Service Users' Experiences of Receiving Information about a

First Episode of Psychosis:

An Interpretative Phenomenological Analysis

Thesis submitted for the degree of

Doctorate in Clinical Psychology

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by

Emma Nicholas

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Declaration

The research submitted here is original and my own work and has not been submitted

for any other academic award.

Emma Nicholas

Service Users' Experiences of Receiving Information about a
First Episode of Psychosis:
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Thesis Abstract

Literature Review

There is scant literature available on service users' experiences of receiving a mental health diagnosis. Six databases were methodologically searched for qualitative research addressing this area. Seven papers were found to be appropriate for inclusion into this qualitative literature review. These papers were found to be methodologically sound following quality appraisal using criteria suggested by Yardley (2000) and Meyrick (2006). Papers were then subject to a narrative synthesis to explore them for themes that were common across all papers. Five themes were discovered to describe service users' experiences of receiving a variety of mental health diagnoses: 'Growing Awareness', 'Dichotomy of Diagnosis', 'Relationships', 'Loss' and 'Access to Support'. Clinical implications of this review are considered.

Research Report

A search of six databases identified a gap in the literature for a paper exploring service users' experiences of receiving information about a first episode of psychosis. This research aimed to investigate the experiences of service users in Early Intervention in Psychosis Services receiving information, which may include a diagnosis or psychosis or schizophrenia. A qualitative approach was favoured and Interpretative Phenomenological Analysis was selected to analyse the semi-structured interview transcripts of seven participants. Three themes were found during analysis: 'Having an Official Condition', 'Being the Patient 'and 'Construing Identity'. These themes emphasise the official nature of diagnosis and participants' experiences of feeling subordinate as well as the influence of participants' existing knowledge and popular social representations on the impact of the diagnosis. Clinical recommendations are discussed.

Critical Appraisal

The Critical Appraisal offered the opportunity to reflect on the research process. Recruitment was problematic in this research, which is discussed. Methodological limitations of the research are considered and proposals for future work are suggested. Reflections on the personal journey of the research process are also discussed.

Acknowledgements

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Literature Review

Service Users' Experiences of Receiving a Mental Health Diagnosis:

A Narrative Synthesis of Qualitative Research.

This paper has been formatted for the British Journal of Clinical Psychology but has

exceeded the maximum number of words allowed for this journal in order to fulfil the

marking criteria for the Leicester Doctorate in Clinical Psychology Thesis.

Abstract

Objectives: There is a paucity of research focussed on service users' experiences of receiving a mental health diagnosis.

Method: A methodical search of six databases undertaken to review qualitative literature regarding service users' experiences of receiving mental health diagnosis found seven papers suitable for this review. Quality appraisal of the selected papers using criteria suggested by Meyrick (2006) and Yardley (2000) found each of them to be methodologically sound. Narrative synthesis was applied to this review to extrapolate themes common to all of the papers reviewed.

Results: Five themes emerged: 'Growing Awareness', 'Dichotomy of Diagnosis', 'Relationships', 'Loss' and 'Access to Support'. Conclusions: These themes describe the experience of service users being given a variety of mental health diagnoses, although there was different emphasis for each specific diagnosis. Clinical implications of this synthesis are discussed.

1. Introduction

1.1 Introduction Overview

It has been identified that one in four people in the United Kingdom will develop mental health difficulties at some point in their lives (Department of Health, 2001). The Office for National Statistics Adult Psychiatric Morbidity Survey of England (2007) found that 17.6% of the working age population currently have at least one mental health problem or diagnosis. This introduction briefly describes the diagnostic process and presents a critique of the reliability and validity of the continued use of mental health diagnosis. The influence of diagnosis on service users is also considered. Finally a rationale for the current review is outlined along with brief description of the methodology.

1.2 Mental Health Diagnosis

There are no reliable biological indicators for a mental health diagnosis and the diagnostic process relies upon the subjective opinion of mental health professionals based on the reported or observed experiences and symptoms of the service user. Diagnosis is then ascertained according to the International Classification of Diseases (ICD -10) or the Diagnostic and Statistical Manual IV Text Revision (DSMIV - TR) which cluster symptoms together into categorical diagnoses. These diagnostic categories are used by both mental health professionals and research that informs evidence-based practice and National Institute for Health and Clinical Excellence (NICE) guidelines.

1.3 Critique of mental health diagnosis

There can be variability within and overlap between psychiatric diagnostic categories which can result in service users being provided with changing diagnoses over time. There has been much debate between health professionals about the validity and reliability of mental health diagnosis (Boyle, 2007; Johnstone, 2009; Pilgrim, 2007). A further criticism of diagnosis is the suggestion that it creates a power imbalance between service users and the health professionals who hold the power to diagnose and implement associated restrictions (Hagen & Nixon, 2011).

Mental health diagnosis infers a biological or medical label which does not take account of or emphasise the situational variables which may have contributed to the service users' difficulties (May, 2007). Rufus May comments that "The diagnostic process converts someone's distress from a psychosocial problem into an individual problem – it takes the person's experience out of its social and historical context" (May, 2007, p.300).

Perhaps the most important difference between physical and mental health diagnoses is that "physical injuries and ailments *happen to us*, whereas *we are* mentally ill" (Pilgrim, 2007, p. 540). There is evidence that this internalising or labelling aspect of mental health diagnosis has the potential to impact on service users' self concept or identity (Haghighat, 2008). Research suggests that the way a mental health diagnosis is delivered can influence service users' beliefs and perceptions about their diagnosis which has been found to be more influential on quality of life than symptom severity (Stainsby, Sapochnik, Bledin & Mason, 2010).

Society holds negative views and beliefs about those with a mental health diagnosis (Crisp, Gelder, Goddard & Meltzer, 2005) and research has shown that

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receipt of a mental health diagnosis may result in service user experience of stigma, discrimination and social isolation (Horn, Johnstone & Brooke, 2007).

Although mental health diagnosis is one way of understanding an individual's difficulties it is often reified and presented as fact to the service user (Pilgrim, 2007). Alternative explanations for difficulties, such as psychological formulation, can also direct clinical work, pay closer attention to situational variables and do not have the same stigma attached.

1.4 Continued use of diagnosis

Despite the current debate around the validity and reliability of mental health diagnosis and the impact of diagnosis on service users, diagnosis continues to be a routine part of care within a mental health system. Explanations for the continued use of mental health diagnosis is to aid communication by providing a common understanding of a service user's difficulties across disciplines (Cromby, Harper & Reavey, 2007), for administrative and financial simplicity (Boyle, 2007) or to plan for service provision (Pilgrim, 2007).

1.5 Summary and Rationale for review

The evidence presented here has shown that there are debates about the validity and reliability of mental health diagnosis (Boyle, 2007; Johnstone, 2009; Pilgrim, 2007) and that receiving a diagnosis can impact on service user identity and self concept (Haghighat, 2008) and can lead to the experience of stigma (Horn et al., 2007). Little research has been conducted to explore the lived experience of receiving a mental health diagnosis (Hayne, 2003; May, 2007). Given the evidence presented here, the large number of people affected by mental health difficulties and the continued use of

diagnoses to explain these difficulties there is a need to understand how these diagnoses are received and impact on the individual.

