But that's not true of the hallucinations? R: No"</p>
John	<p>"I see him pass the door today, the one that was saying last night 'where is he'."</p>
Sally	<p>"S: I just picture them there and just like ermm picture knives and things like that and I can see them cutting my throat at the back of me and stuff. I: so you said you can picture and you can see them. Is that two different sorts of experiences or is it the same? S: the same"</p> <p>"S: when I was at home, I'd just be there thinking about my mum and just picture them and stuff. I: and do you see them here like you would see this chair or is it a bit different? S: Erm, bit different I: can you tell me how its different? S: doesn't bother me, I just think its myself sometimes so it doesn't bother me. I: what do you mean, you think its yourself? S: probably that I'm imaging things myself and but the, when that, when someone was in the kitchen and tried to hit me in the face that wasn't myself. I: that was different? S: that was different. I: what was different about that? S: because it was actually there"</p>

	<p>“S: They come well, I’ll tell you the truth. When they happen to me in the xxxx my mum was asleep on the seatee and I had a friend with me, his name was Simon and I fell asleep and, I woke up in my dream that I was chopped into little pieces and I didn’t know how to wake up from that. I: so you’re there with your friend and you fell asleep and you had a dream. S: I didn’t have a dream it actually happened, I was dreaming that actually well, it wasn’t a dream it actually happened. I: tell me a bit about what happened. S: I was just asleep, and someone let some people in whilst I was asleep and I felt like as if I was chopped up in little pieces”</p>
Subtheme 2.2	The role of agency in the emotional experience
Description	A relationship between sense of agency and the emotional experience of the hallucinatory experience emerged.
Participants contributing	All
Darren	<p>“I: So tell me more about the spiritual feeling D: I dunno, it’s just the spiritual side like. I: What is, was there a particular quality about it? D: There was just a warm feeling in the room like. Sort of [pause] I had three words going in my head, that it was actually telling me like. Authority, love and care. I: Authority, love and care? D: of myself. Erm it was when I sort of thought I was experiencing God in the hospital. That’s how I explain it.”</p>

Jess	<p>“Some [of the visual hallucinations are] more distressing than others, especially the time just before hospital, before I went into hospital. The period of time that I spent in my flat on my own, that was the most disturbing. Thinking that people are being killed, watching people be killed, actually seeing it with your eyes.”</p>
Kathryn	<p>“K: I told this medium, an international medium what was happening to me and he said ‘tell the spirit when they visit you at night that they’re disturbing my rest and that I will work with them in the day time’. And I did and I don’t get any spirit visitation at night now. I: OK that’s better, so you can rest now? K: Yes K: Yes I’m in control. I: How does that feel? K: Good “</p>
Rashid	<p>“R: difference is, y’know in your imagination you can imagine just about anything. But then with the visionary hallucinations I want them to stop sometimes. When they get too strong, they get too violent, too violent, and with imagination, a lot I can imagine nice things and sometimes being in your mind on holiday, nice hot place. I: But that’s not true of the hallucinations? R: No”</p>
John	<p>“J: Just like I’m with you now, I see you now I see these visions, these people and hear these voices just the same. I: so they seem exactly the same the feel the same J: quite physical I: can you describe that to me, what that’s like? J: What that’s like, let me see. Traumatizing. Disturbing. Upsetting. Nerve wrecking. Shocking. Nightmare. Horrific. Horrendous and the likes. Why don’t they leave me alone? They’re not giving up, they’re not letting it go, I know that much, I’ve heard them say that”</p>
Sally	<p>“S: when I was at home, I’d just be there thinking about my mum and just picture them and stuff. I: and do you see them here like you would see this chair or is it a bit different? S: Erm, bit different</p>