1.6 Aim of review

The aim of this paper was to explore the experience of service users receiving a mental health diagnosis. The experiential focus of this review favoured qualitative research as this methodology can provide detailed accounts of participants' experiences (Smith, 2003). This review employs narrative synthesis, which includes a thematic analysis of the included papers to draw out common themes across the existing literature. It was hoped that synthesising findings from the small body of qualitative research would inform future research and improve clinical practice by identifying common experiences or issues that were important to service users.

2. Method

2.1 Analytic Question

What are service users' experiences of receiving a mental health diagnosis?

2.2 Search Strategy

A methodical search of peer-reviewed journal articles written in English was undertaken of the databases, Scopus, Medline/Embase, Web of Science/Knowledge and PsycInfo. Key words around the topic were identified and used to interrogate the databases: (diagnos* OR news OR information) AND (service user OR patient OR client) AND ("mental disorder" OR "mental health" OR "mental illness" OR psychiatric). No date parameters were set as this was an exploratory search to find literature about service users' experiences of receiving a mental health diagnosis. The

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search terms generated a large number of results in each database. These were then searched by title and keywords for papers that seemed relevant to the topic. Reference lists were also read for further papers and where it was possible the search similar function was also utilised on database results. Where papers seemed relevant the abstracts were read. If the abstract also seemed relevant the paper was read in full. See Figure 1.

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┌──────────────┐                    ┌──────────────┐
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│  selected    │                    │  identified  │
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│  Psycextra   │  │         │  │              │  │              │  │  Science/    │
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│ Titles and keywords screened; 331 relevant abstracts read         │
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11 papers rejected for not meeting inclusion criteria:

4 employed quantitative methodology

6 not focussed on diagnosis

1 focussed on family experience

19 papers read in full for more detail

8 papers assessed for quality

1 paper rejected following screening with CASP for poor methodology

7 papers included in narrative synthesis

Figure 1. Flow chart showing literature search procedure.

2.3 Inclusion Criteria

Rich qualitative research methodology is particularly helpful in exploring service users' experiences (Smith, 2003). To be included in the narrative synthesis, papers were selected where they used a qualitative methodology and were focussed on service users' experiences of receiving a mental health diagnosis.

Nineteen papers were read in full with each paper being assessed according to the inclusion criteria. This process led to 11 papers being rejected (Figure 1). On closer inspection four papers were found to be written quantitatively, six were not focussed on diagnosis provision and one concentrated on family experience.

2.4 Quality Appraisal

The eight remaining papers were screened using the Critical Appraisal Skills Programme checklist for Qualitative Research (CASP, 1998) which resulted in one paper being rejected due to its vague methodology. Seven papers were selected for review and then appraised for quality using criteria suggested by Meyrick (2006) and Yardley (2000). See tables in Appendices A and B.

2.5 Included articles

Consideration was given regarding inclusion of a paper on receiving a diagnosis of dementia (Derksen, Dassen, Gillisen, Rikkert & Scheltens, 2006) as this is a progressive neurological condition. The Mental Health Act 2007 classifies Dementia as a mental health condition so it was included.

Two papers included family member perspectives (Delmas, Proudfoot, Parkern & Maniscacasagar, 2011; Derksen et al., 2006). These papers were selected for

inclusion as they also presented separate service user perspectives. The family perspectives were disregarded to allow the focus on service user experiences.

2.6 Synthesis of research

Narrative synthesis was selected as it offers a systematic and transparent procedure for extracting and analysing pertinent data from the chosen papers (Popay et al., 2007). Narrative synthesis draws together information from papers and then explores the relationships within and between the papers for further meaning (Popay et al., 2007).

2.6.1 Procedure.

Transparency of the decision making process is recommended (Popay et al., 2007). As such, a reflective diary was kept which contained the author's thoughts, decisions and rationale throughout the process and provides an audit trail for the synthesis.

The procedure for narrative synthesis in this report follows four stages identified in guidance (Popay et al., 2006; Popay et al., 2007) and piloted by Rogers and colleagues (2009). The initial stage of developing a synthesis encompasses the identification of the review question, the systematic search methodology and the selection of papers to address the question (Popay et al., 2007).

Developing a primary synthesis is the second stage in the guidance. This is created through the tabulating of data from the chosen papers to determine which aspects of the papers will be drawn out (Appendix C). The final aspect of this stage is the organisation and integration of themes and ideas across all papers by performing a thematic analysis (Braun & Clarke, 2006) of their findings. The existing themes

identified in each paper were generated by the original authors and so the papers were subject to translation by the review author. Translation was achieved by applying a thematic analysis to consider any differences in language used and meanings between papers. The papers were then read and re-read by the reviewing author who noted important elements regarding diagnostic experience. These notes were then reviewed with the primary synthesis data and amalgamated into themes embedded in all of the papers. A thematic map (Appendix E) was produced to illustrate how these themes related to each other. The papers were then analysed for shared meanings within and between initial themes. As the papers considered various diagnoses they could not be grouped and were thematically analysed together.

The papers were then analysed for differences in thematic content according to diagnosis. Three papers were excluded from this process as they considered a range of diagnoses that were not separated in the text (Gallagher Arber, Chaplin & Quirk, 2010; Hayne 2003; Pitt, Kilbride, Welford, Northard & Morrison, 2009). Although there were common themes across all of the papers regarding the receipt of a diagnosis, differences in emphasis were discovered for individual diagnoses.

The methodology of the Hayne (2003) paper included more abstract interpretation than the other papers and themes were not as obvious from the quotes. This made it difficult to analyse with the more concrete descriptions in the other papers and so the thematic analysis process was utilised to translate this.

The final stage of the narrative synthesis was to assess the robustness of the synthesis. This included the critical appraisal of the quality and methodological rigour of the included papers to assess the strength of the research. In this review the papers were appraised prior to the synthesis as part of the selection process.

3. Quality Appraisal

There are many methods available to appraise the quality of qualitative research. This paper adopted the criteria suggested by Yardley (2000) which was recommended by several authors (Meyrick, 2006; Smith, 2003; Smith, Flowers & Larkin, 2010).

Yardley (2000) proposes four essential criteria to assess the quality of good qualitative research papers: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Each of these was explored in relation to the selected papers in an attempt to judge their quality.

3.1 Sensitivity to context

i.   *Relevant literature.*

The selected papers grounded their research within a background of relevant literature. Some focussed on the experience of receiving a mental health diagnosis (Derksen et al., 2006; Horn, Johnstone & Brooke, 2007; Pitt et al., 2009). Other papers acknowledged diagnosis as a psychiatric tool (Pitt et al., 2009) and the power associated with diagnosis (Hayne 2003). Gallagher and colleagues (2010) consider diagnosis as a form of bad news and present research on the breaking of bad news to service users. Consideration was also given to the presentation of bad news dependant on the orientation of the clinician (Gallagher et al., 2010). More diagnosis-specific literature was used by other papers (Delmas et al., 2011; Young, Bramham, Gray & Rose, 2008).

The themes in the papers were empirically grounded in the data as evidenced by quotes from the dataset and linked to both the context of the diagnosis (Derksen et al.,

2006; Gallagher et al., 2010; Hayne, 2003; Horn et al., 2007; Pitt et al., 2009) and existing literature and theory (Delmas et al., 2011; Horn et al., 2007; Young et al., 2008).

ii.   *Participants' perspectives and sociocultural setting.*

All of the papers reviewed researched service user participants' experiences and perspectives. Some stronger papers paid attention to the social context between the researcher and participants in the study by stating the occupation of the interviewer and recognising that the resulting interview data was co-constructed (Gallagher et al.,2010; Hayne, 2003). Other papers gave some information about the researcher but did not reflect on the influence this may have had on the data collection or analysis process (Derksen et al., 2006; Young et al., 2008). Pitt and colleagues (2009) used service user researchers who were in the same sociocultural group as the participants being interviewed, which increased the sensitivity to context in this paper. Horn and colleagues (2007) attended to the issue of the impact of *a priori* ideas or the approach favoured influencing the analysis and discussed their analysis with participants to overcome this.

With the exception of Young and colleagues (2008), all of the papers took steps to triangulate their analysis. Several used more than one researcher to analyse the data (Delmas et al., 2011; Derksen et al., 2006; Gallagher et al., 2010) or inclusion of service users (Pitt et al., 2009) or participants (Horn et al., 2007) in the analysis process. In addition, Hayne (2003) used bracketing interviews with a supervisor to discuss and monitor reflexivity during the entire research process.

iii.   Ethics.

There was limited discussion about ethical issues reported in the papers. Some papers indicated informed consent (Pitt et al., 2009, Delmas et al., 2011, Derksen et al., 2006; Hayne 2003). Hayne (2003) referenced ethical permission for the research. Horn and colleagues (2007) provided no information about ethics in their paper.

There is no information in any study about if or how the interview data was anonymized, which poses an ethical issue of the potential for participants being identified by their quotes in the final paper. The lack of information about ethical issues may be due to limitations on publication word count.

3.2 Commitment and Rigour

i.   In depth engagement.

In-depth engagement with the topic was evidenced through the use of videoed interviews to include interpretation of non-verbal information (Derksen et al., 2006) and the use of reflective notes, memos and clippings during the interview to support the transcription and analysis (Hayne, 2003; Horn et al., 2007).

ii.   Methodological competence and skill.

There was considerable methodological competence and skill demonstrated in the papers. Pitt and colleagues (2009) employed service user researchers supervised by two clinical psychologists, while Young and colleagues (2008) used a researcher specifically trained in Interpretative Phenomenological Analysis (IPA). Other papers increased their methodological rigour through the use of multiple analysts (Gallagher et al., 2010), by using various forms of information to supplement the analysis (Hayne 2003) or seeking participants' feedback on the analysis (Horn et al., 2007).

iii.   Data collection.

Sample sizes ranged from five to 36 participants; most studies employed fewer than ten. The majority of participants were service users although two studies also included relatives or care givers (Delmas et al., 2011; Derksen et al., 2006). Some papers provided good demographic information about their sample (Gallagher et al., 2010; Young et al., 2008; Pitt et al., 2009) while others gave little information about participants (Hayne, 2003).

With the exception of Pitt and colleagues (2009) who cite convenience sampling methods, all of the remaining papers utilised purposive sampling to recruit participants. This was not always explicitly stated but was indicated by their description of recruitment processes (Gallagher et al., 2010; Young et al., 2008; Delmas et al., 2011; Horn et al., 2007). Derksen and colleagues (2006) describe their use and rationale for purposive sampling and Hayne (2003) indicates that purposive sampling was used. This method of sampling is congruent with the research methodology as the purpose is not to have a representative sample but rather a sample that can give an account of the experience under analysis (Smith et al., 2009). Delmas and colleagues (2011) indicate that they sampled to saturation in line with requirements for Grounded Theory.

Some authors considered that their sample may be biased because they are involved in service user groups (Pitt et al., 2009), or that agreeing to participate in research might indicate they have a strong opinion on diagnosis that may not reflect the experience of others who did not take part (Delmas et al., 2011).

All of the papers used interview as their main source of information. Some interview schedules had been piloted prior to the research (Young et al., 2008;

Gallagher et al., 2010; Delmas et al., 2011) or created with support from service users (Pitt et al., 2009) or professionals working in the field (Derksen et al., 2006).

Most papers used single semi-structured interviews with each participant to gather data. However, Delmas and colleagues (2011) and Derksen and colleagues (2006) interviewed participants at two points in time which triangulated and enriched the data.

3.3 Transparency and coherence

i.   *Transparent methods.*

Some papers stated that interviews were audio recorded and transcribed verbatim (Delmas et al., 2011; Hayne, 2003; Horn et al., 2007; Pitt et al., 2009). Other papers provided no information about how the interview data was recorded or transcribed (Gallagher et al., 2010).

A good description of analysis procedure was reported in some papers (Derksen et al., 2006; Gallagher et al., 2010; Hayne, 2003; Young et al., 2008). Horn and colleagues describe the audit process in their research (Horn et al., 2007).

ii.   *Fit between theory and methodology.*

The fit between theory and methodology was generally good. Hayne (2003) stated their approach directly as being phenomenological, while both Gallagher and colleagues (2010) and Horn and colleagues (2007) report a constructionist epistemological approach to their research. The remaining papers reviewed adopted a phenomenological approach as defined by their methodology and the aims of their research to explore or uncover participants' experiences. The methods employed were IPA (Horn et al., 2007; Pitt et al., 2009; Young et al., 2008), Grounded Theory

(Gallagher et al., 2010; Derksen et al., 2006), Phenomenological Thematic Analysis (Hayne, 2003) and Phenomenology and the Lived Experience Framework (Delmas et al., 2011).

Constructionist epistemology and phenomenological methodological approaches consider the participants' descriptions as an interpreted or constructed account of their experiences rather than a 'true' account. These approaches also recognise the importance of reflexivity and the role of the researcher in collecting participants' accounts of their experience (Barker, Pistrang & Elliott, 2008). All of the papers were successful in generating good information about the experience of receiving a mental health diagnosis.

iii.   *Reflexivity.*

While some papers acknowledge reflexivity and the role of the researcher in interpreting the data (Pitt et al., 2009), they do not give any details of how this may have influenced their research. Other papers make no mention of reflexivity issues (Delmas et al., 2011; Derksen et al., 2006; Gallagher et al., 2010).

Young and colleagues (2007) gave a good account of the researcher's credentials and impartiality to the service. They also considered the researcher's exposure to the literature which may have influenced her analysis. Given the importance of interpretation of spoken information, the difference in construing between researcher and participants is addressed (Young et al., 2008). Hayne (2003) recognises the potential influence of bias in analysis and uses bracketing interviews to reduce this possibility.

3.4 *Impact and importance*

Findings from the reviewed papers revealed information about the experience of receiving a mental health diagnosis. This will be discussed further in the narrative synthesis process. All of the papers reviewed recognised the clinical implications of their findings and suggested ways that clinical practice might be informed by their research. Briefly, the importance of a trusting therapeutic relationship for providing diagnosis was stipulated (Gallagher et al., 2010; Horn et al., 2007). Clinicians being aware of the probable impact of diagnosis (Hayne, 2003; Horn et al., 2007) and the provision of information to help service users understand the diagnosis being given was also referenced (Gallagher et al., 2010; Hayne, 2003; Horn et al.,2007; Pitt et al., 2009). In addition, Delmas and colleagues (2011) added to theoretical knowledge linking their findings to Shifting Perspectives Model of Chronic Illness (Patterson, 2001, cited in Delmas et al., 2011).