	<p>I: can you tell me how its different? S: doesn't bother me, I just think its myself sometimes so it doesn't bother me. I: what do you mean, you think its yourself? S: probably that I'm imaging things myself"</p>
Subtheme 2.3	The role of agency in the sense of real-ness
Description	A relationship between sense of agency and the felt sense of realness of the hallucinatory experience emerged.
Participants contributing	All
Darren	<p>"D: There was two veins sticking out where they operated like. When I was looking at that [gestures to surgical scar on his wrist] when I was in hospital it was like it was being cured like. I: Ok D: the healing of the wound like I: So what did you see? ... D: I had a cut on my wrist from where the doctors had done the operation and I was visualising that it had been cured. Like a hallucination towards the wound like."</p>
Jess	<p>"I remember sitting at the porch and the door, the front door being opened because I pushed it the door was open and I pushed it ajar. Up until then my hallucinations were visual hallucinations, were only visual I weren't, I wasn't interacting with them but this time I was. ... But I know, I feel it was so real sitting on the porch step, the door was open, it was definitely open, but it couldn't have been it must have been an hallucination"</p>

Kathryn	<p>I: So what... how did it feel seeing him there physically I front of you? K: Angry, I felt Angry. I thought what the hell are you doing in my bed room! I mean this was about half past 11 at night. And then when he disappeared I realised it was a ghost. And the next day I asked some of the girls in the house if anybody had died in the house. And they said yes an old man had dies in the house. I: Ok. So what led you to the conclusion that it was a ghost? K: Well what could it have been!"</p>
Rashid	<p>"R: It was like yknow reality. Real. I: Tell me a bit more about that realness R: they were like moving and I could actually see them, I could actually see their helmets their faces, their uniforms, their shoes, their weapons, their green camouflage uniforms yknow."</p>
John	<p>"if I'm seeing things I've got two eyes, I've got two ears just like everybody else. I've got very sensitive ears I can hear a pin drop so never the less I'm hearing (whispers) *voices*, not very pleasant look. I'm seeing people, stalking me and plotting to harm me. Let's see, I go to the team, explain to the team, the team say they don't exist they're not real only heaven exists. Mmmm? So where does that leave me?"</p>
Sally	<p>"S: I just think its myself sometimes so it doesn't bother me. I: what do you mean, you think its yourself? S: probably that I'm imaging things myself and but the, when that, when someone was in the kitchen and tried to hit me in the face that wasn't myself. I: that was different? S: that was different. I: what was different about that? S: because it was actually there"</p>

<u>Superordinate Theme 3</u>	<u>Role of others</u>
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Description	Participants talked about other people in their lives, both professionals and non-professionals as contributing to how they understood their experiences, which in turn seemed to relate to the experiences they had. The role of others appeared to be experienced in two main ways: it either helped and felt positive to the participants or it felt negative: alienating and angering them
Subtheme 3.1	Shared experience or understanding
Description	Other people were at times experienced by some participants to be helpful, and contributing to the participants feeling calmer, safer, more in control, hopeful and normal.
Pps	Jess, Kathryn, John
Jess	<p>“I feel more normal when I come to drop in (informal social group within EIP) than I do anywhere else.”</p> <p>“I can open up more to other service users than I can to my best friend that I’ve know for all of my life. Because they know what you’re going on about is real.”</p> <p>“I: I guess I’m wondering, the people who haven’t had visual hallucinations, but have had other sorts of hallucinations. How did they respond to you? Jess: Alright, strangely. And that puts you at ease as well. But alright. [they] knew that I wasn’t talking y’kn they understand that. And that makes me feel better within myself.”</p>
Kathryn	<p>“And my sister in America who I told about it a couple of weeks ago and described to her what had happened. She’s studying her PhD in California university in mind and consciousness and she said I’m very lucky to experience this. She said once you’ve made the connection to the other side you come back with psychic abilities.”</p> <p>“K: They’re trying to communicate with me. And I told this medium, an international medium what was happening to me and he said ‘tell the spirit when they visit you at night that they’re disturbing my rest and that I will work with them in the day time’. And I did and I don’t get any spirit visitation at night now.”</p>