4. Results

4.1 Preliminary Synthesis

Original themes were taken directly from the papers and clustered into groups across studies (Appendix D). These clusters were: 'Knowledge as Disempowerment', 'Knowledge as Power', 'Rejection and Stigma', 'Uncertainty', 'Access to Support', 'Hope', 'Reactions', 'Information' and 'Relationships'.

4.2 Thematic analysis and narrative synthesis

The clusters of themes from the papers were further investigated adopting an interpretative position. Thematic analysis of the data presented in the reviewed papers

yielded several new themes of: 'Growing Awareness', 'Dichotomy of Diagnosis', 'Relationships', 'Loss' and 'Access to support'. These will be discussed in turn below.

4.2.1 Growing Awareness.

The theme of 'Growing Awareness' captures the context for the receipt of the mental health diagnosis. Participants were conscious that they had a problem or difficulty of some sort prior to receiving their diagnosis (Delmas et al., 2011; Derksen et al., 2006; Hayne, 2003; Pitt et al., 2009; Young et al., 2008). Diagnosis was more likely to be accepted positively when the service users anticipated it (Delmas et al., 2011, Derksen et al., 2006). Where a diagnosis was not expected participants found it a shock (Derksen et al., 2006).

This theme was particularly important in the paper reporting experiences of service users receiving a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in adulthood (Young et al., 2008). Similarly, participants receiving a diagnosis of Bipolar Disorder had also experienced a growing awareness of difficulties over time which had impacted on their relationships and careers (Delmas et al., 2011). In the case of a dementia diagnosis, participants reported a growing awareness of cognitive difficulties, although they had attributed different causes for this such as falls or physical problems rather than expecting a diagnosis of dementia (Derksen et al., 2006).

The context of 'Growing Awareness' was important following diagnosis too. For some participants it meant having to face difficulties from the past, such as childhood abuse (Hayne, 2003; Young et al., 2008). This aspect of realisation around diagnosis was an indicator that there would be no "easy mend" (Hayne, 2003, p. 725).

4.2.2 Dichotomy of Diagnosis.

The selected papers reported the experience of the receipt of a mental health diagnosis in terms of contradiction and dichotomy. This is observed in the way that for some participants a diagnosis is seen as an explanation of their difficulties and experiences (Delmas et al., 2011). For some, this explanation came as a relief (Hayne, 2003; Pitt et al., 2009; Young et al., 2008). Others felt that diagnosis confirmed the presence of a problem or illness (Hayne, 2003, Young et al., 2008), legitimised their difficulties (Pitt et al., 2009) and validated their experiences (Delmas et al., 2011). Conversely for some, although the diagnosis explained their growing awareness of difficulties, it was not the explanation that they had hoped for (Derksen et al., 2006).

Diagnosis did not fit with some participants' understanding of their difficulties or offer any explanation for their experiences (Horn et al., 2007). The diagnosis of Borderline Personality Disorder was interpreted by some participants to be an explanation of their difficulties "not fitting" into other diagnostic categories and was seen as a "dustbin label" (Horn et al., 2007, p. 262).

Further complexity within the data was found with regard to the perceived validity of the diagnosis that was conveyed. Knowledge was seen to be powerful in the papers reviewed. Professional opinions and diagnoses were seen as being powerful with the experts in a position of knowing and service users not knowing, creating an imbalance of power (Horn et al., 2007). Hayne (2003) found that for some a diagnosis was received as the truth or fact of "indisputable illness" that cannot be challenged (Hayne, 2003, p.725). While Horn and colleagues (2007) reported that participants felt unable to challenge expert opinion on their diagnosis.

Some participants felt that knowing their diagnosis was empowering (Horn et al., 2007). This knowledge about diagnosis afforded a sense of control and containment (Horn et al., 2007). The amount of information about the condition diagnosed provided at the time of diagnosis was important to the perception of the service user (Gallagher et al., 2010) and was found to be an important part of coming to terms with and accepting the diagnosis (Delmas et al., 2011). There were various accounts of very little information being provided at the point of diagnosis and a reported struggle to receive information (Horn et al., 2007). Where there was a lack of information, the diagnosis was more likely to be experienced as stigmatising or labelling (Pitt et al., 2009). Clinicians withholding knowledge of a diagnosis, or a lack of information provided about the diagnosis (Horn et al., 2007; Pitt et al., 2009) were viewed as disempowerment.

The dichotomy of diagnosis continued in the way that some participants were able to use their diagnosis to externalise their difficulties, so that their diagnosis was separate to their sense of self (Gallagher et al., 2010; Pitt et al., 2009; Young et al., 2008). While other participants felt they had been labelled and internalised the diagnosis (Pitt et al., 2009).

For some participants, receiving a mental health diagnosis was a frightening experience due to their preconceptions of the illness based on media and societal portrayal (Derksen et al., 2006; Pitt et al., 2009). For example, a diagnosis of Alzheimer's disease was most feared among the participants experiencing cognitive decline and they expressed relief if this was not the diagnosis ascribed to them (Derksen et al., 2006). These participants failed to realise the significance of other forms of dementia which receive perhaps less media coverage

Fear of stigma was found in some participants' accounts (Delmas et al., 2011; Gallagher et al., 2010; Pitt et al., 2009; Young et al., 2008). Such concern resulted in an avoidance of disclosing their diagnosis to others. Participants were concerned that the stigmatising label of their diagnosis would change the way others saw them (Young et al., 2008) and would result in rejection or discrimination (Delmas et al.,2011; Gallagher et al., 2010; Pitt et al., 2009).

Diagnosis also resulted in new feelings of vulnerability and a fear of becoming ill again (Hayne, 2003). The permanence or long term nature of some of the diagnoses was anxiety provoking (Gallagher et al., 2010; Young et al., 2008) with the possible need for lifelong medication and lifestyle changes (Delmas et al., 2011).

Some participants experienced uncertainty about their diagnosis (Derksen et al., 2006), for some this was because they had been given multiple or changing diagnoses over time (Gallagher et al., 2010).

4.2.3 Relationships.

Trust in therapeutic relationships was found to be very important for service users receiving a mental health diagnosis (Gallagher et al., 2010). Interpersonal relationships were also very important for healing and hope and for being seen as a person and not just a diagnosis (Horn et al., 2007).

Personal relationships were seen to be altered by the receipt of a diagnosis of dementia with the realisation that the cognitive changes already observed were permanent. Roles in relationships changed to care giver and recipient. The importance of relationships was stressed for the receipt of support and for maintaining social roles (Derksen et al., 2006).

Diagnosis could also result in the ending of some relationships due to the stigma attached to it and some participants reported losing friendships (Pitt et al., 2009, Hayne, 2003).

4.2.4 Loss.

Diagnosis was internalised by some as a new identity ("I'm bipolar"), which can lead to a loss of previous identity (Pitt et al., 2009). This loss of pre-diagnosis self (Delmas et al., 2011) needed to be mourned in order to move on to acceptance. Hayne (2003) describes diagnosis as "a power that impacts directly to the centre of one's being" (Hayne, 2003, p. 725), resulting in distress and confusion about identity. Diagnosis can also include the renaming and subsequent loss of a quality into a symptom of an illness (Hayne, 2003).

As previously discussed, diagnosis led to a loss of friendships (Pitt et al., 2009). Hayne (2003) also describes a participant's experience of the loss of collegial relationships when she was hospitalised where she worked.

Diagnosis of dementia was accompanied by a variety of losses. Loss of autonomy and loss of independence including loss of driving licence for example (Derksen et al., 2006). Participants reported experiencing grief and sadness over their losses and changed circumstances (Derksen et al., 2006). These participants reported using hobbies, humour and trying to be brave as coping strategies to manage their feelings of loss and their changed situation (Derksen et al., 2006).

4.2.5 Access to support.

Pitt and colleagues (2009) use the theme of "means of access" to describe how diagnosis facilitated support, not just in terms of medicine and therapy but also

increased care and understanding from health professionals and family members. This was a theme that also emerged in the other papers reviewed.

An important element noted across the studies was the power of peer group support. Following diagnosis, some participants were able to meet people with similar experiences where they were able to talk openly about their diagnosis without fear of recrimination (Pitt et al., 2009). Attending such support groups and receiving education about diagnosis facilitated acceptance (Delmas et al., 2011).

A healing and hopeful perspective was achieved through access to support and treatment (Hayne, 2003) and belief in recovery (Horn et al., 2007). Once diagnosed participants knew what they were up against and felt empowered to work on recovery (Hayne, 2003; Young et al., 2008). Treatment such as medication and symptom control created hope for a better future even without prospect of a full recovery (Young et al., 2008). However, when diagnosis was proffered with no treatment options it was seen as the killing of hope (Horn et al., 2007).

A diagnosis of dementia was found to be used as a prompt to seek out information and support such as support groups and respite care (Derksen et al., 2006). Disclosure of a dementia diagnosis to others was selectively undertaken in an attempt to secure resources and support from close relatives and friends (Derksen et al., 2006).

While most of the papers reported diagnosis as a facilitating access to support, Horn and colleagues (2007) reported that a diagnosis of Borderline Personality Disorder resulted in removal of services and rejection by health professionals. For some, anxiety around diagnostic disclosure to friends and relatives for fear of being stigmatised reduced the amount of support they were able to receive (Delmas et al., 2011).

4.3 Differences between papers reviewed

The synthesis of themes identified during the thematic analysis applies broadly to all of the papers, however a difference in emphasis of themes was observed for papers with specific diagnoses. It must be stressed that the themes discussed below are not representative in the entirety for each paper, but they are themes that emerged more powerfully than others from the author's analysis.

4.3.1 Bipolar Disorder (Delmas et al., 2011).

Themes of 'Growing Awareness' and 'Dichotomy of Diagnosis' were observed in this paper on Bipolar Disorder. Participants' difficulties had bothered them for some time prior to diagnosis. Their mood swings and behaviour had affected their relationships and careers. As such, the diagnosis offered an explanation for their difficulties and validated their experiences. The long term nature of the diagnosis was difficult to accept and led to reluctance in disclosing the diagnosis to others for fear of being stigmatised. Coming to terms with this diagnosis required support and information about the condition.

4.3.2 Borderline Personality Disorder (Horn et al., 2007).

'Dichotomy of Diagnosis' and 'Access to Support' were important themes in this paper. 'Knowledge as Power' is named in this paper, and perceives the diagnosis as knowledge received, which can elicit a sense of control. However, this knowledge can also be withheld, affording power to health professionals. Lack of understanding about the diagnosis through lack of knowledge led to uncertainty and feelings of rejection. The diagnosis was seen as a "dustbin label" given because they didn't fit the criteria for other diagnoses (Horn et al., 2007, p. 262). Diagnosis of Borderline

Personality Disorder meant reduced access to services and support for some. While for others accessing treatment, diagnosis was seen to engender hope.

4.3.3 Attention Deficit Hyperactivity Disorder (ADHD) (Young et al., 2008).

'Growing Awareness' was a large theme in this paper on the adult diagnosis of ADHD as participants had a growing awareness of their difficulties. Internalisation of negative labels was cemented by unhelpful comments from others regarding their behaviour and problems. Diagnosis offered an explanation for these lifelong difficulties and was received with relief and some elation. The diagnosis offered an opportunity to externalise the source of the difficulties and provided hope for the future with treatment to manage symptoms. Participants also described anger and rumination about their history once their elation had passed (Delmas et al., 2008).

4.3.4 Dementia (Derksen et al., 2006).

This paper on the diagnosis of dementia emphasised the theme of 'Relationships'. A diagnosis of dementia changed relationships. Participants felt they were a burden to their partners as their roles changed into carer. They were reliant on their partners for strength and trust was an important factor. There were also positive aspects to relationships. A dementia diagnosis focussed couples on the here and now and making the most of their time together.

Familial relationships were also important, particularly with a view to long term emotional and practical support (Derksen et al., 2006). Following a dementia diagnosis the maintenance of social relationships and roles such as Grandparent were valuable (Derksen et al., 2006).

Loss was another strong theme within this paper. Loss of cognitive ability led to a loss of autonomy such as loss of driving licence leading to a loss of independence and increased reliance on others. This reliance on others was perceived by participants as being a burden on their loved ones. It is unsurprising then that grief and sadness were reported following a diagnosis.

5. Critical Appraisal of Narrative Synthesis

This section provides an evaluation of the narrative synthesis. Reference is made regarding the quality of the reviewed research earlier in this paper.

Procedurally there are some limitations to this narrative synthesis. Only one researcher was used for the entire process, which might have influenced the selection of papers for review, the quality appraisal and the thematic analysis for the synthesis of the data. Supervision was used to discuss the process and an audit trail of notes and a reflective diary was used to aid transparency.

This is the author's first narrative synthesis, and as such guidance for the procedure was followed (Popay et al., 2007). However, all of the guidance found focussed on the synthesis of quantitative papers and so the author has had to adapt this to applying it qualitatively. The author noted that in other qualitative narrative synthesis papers the methodology was vague which could indicate a lack of confidence in the procedure and the need for specific qualitative guidance. The current author was very clear in the procedure she undertook for this synthesis to allow replication.

Due to the paucity of qualitative research in this area, there were no common diagnoses in the papers selected to allow for clustering of themes. Therefore all diagnoses were considered together. However, where papers reported a specific

diagnosis these papers were also considered separately and their dominant themes reported.

Synthesis of the papers included in the review was difficult given their diagnostic diversity. Further research may prefer to focus on a single diagnosis or diagnoses which are more similar. On reflection it may have been preferable to exclude the paper on Dementia diagnosis as this is a progressive condition, which differs to the other diagnoses represented which may be alleviated over time with support.

6. Discussion

The five themes: 'Growing Awareness', Dichotomy of Diagnosis', 'Relationships', 'Loss' and 'Access to Support' describe the complex and often contradictory impact of the receipt of a mental health diagnosis. These themes are summarised and considered with relevance to existing literature. Clinical and research implications of this review are discussed.

6.1 Summary and discussion of themes

The theme of 'Growing Awareness' indicated the importance of the context, including service users' awareness of difficulties, within which the diagnosis was received. Participants were often aware of some difficulty but did not necessarily expect the diagnosis they received, which came as a shock to some.

'Dichotomy of Diagnosis' was the strongest theme in this review and captures the contradictory experience of receiving a diagnosis. This contradiction is present in previous research but has not been directly addressed as such. This theme concurs with previous research which has suggested that the presentation of a diagnosis can be influential for service users' experiences and perceptions of their diagnosis (Stainsby et

al., 2010). The power relationship described in other research between service users and health professionals was also evident (Hagen & Nixon, 2011). Explanation and validation of difficulties and information were important in this theme to promote service user empowerment.