	<p>“K: I’m in an environment where I go to psychic meetings, I’m with other psychics who have had similar experiences to me and people who I can relate to. I: and what’s that like? K: It feels comforting. I feel errrm, right where I am. I feel great that I can actually talk about my experiences to people who have had similar experiences like hearing voices not realising what they are, and then realising and finding out that they’re spirit.”</p>
John	<p>“J: A clearer horizon, that’s what I’m hoping for. A whole new horizon I: So that’s what you’re hoping for the future? J: Mmm that’s what I’m hoping to get out of the likes of this and cooperating with the team I’ve been in the service for a good 35 years and I’m a volunteer and I was helping. ... Psych: So we have voluntary and involuntary patients here J: For the doctor to try and help me, and me to help myself.”</p>
Subtheme 3.2	They can’t/won’t understand
Description	Other people, including professionals were at times experienced by participants in a negative way. Participants described feeling dismissed or scared and felt less inclined to share their experiences.
Participants contributing	All
Darren	<p>“Darren: Not really no. I don’t talk to people, I don’t talk about it. I: What do you think stops you from talking to people? Darren: Probably they won’t understand I don’t think. I: So they wouldn’t understand? Darren: I don’t think... not many people been through what I have. I: and how does that feel, that not many people have been through what you have? Darren: I don’t know, It’s probably a lack of understanding I suppose, like. I think, I’ve had a different life to most people haven’t I. It goes back all over the years and everything.”</p>

<p>Jess</p>	<p>“I: So did you talk to other people about it? Jess: Yeah, my ex-partner’s sister at the time. She was pretty close to me and she was pretty freaked out by what I was saying.”</p> <p>“Jess: look on people’s faces when you tell them that hear and see things that they don’t hear and see there’s a look of fear that I get sometimes with people. And that makes you feel about anxious.</p> <p>...</p> <p>I: And when you’re talking to other people and you see that fear go across their face? Jess: You know that it’s time to shut up. You’re freaking them out.”</p>
<p>Kathryn</p>	<p>“Yes, yes. Now I know I’m dealing with professional people, but they’ve wrongly diagnosed me and they don’t know anything about the spiritualism. As far as they’re concerned it’s schizophrenia and it’s not. I: and that’s, it makes you very angry? K: It does yes, I’m dealing with ignorant people. People that don’t know anything about spiritualism”</p> <p>“K: if you haven’t had experience of spiritualism you’re a bit kind of ignorant to the fact that spirit communication with actual spirits is what I’ve been doing.”</p> <p>“K: the doctors, the psychiatric doctors because they’re that bloody ignorant they don’t know what they’re dealing with. I: Ok, so you put the psychic circle on hold whilst you were in the acute ward and then for some time whilst you were here. K: Yes, yes. For two years I’ve been incarcerated in hospital, they’ve been thinking and saying ‘Oh it’s schizophrenia, she’s a paranoid schizophrenia and I’m not. My friends know I’m not a paranoid schizophrenia, it’s only these doctors who think it. And its on my notes and I don’t like it and I want to prosecute them”</p>
<p>Rashid</p>	<p>“Sometimes y’know at home when I’m lying down on the sofa that’s when they’re worse, when I’m alone. Then my wife says to me what’s wrong and I never ever tell her y’see.”</p>

John	<p>“J: I’m convinced they’re real and I’m thinking that the team work in collaboration and hoping I just to go along with it I: the team are in collaboration with? J: with the voices and the hallucinations because they’re not taking their time when they say its not real. ... I’m seeing people, stalking me and plotting to harm me. Let’s see, I go to the team, explain to the team, the team say they don’t exist they’re not real, only heaven exists. Mmmm? So where does that leave me?”</p>
Sally	<p>“S: erm, its confusing I mean from there on, from that day to this I haven’t been very well. But I did tell my mum about it but she thought I was silly. Mmm. People think I was going crazy they didn’t, um they think that I’m pathetic probably and things like that. I: Ok, so quite, yeah negative things. Is that something they’ve said to you? S: nods I: yeah. Erm so it sounds like sharing what you’ve experience has been, what, I don’t know quite hard maybe? S: Erm, I know deep down my mum and dad did care but people around me didn’t.”</p>

<u>Superordinate Theme: 4</u>	<u>Coming to know the experience</u>
Description	Participants that they had been and were still working through a process of coming to know what was real and what wasn’t. The importance of this reality varied across the participants. This process of coming to know was quite an emotionally fraught experience for participants.
Subtheme 4.1	Hard to make sense of: wrestling and testing reality
Description	Participants described that their hallucinatory experiences were difficult to make sense of and talk about. A sense of wrestling with reality emerged, as did the idea that reality is a shared experience.