The theme 'Relationships' emphasised the importance of trusting therapeutic relationships for the delivery of a diagnosis, but also stressed the importance of personal relationships for support and recovery. For some participants a diagnosis led to the experience of 'Loss' such as loss of relationships and in the case of a dementia diagnosis, loss of independence. Loss of identity was also reported, which supports previous research which suggests that diagnosis can impact on service users' self concept (Haghighat, 2008).

Diagnosis did facilitate help in the theme 'Access to Support' for many participants. This included increased understanding by professionals and family, access to services and peer support. There was an exception for some participants diagnosed with Borderline Personality Disorder who found they were rejected from services because of their diagnosis.

6.2 Clinical implications

The findings from this review allow some clinical recommendations to be suggested as described below.

 i.   *Explore service users' current beliefs and provide information about the diagnosis.*

This review found that an unexpected mental health diagnosis came as a shock and was perceived negatively (Dersken et al., 2006; Hayne, 2003). Exploring service

users' ideas about what might be causing their difficulties might support them to become aware of their difficulties and prepare them to receive the diagnosis. Accessible information could also be helpfully provided at the point of diagnosis. This review found the provision of information was important for service users to understand and accept their diagnosis and to feel empowered and efficacious about their recovery.

ii.   Clinicians could consider alternatives to diagnosis.

Diagnosis is one way of understanding a person's difficulties but it is often presented as fact to service users. Clinicians should be conscious of the reification of diagnostic labels (Pilgrim, 2007) and consider alternative ways of thinking about service users' difficulties such as sharing a psychological formulation (Johnstone, 2007).

iii.   Provide access to peer support.

This review found that access to peer support was important to facilitate service user acceptance and understanding of their difficulties. They also appreciated the opportunity to talk openly about their problems without the fear of discrimination, prejudice or stigma.

6.3 Research Implications

Participants in the reviewed papers felt empowered when they were in receipt of information, which increased their sense of efficacy to recover and was important for understanding and accepting their diagnosis. Future research could further investigate the role played by information in the diagnostic process. Consideration could be given

to what information is routinely provided at the point of diagnosis and what service users find most helpful and empowering.

'Dichotomy of Diagnosis' describes the often contrary nature of the experience of receiving a diagnosis. This is an area which may warrant further research into the mechanism behind the positive and negative attributions service users made about diagnosis. Research into this phenomenon would benefit from being diagnosis specific initially but it would be of interest to compare between diagnoses also. Gender or cultural differences in attributions about diagnosis may also be investigated.

Although the themes extrapolated using thematic analysis in this review were common in all of the papers, different diagnoses were experienced differently as evidenced by different emphasis of themes in individual research. This suggests that more diagnosis specific research is needed to understand the experiences of service users, particularly where the diagnosis is contentious (Boyle, 2007; May 2007) or is associated with stigma such as schizophrenia and psychosis.

6.4 Conclusion

This review adds to the paucity of qualitative research in this area by pulling together themes from papers on a variety of diagnoses. The review has revealed a complexity of positive and negative impacts of receiving a mental health diagnosis. Although the themes were broadly present in all papers there were diagnosis-specific differences in their emphases. This suggests that although some experiences are common, some diagnoses engender different responses and have a different impact to others.

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Research Report

An Interpretative Phenomenological Analysis of

Service Users' Experiences of Receiving Information about First Episode Psychosis

Service Users' Experiences of Receiving Information about a

First Episode of Psychosis:

An Interpretative Phenomenological Analysis.

Emma Nicholas

Abstract

Objective: A gap was identified in the literature for research addressing service users' experiences of receiving information following a first episode of psychosis which may include receiving a diagnosis of psychosis or schizophrenia.

Method: Seven participants were recruited from Early Intervention in Psychosis Services and took part in semi-structured interviews. Interpretative Phenomenological Analysis was applied to the interview data to explore the way participants created meaning from their experiences.

Results: Three themes were uncovered: Having an Official Condition; Being the Patient; and Construing Identity.

Conclusions: These themes illustrate the influence of information outside the diagnostic process, such as service users' existing knowledge or societal representations of the diagnosis, which was important in the way the diagnosis was perceived by participants. Power relationships between service users and clinicians are addressed in relation to the provision of information. Clinical implications of these findings are discussed.

1.   Introduction

1.1 Introduction Overview

A First Episode of Psychosis (FEP) can be a distressing, traumatic and frightening experience (Mauritz & van Meijel, 2009). A literature search found there has been little research into service users' experience of receiving information about FEP, which may include a diagnosis of psychosis or schizophrenia. This introduction provides an overview of the current debate around the mental health diagnosis of schizophrenia and its impact on service users. There is a description of Early Intervention in Psychosis Services including the principle of working with diagnostic uncertainty and provision of information. Finally, a rationale for the current research is provided in addition to an outline of the current study.

1.2 *Debate around the schizophrenia diagnosis*

There is considerable debate about the validity and reliability of the diagnosis of schizophrenia. It is argued that there is no objective way to diagnose schizophrenia (van Os & Kapu, 2009). Currently, diagnosis relies on the identification of a set of symptom clusters determined by the Diagnostic Statistical Manual IV Text Revised (DSMIV-TR) or the International Classification of Diseases 10 (ICD10). Bentall (2006) argues that there is no scientific basis for these symptom clusters for diagnosis, which is based on assumptions that discrete mental illnesses exist. There is considerable overlay between the symptoms of psychosis or schizophrenia and experiences in the 'normal' population (McGorry, McFarlane, Patton & Bell, 1995). For example, auditory hallucinations, one of the symptoms associated with these diagnoses, has been found to be experienced by many individuals in society (Romme & Escher, 1994).

In line with this debate there has been action by health professionals to address concerns about the inconsistency of the schizophrenia label. There are several critiques and positions taken which challenge the diagnosis. For example, the East Midlands Psychosis and Complex Mental Health Special Interest Group (SPIG), comprised of Clinical Psychologists, has prepared a document stating its position, which calls for the diagnosis of Schizophrenia to be challenged (SPIG, 2010). The British Psychological Society has also written an open letter to the American Psychological Association DSM-V consultation outlining their concerns at the inclusion of new diagnostic categories in the new manual (BPS, 2011). These views are not shared by all health professionals and new service structures, such as clustering service users' presentations, potentially encourage the continued use of mental health diagnoses including schizophrenia.

1.3 Receiving a diagnosis of psychosis

A further critique of the diagnostic process is the impact diagnosis can have on service users. Mauritz and van Meijel (2009) report a diagnosis of schizophrenia as a shock to the service user, which can explain the person's experiences but also has the negative and stigmatising label of a severe psychiatric illness.

A literature search found only one qualitative paper alleging to directly explore service users' experiences of receiving a diagnosis of psychosis (Pitt, Kilbride, Welford, Northard & Morrison, 2009). On closer evaluation, the participants in this research had a range of or multiple diagnoses, so this was not a specific study into psychosis as purported. In this research, diagnosis was found to facilitate access to support for service users from professionals and family members. However, diagnosis was also found to be disempowering where information provided was not adequate, or where there was a lack of understanding. Similarly to Mauritz and van Meijel (2009),

participants reported relief at the explanation of their experiences but were also concerned about stigma and rejection (Pitt et al., 2009). This research reflects the complexity and contradictory nature of the experience of receiving a diagnosis for service users.

Quantitative research has found that the delivery of a diagnosis of schizophrenia can influence the service users' perception of the diagnosis (Barret, 1996) and that this can influence their self concept (Haghighat, 2008) and their experiences (Lobban, Barrowclough & Jones, 2005; Stainsby, Sapochnik, Bledin & Mason, 2010). That is, the way that the diagnosis, symptoms and prognosis are interpreted by the individual is likely to impact upon the meaning that is created (Wittman & Keshaven, 2007). Stainsby and colleagues (2010) reported that service users' perception of 'schizophrenia' had more influence on their perceived quality of life than the severity of their symptoms. Another study interviewing fathers with psychosis found their beliefs about their diagnosis engendered fear that their children would also suffer with the condition (Evenson, Rhodes, Feigenbaum & Solly, 2008).

The evidence presented so far demonstrates some of the difficulties with the validity and reliability of the schizophrenia diagnosis. It also outlines the potential impact of receiving a diagnosis for the service user.

1.4 Stigma

There is a large evidence base associating mental health diagnoses such as psychosis and schizophrenia with stigma. Service users may fear stigma such as being talked about, being discriminated against in the workplace or being rejected (Lam, Pearson, Ng, Chiu, Law & Chen, 2011). Knight, Wykes and Hayward (2003) report that negative judgement, prejudice and discrimination were expected and experienced

by service users from friends, family, professionals in medicine and the police. Unsurprisingly then, service users have been found to be anxious about disclosure and withheld information about their diagnosis from others (Knight et al., 2003; Lam et al., 2011; Pitt et al., 2009). Service users may also struggle with their own prejudice about the diagnosis they have been ascribed (Knight et al., 2003). In addition to experiences of stigma, the symptoms associated with psychosis and schizophrenia, as well as the impact of the diagnosis itself, can result in the breakdown of relationships and social isolation (Mauritz & van Meijel, 2009; Wood, Price, Morrison & Haddock, 2010).

1.5 Alternatives to diagnosis

Explanations alternative to diagnoses have been proposed to account for experiences of psychosis as discussed by Bentall (2007). There is much evidence to suggest that psychotic complaints are influenced by trauma, environment and attachment type (Bentall, 2006). Bentall (2006) suggests that moving to a complaint-focussed approach, targeting service users' individual complaints, would be both more scientific and humane than diagnosis. To date, the preference of service users regarding alternative explanations compared to diagnosis has not been explored.

1.6 Early Intervention in Psychosis Services

Psychosis most often occurs between the ages of 16 and 30 years (Lester, Birchwood, Bryan, England, Rogers & Sirvastava, 2009). Long periods of untreated psychosis have been linked with a poor outcome (Spencer, Birchwood & McGovern, 2001) and the time immediately following a FEP has been construed as a critical period where timely and effective intervention could have positive effects on the course of the illness (Spencer et al., 2001). Early Intervention in Psychosis (EIP) services were established in the UK to provide three years of comprehensive community-based

support for young people aged between 14 and 35 years who are experiencing a FEP (Department of Health, 2001). There is a growing body of international evidence that assertive intervention during a FEP can improve outcomes (Singh & Fischer, 2005).

The Early Intervention in Psychosis IRIS Network provides guidance principles for EIP Services. They advocate a focus on issues important to the young service users, perseverance with service users despite difficulties with engagement, support focussed on social roles, least restrictive psychiatric treatment in low stigma settings with an emphasis on choice and low dose medication, the embracing of diagnostic uncertainty and inclusion and support of family (IRIS).

1.7 Diagnostic Uncertainty

EIP services were established to embrace diagnostic uncertainty as the early symptoms of psychosis can be observed in many normal teenagers (McGorry et al., 1995) and treatment should not be delayed until a diagnosis can be ascertained. Further, the early application of a diagnosis can be both harmful and unreliable and interventions addressing specific symptoms rather than based on a diagnosis is advocated (Spencer et al., 2001; McGorry, 2011). This allows diagnosis to be deferred until symptoms have stabilised over time and avoids changing diagnoses or stigma.

With the national trend towards grouping mental health difficulties into clusters, it would appear that there has been a shift within some services towards discussing and providing diagnoses routinely. However, some services continue to aim for a position of diagnostic uncertainty and avoid providing diagnoses of schizophrenia for example where possible.

1.8 Information Provision in Early Intervention in Psychosis Services

Provision of information about their experiences from EIP services is important to service users as it helps them and their families to understand how they have come to be unwell and to identify early warning signs for the future (Lester et al., 2011; Wood et al., 2010). Information may take the form of peer support provided as part of group psycho-education which can facilitate acceptance and understanding of the diagnosis and condition (Mauritz & van Meijel, 2009). Information provided by the EIP service helps service users to challenge their negative views about mental health difficulties and overcome their embarrassment and shame around their diagnosis (Mauritz & van Meijel, 2009). This information can increase their confidence and facilitate an improved view of their future. It also helps them to share information with others (Lester et al., 2009).

1.9 Rationale for Current Research

The evidence here presents a critique of the reliability and validity of the diagnosis of schizophrenia and the impact of a diagnosis on service users. Information has been shown to be important to help service users to understand their experiences and to recover. Using these principles, EIP services were established to embrace diagnostic uncertainty and to delay the provision of diagnosis until symptoms settle and diagnosis can be certain. However, changes in policy may require some services to provide diagnosis more routinely.

May (2007) proposed that research into the service user experience of diagnosis and understanding of information provided is overdue. The aim of the current study was to expand upon the existing literature using the richness of qualitative data. Given the paucity of qualitative research in this area, the current debate and changes in policy

regarding diagnosis, the need for an understanding of service users' experiences and hearing their voices appears vital (May 2007). The focus of the current research was to understand the subjective experience of receiving information about a FEP, which may include a diagnosis of psychosis or schizophrenia. Increased understanding of how the process of receiving information about FEP or a diagnosis is experienced will facilitate improved services for service users, for example, how information could be most helpfully provided, by whom and in what format.

2. Method

2.1 Research question

The principle aim of this research was to answer the research question: "What are service users' experiences of receiving information about their psychotic experience?"

The research was also interested in the information service users receive from Early Intervention in Psychosis (EIP) services about their experience of first episode of psychosis (FEP), how service users' experiences of receiving information shape their understanding and the meaning they make of their experience.

2.2 Design

A qualitative study design was selected to explore service users' subjective experiences and perceptions of receiving information from an EIP Service. Semi-structured interviews were the favoured method for data collection as they allowed participants to talk freely about their experiences and the issues that were important to them, which may be outside the researcher's current awareness. It was hoped that this approach would generate rich information about participants' experiences which would

enhance current literature around the experience of receiving a mental health diagnosis, specifically a diagnosis of Psychosis or Schizophrenia.

2.2.1 Epistemological position.

As the research question was focussed on participants' interpretations of their experiences, a contextual constructivist epistemological stance was adopted (Appendix F). This position recognises the interpretation present in the participants' accounts of their experience and the contextual effect of the interview to take account of the relationship between the interviewer, the participant and the interview context (Madill, Jordan & Shirley, 2000).