Pps	Darren, Jess, Sally
Darren	<p>“Darren: er, (the old asylum) is in (place-name) somewhere. I saw, I thought I saw my double on the other side of the room, I didn’t know what was happening.”</p> <p>“D: I just looked behind me and he was gone like. He was there and then he wasn’t. I think I can see things but I don’t know if it’s my mind playing tricks or what. I: So did you have a question in your mind as to whether it was real or not? Darren: yeah, whether its real. I: Can you tell me a bit more about that questioning? Darren: (My psychologist) said it feels real to me like so, it must be happening. It’s real to me, like I say I: Can you tell me a bit more about that questioning? I: And at the time did you have a question, a wondering if it was real or not? Darren: erm. No it was what I saw and feel. It was real to me what happened”</p> <p>“I: So do you think you make sense of it, the hallucinations, differently now to how you did at the time? Darren: I dunno really. I dunno why, what is happening like. ‘Cus I was probably ill at the time like. I: So it sounds like you’re quite confused, quite scared? Darren: Yep.”</p>
Jess	<p>“Is this a calling from God? How am I supposed to deal with this? How am I supposed to, What, How am I seeing a monk in the garden?”</p> <p>“J: Now this must be a hallucination, because I can’t, because it was so real. I remember sitting at the porch and the door, the front door being opened because I pushed it, the door was open and I pushed it ajar... I could hear my nan and my dad saying ‘just shoot her, get rid of her, everything will be normal again’ I remember them saying that. I could hear them saying that. But I mean, I’m not in contact with them to be able to speak to them. But I know, I feel it was so real sitting on the porch step, the door was open, it was definitely open, but it couldn’t have been it must have been a hallucination. I: What makes you say it must have been a hallucination? J: Because, err, because, I don’t think they really had a gun. And, but I still don’t, it was so real,</p>

	<p>pushing that door that door was open and those voices I heard it. But now I know, well, well I don't actually."</p> <p>"J: I think I've accepted it well, at first it was a bit weird. Hallucination, visual hallucination like. I thought people could see what I was seeing because it was that real. I: and when you say it was a bit weird, tell me about that J: Bit weird? I: Yeah J: Then you know you've got problems don't you. So that's what I meant by weird. That erm, coming to terms and accepting what I'm experiencing is a visual hallucination, that it's not something that everybody's seen."</p> <p>"Jess: It's scary at first, but then you know that you're in trouble if you're the only one who's experiencing this. So I knew that something was going on in my brain, I just didn't know what. I could hear and see things that other people weren't hearing and seeing."</p>
Sally	<p>"I: How are you finding thinking about them like this? S: Hard, because I've never really hard to speak to anyone about it before and I just, yeah."</p> <p>"I: she didn't get it OK. So you were being chopped up into pieces. How did you kind of come back together again because I can see that you're all one S: Laughs. Erm. I don't know, its just happened. (laugh), I don't know what happened I: can you try and remember? S: sorry I don't I find it very confusing"</p>
Subtheme: 4.2	Importance of reality
Description	The question of whether it is important that experiences are real or not varied across participants. Some made it clear that it was very important that their experiences were real, and it seemed important for them to communicate this in their interviews. Whilst other participants did not focus of the importance of real-ness of their experiences.

Participants contributing	Kathryn, Rashid, John
Kathryn	<p>“I: First off I guess I want to ask, have you experienced what people might term visual hallucinations? K: They’re no hallucinations they’re visions. I: They’re visions OK. K: erm, I’ve had premonitions, visions and I’ve had spirit visitations. I’m a psychic. I: And visions is what you prefer to call them? K: Yes I: Ok, that’s good to know because people have different ways they like to talk about it. K: Spiritualism has been around for donkeys’ years. And if you haven’t had experience of spiritualism you’re a bit kind of ignorant to the fact that spirit communication with actual spirits is what I’ve been doing.”</p>
Rashid	<p>“I: and has that (professionals’ explanation of his experiences as visual hallucinations) changed your understanding of what you see? R: not really no, because I think I’d always get them I think. There’s no way I’d ever stop them. No way. Never stop them. So I don’t want it to have a big impact on me, so that’s why I don’t make a great deal out of it. I don’t really wanna act on them. I think so long as they’re managed or you’re in control of them then it’s not too bad”</p> <p>“I don’t want to believe they’re real, see. I don’t think, No I’ve never thought they’re real ... because y’know if I start believing that they’re real then I’d really think to myself that I’m not y’know like sane. I’d think that I’m mentally unwell”</p> <p>“R: They were just like people, they felt real. It wasn’t like it was a picture or a video on a screen. It was like y’know reality. Real.”</p>
John	<p>“I: is there, is there a way that you can work out what’s there and what’s not really there, or, what’s it like? J: I know what’s there. I’m not daft I might be daft but I’m not stupid. It’s not a dream”</p>

<u>Superordinate Theme 5</u>	<u>Creating a narrative</u>
Description	Across all participants there was a theme of creating a narrative to explain their experiences. Multiple narratives were considered, the relationship of participants' explanations of their experiences to the experiences themselves is explored. Across participants it varied within transcripts as to how firmly these explanations were held on to.
Subtheme: 5.1	Incorporating the experiences into pre-existing ideas
Description	All participants seemed to use knowledge or experience they already had to make sense of their hallucinatory experiences. This fell into three main categories: a spiritual explanation, a link to previous trauma and a medical/biological explanation.
Participants contributing	All
5.1.1	The spiritual side
Participants contributing	Darren, Jess, Kathryn
Darren	<p>"D: well it sort of tells you there's something there anyway. I mean I hadn't believed in anything like that but it shows you that there's something there I: when you say that there's something there, what do you mean by that? D: Well it's a spiritual side, I've experienced ghosts and stuff y'know it's like there, after death or something. Y'know it's real"</p> <p>"I don't know, I don't really why it was happening anyway. I think it's all to do with my mum dying and stuff, my mum and brother. I mean it happens on her birthday two years after she died"</p>

Jess	“I could see it ... and I remember thinking maybe, maybe this is a calling ... I questioned all of my beliefs and what, y’know I’m seeing Jesus Christ on a cross here! What the, what is it time for me to change or is it a sign for me?”
Kathryn	<p>“I’ve had premonitions, visions and I’ve had spirit visitations. I’m a psychic”</p> <p>“I: And what lead you to use the term visions? K: Everybody’s got a pineal gland just above the eye, above the nose in the brain. And once that’s activated people can experience psychic abilities. Now everybody’s got one but everybody’s pineal gland is not activated. I: yours was activated? K: Yes, some years back. Back in 1986, after my stepmother died”</p> <p>“I: what about your parents? K: They died, their both dead. Passed over. I: and do they communicate with you at all? K: My father does. I: And what’s that like? K: It’s very emotional, I mean if your parents communicated with you you’d feel emotional. I miss him, I love him, y’know”</p>
5.1.2	Link to previous trauma
Participants contributing	Jess, Sally, John
Jess	“The visual and the auditory hallucinations were based on what I was going through at the time. I had I’d gone to the police station to report my Uncle, he erm. He erm he sexually abused me when I was a child and I took the first step in going to the police station and telling them that. Disconnected with my family because they don’t believe me. Then I moved into my flat and I hadn’t seen any of my family for quite a while. And the auditory hallucinations and the visual hallucinations were all based around the fact that I’d gone to the police. That there were people that didn’t believe me, that thought I’d ruined their lives by going to the police and telling them this, and how I’d affected them”

Sally	<p>“Psych: before the voices and that, and do you make a link between that the experiences with these girls that were kind of bullying or, because I just know that you’ve had some quite difficult or traumatic experiences with, erm, do you think that they are related to the voices in anyway? S: (nods) I: how do you think they were related S: I think they used to know each other. I: so you think the voices used to know these girls? S: (nods) I: and what about the people that you see? did they used to know the girls as well or? S: (nods)”</p>
John	<p>“J: well my face it doesn’t fit in. I: what do you mean by that? J: you need to have a word with my team, they can give you a lot more information.”</p>
5.1.3	Medical/biological explanation
Participants contributing	Darren, Jess, Rashid
Darren	<p>“D: [My psychologist] said it was because I wasn’t well at the time which is probably right yeah. I: It was because you weren’t well at the time? D: I probably wasn’t well at the time. “</p>
Jess	<p>“I knew that something was going on in my brain, I just didn’t know what. I could hear and see things that other people weren’t hearing and seeing.”</p>
Rashid	<p>“My thoughts are that I don’t think they’re normal, the visionary hallucinations I don’t think they’re normal so I don’t think everybody gets them. I think they’re related to mental health, so I think if you don’t suffer from depression or mental health issues or bipolar I don’t think you get them. That’s what my thoughts are. I think my thoughts are that suffers of illnesses get them. But normal people don’t.”</p>
Subtheme: 5.2	The loop of experience and sense making

Description	The experiences (during psychosis or prior to it) were used to help make sense of their visual hallucinations, and that this understanding of the hallucinatory experiences then seems to have a relationship with their subsequent experiences. It is not clear at what point in the cycle this process starts, but it seems evident that experience and sense making were relating to each other as if in a loop.
Participants contributing	All
Darren	<p>“D: I was sensing things at the time, that was while I was in (old asylum), my mum and brother had died [pause]</p> <p>...</p> <p>I: OK, and you were sensing and feeling things?</p> <p>Darren: It’s this: I was rushed into hospital, it started there like. The room went freezing cold and smoke came down outside, I felt like a ghost in the room”</p> <p>“probably It’s a good thing though, got to be, it’s got to be spiritual.”</p>
Jess	<p>“J: it [visual hallucinations] could be quite dangerous.</p> <p>I: quite dangerous?</p> <p>Jess: Yeah, yeah I think so.</p> <p>I: dangerous in what way?</p> <p>J: How you interpret your hallucinations. Or if you’re even able to tell that you’re having a hallucination, because at first I didn’t know they were hallucinations”</p> <p>“J: The hallucination at the time, it was, I remember seeing my brother walking towards my flat because he wanted to speak to me because of what I’d done, because I’d gone to the police station and because he’d come into contact with me that’s why he was shot. That’s what I thought was going on, in my brain. Seeing my brother shot. And then shortly after that I erm I think I went a bit crazy actually after that.</p> <p>I: Do you remember what happened?</p> <p>J: I ran out into the street, without any shoes on erm, I thought that, the message that, what I was</p>

	<p>experiencing at the time was telling me that I had to martyr myself in order to save the rest of family because they too would be affected and maybe killed. So I ran in front of a lorry. Because I thought that was going to be able to save everyone.”</p> <p>“The mind is powerful, I understand that now</p> <p>...</p> <p>powerful in the sense that erm, these could, hallucinations could either make me feel, I could feel at ease and at peace or they could be quite disturbing and, to a point where I would harm myself or something”</p>
Kathryn	<p>“K: They [my parents] died, they’re both dead. Passed over. I: and do they communicate with you at all? K: My father does. I: And what’s that like? K: It’s very emotional, I mean if your parents communicated with you you’d feel emotional. I miss him I love him, y’know”</p> <p>“K: they’re my guides and they make sure that I’m safe and I ground myself and I talk to spirit. I: and they’re quite positive then? K: yes they are yes”</p>
Rashid	<p>“its that I don’t want to believe that they’re real. I don’t think I’ve ever, I’ve never really opened up to a lot of people about the things that I go through. That’s why I think: I don’t want to believe they’re real, see. I don’t think, No I’ve never thought they’re real... because y’know if I start believing that they’re real then I’d really think to myself that I’m not y’know like sane. I’d think that I’m mentally unwell”</p>
John	<p>“J: They’re quite normal people, quite normal individuals Psych: so so you’re not able to differentiate whether they are like a visual hallucination or an actual person is that right? J: I know it’s an actual person Psych: you know J: I’m convinced</p>

	<p>Psych: Yeah but you know that they want to harm you, you believe that they want to harm you J: Indeed, indeed, indeed”</p> <p>“J: Traumatizing. Disturbing. Upsetting. Nerve wrecking. Shocking. Nightmare. Horrific. Horrendous and the likes. Why don’t they leave me alone?”</p> <p>“J: I ask her am I in trouble? The lady [CPN] turn round and tell me no. Now that’s a weight off my shoulders. I: so you thought you might have been in trouble? J: Indeed, big trouble”</p>
Sally	<p>“S: Its like as if, someone’s got a grudge against me or something and I’ve not, I’ve done, I haven’t hurt no one. I know I haven’t. I: but you feel like someone must have a grudge against you, what makes you say that? S: Erm, I don’t know, because, they [visual hallucinations] think like because I’m a good person and that they take the piss and thinking that, erm they think that they can do anything they like to me and stuff”</p>
Subtheme: 5.3	This new way of thinking about myself and the world has changed things.
Description	Participants explained that their experiences have altered their understanding of themselves and of the world, either for the better or for the worse.
Participants contributing	All
Darren	<p>“I’ve heard people have had visits of spirits, when they’ve lost members of their family y’know. And I wouldn’t believe them if it didn’t happen to me like. It’s changed my perspective of things anyway.”</p> <p>“Darren: No not really. Well it’s been positive and negative. It more like the spiritual side, it’s made me stronger. That’s all I can say.”</p>

	<p>“Darren: I don’t know I think the spiritual side came out when my mum died. He Helped me get through it when I was in that house anyway I was only there for two weeks.”</p> <p>“D: it changes your belief system like. I never believed in anything like that spiritual side) until then y’know. I mean I was just getting on with my life, football, music and I ended up in hospital and it changes your whole life perspective”</p>
<p>Jess</p>	<p>“J: strangely despite everything that’s happened I’m actually a better person now. I: Better how, in what way? J: The way that I look at things, the way that I perceive things. I try and be a nicer person now towards people.”</p> <p>“Jess: I wasn’t a very nice person to some people and to myself. So, I thought that all of this was to, maybe it was, maybe I needed to be within a monastery kind of.. yeah, I just thought maybe it was time, this is it now. Someone’s looking over me and they need me to change, I need to change. Somethings happening, why is it all religious at the time. I: and did you think that was a positive or a negative thing? Jess: Yeah, good, I: what makes you think that it was a good thing? Jess: Because strangely despite everything that’s happened I’m actually a better person now. I: Better how, in what way? Jess: The way that I look at things, the way that I perceive things. I try and be a nicer person now towards people. ... Jess: Erm, I used to be a very angry person. Quite angry and erm, I don’t know what the word is, quite aggressive towards some people. I’m not as aggressive now I: and you said it’s changed the way you looked at things as well? Jess: Yeah I: how’s it changed the way you look at things?”</p>

	Jess: errmm, a little bit more open minded and more open to new things.”
Kathryn	<p>“I: imagine, you’d not had these experiences, you’d not seen the visons how would your life be different? K: well it would just be boring to be quite honest. I’d just be plodding along getting through various experiences. This is going to change my life”</p> <p>“K: It’s altering me already its already started. I: And how do you think its altered you? K: It scares me a little I: It scares you a little, tell me a bit about that K: Well its all to do with change isn’t it. Changing my outlook on life. I: And how’s that changed, or how is that changing? K: It’s opened me up to the spirit world.”</p>
Rashid	<p>“R: And I think these thoughts the hallucinations they, in my experience they make me very negative. You know before was positive. You know the positive and the love and the affection towards people is replaced by negativity, anger, hatred. I: so its changed the way you feel about other people? R: and life, life in general, and you know society, the world.”</p>
John	“I was pinned to the sofa (with fear) ... and I’ve never been right since”
Sally	<p>“I: is there anything that we’ve not talked about that you feel is important? S: No I think you’ve asked lots about what I’ve seen, I think it’s really important because I just want it all to stop really. I mean what has happened and that, its like as if (voice starts to break) my whole life has been taken away (deep breath)”</p>

Appendix L: A Concluding Note on Reflexivity

Engaging with IPA and the participants' experience of psychosis has shifted my ontological position along a continuum; moving from a critical realist position at the outset towards the relativist during analysis, reflecting the varied accounts of reality in participants interviews, before moving back towards the critical realist, albeit slightly closer to relativism. The double hermeneutic has made it clear to me that there is no Archimedean point from which an experience can be objectively observed.