2.2.2 Interpretative Phenomenological Analysis.

The present study was interested in how participants have made sense of their experience of receiving information following a FEP. A phenomenological approach using a method of thematic analysis was most suited to this aim. The aim of phenomenological research is to understand the participants' perceptions and the meanings they create rather than pursuing facts (Barker, Pistrang & Elliot, 2008). This position allows the researcher to accept multiple perspectives as valid. Interpretative Phenomenological Analysis (IPA) was chosen to analyse the interview transcripts as it offers access to the respondents' experiences through their accounts to explore how they make sense of them (Chapman & Smith, 2002). Further, it offers the opportunity for the researcher to interpret meanings from the participants' accounts, that the participant themselves may be unaware of (Smith & Osbourne, 2004).

2.2.3 Researcher's declaration of interest and experience.

Prior to this research, the researcher had no experience of working with people with a diagnosis of schizophrenia or psychosis and had little detailed knowledge of the concepts or EIP Services. As IPA is an inductive methodology, the researcher felt well placed in a position of having little knowledge or personal experience which facilitated receptiveness to the participants' experience. The researcher was aware of the importance of acknowledging any lay knowledge, prejudices or preconceptions that would influence analysis of the interview transcripts. In view of this, bracketing interviews with the academic supervisor were used to bring into awareness and explore the researcher's thoughts, ideas and experiences during the research process.

2.2.4 Interview schedule.

The interview schedule was developed to support the participants to converse about their experiences (Appendix H). The semi-structured interview schedule was created following guidance by Smith, Flowers and Larkin (2009) and with support from the author's academic supervisor (a Clinical Psychologist in an Early Intervention Service). The schedule covered three main areas in relation to the research questions: What information or diagnosis has been received, the context for the receipt of this information, for example what beliefs the participant already had about the diagnostic label, and what was the meaning of the information to the recipient. All questions on the schedule were open-ended in order to elicit narrative from the participant about their experience. The schedule was used as a guide for the researcher and in addition to the set questions the researcher also asked probing questions to participants as necessary to help them articulate their experience. This schedule was used successfully

in the first interview as it facilitated good narrative and it remained unchanged for future interviews.

2.2.5 Sampling.

Congruent with the research methodology of IPA, purposive sampling was used to gain access to participants who could provide insight into their experiences of receiving information about a FEP. Therefore the sample was representative of a particular perspective rather than a general population (Smith et al., 2009). Participants were recruited from EIP Services in the Midlands region. The inclusion criteria generated a sample that was homogeneous in terms of their length of time in the service.

Inclusion criteria:

- Aged over 18 years

- Under the care of EIP Service for between six months and two years

- Stable presentation for 3 months prior to the interview

- Have capacity to consent to participate

- Speak fluent English

In addition to the inclusion criteria, Care Coordinators had to agree that participants were well enough to take part in the study, that taking part in the study would not adversely affect them and that they posed no risk to the researcher. Individuals were not considered for inclusion into the study if they had a mental health diagnosis other than schizophrenia or psychosis, or if they were considered by their Care Coordinator to be too unwell to participate at the time of the interview.

Sample size in IPA studies should reflect quality over quantity as the focus is on the individual participant's lived experience (Smith et al., 2009). Smaller sample sizes

can be a benefit to the richness of the research, as researchers need time for reflection to

enable a successful analysis of the qualitative data (Smith et al., 2009). Smith and

colleagues (2009) suggest that between four and ten interviews is optimum for doctoral

research. This research analysed seven interviews, one from each of the seven

participants taking part in the study. Participants' details are shown in Table 1.

Table 1: Participants demographic information

Pseudonym	Sex	Age	Ethnicity	Length of time in service	Diagnosis
1. John	M	25	White British	16 months	Psychosis
2. Kate	F	22	White British	8 months	Acute Transient Psychotic Disorder
3. David	M	29	White British	16 months	Psychosis then Schizophrenia
4. Steven	M	24	White British	24 months	Psychosis then Schizophrenia
5.Jesscia	F	25	White British	8 months	Psychosis
6.Jenny	F	24	White British	24 months	Schizophrenia
7.Jack	M	31	White British	18 months	Psychosis

2.2.6 Situating the sample.

Although the participants were recruited from the same EIP service there was variability in their experiences of the diagnostic process. Kate was sectioned but was not given a diagnosis until she came to the EIP service where she was diagnosed by the psychiatrist straight away. David, Jessica and Jack were also hospitalised but were given diagnoses of psychosis while in hospital before coming to the EIP service. Jack has since been advised by the psychiatrist in the EIP service that his diagnosis might change to schizophrenia. John was with his parents when he was told by the EIP psychiatrist that he had psychosis early in his contact with the service. Steven was seen by the crisis team initially but did not receive a diagnosis from them. He was given a diagnosis of psychosis by the EIP psychiatrist after seven sessions with the service; a year later he was diagnosed with schizophrenia. Jenny couldn't recall being given a diagnosis, rather she decided herself that she has schizophrenia based on symptoms that matched a relative with the same diagnosis.

2.3 Procedure

2.3.1 Research development and ethical approval.

The initial research proposal was submitted for peer review within the University of Leicester Clinical Psychology Department and separately for review by the Service User Research Group within the department. Following suggested alterations it was submitted for ethical approval at the Nottingham Research Ethics Committee (REC) in March 2011.The REC provided ethical approval to conduct the research following some minor amendments in April 2011 (Appendix J). Separate approval was also required from the Research and Development (R&D) departments in the trust for each service. This permission was granted by June 2011.

2.3.2 Recruitment and interview.

Following full REC and R&D approval the researcher presented her project during team meetings at three services who had agreed to be involved in order to generate recruitment. Unfortunately, two services were ultimately unable to identify any participants despite repeated attempts, so participants were only recruited from one service. Service users matching the inclusion criteria were identified by their Care Coordinator who made the first approach and invited them to participate in the research. If they were interested in taking part they were provided with further information about the study by the researcher and were given the opportunity to ask questions. Those who wished to proceed after this took part in a semi-structured interview with the researcher at a location that was convenient for them and where they felt comfortable. Before the interview began the participants were asked to provide informed consent. Participants were encouraged to talk freely about their experiences using the semi-structured interview schedule as a prompt.

2.3.3 Transcription.

Participants were interviewed in sessions lasting between 20 and 90 minutes, which were recorded on a digital voice recorder. The researcher transcribed verbatim all of the interviews following Jeffersonion conventions (Jefferson, 2004). As IPA is focussed on the meaning of the content it is not necessary to record detailed information about prosody (Smith et al., 2009). The process of transcription allowed the researcher to become familiar with the data. All efforts were made to ensure that the data was anonymous and any identifying information was changed in order to conceal the identity of the participants.

2.3.4 Analytical Procedure.

The researcher followed procedural guidance by Smith, Jarman and Osbourne (1999) and Smith and colleagues (2009) for the interpretative phenomenological analysis of the data. Each transcript was analysed individually at first and read several times to allow the researcher to become immersed in the data. Initial ideas were noted on the right hand side of the transcript. In addition the researcher also kept reflective notes to enable accurate recall of the process and thoughts. From there the left side of the transcript was used to group together the initial ideas into themes as shown in Appendix I.

These themes were then transferred to a separate document and analysed for relationships. Once a table of themes had been developed the process was repeated with the next transcript. All themes were then analysed for relationships and similarities across transcripts. Throughout this process the original transcripts were consulted to ensure new themes reflected the data. Quotes from the transcripts were then selected to illustrate and support the themes generated.

2.4 Ethical considerations

Previous research involving service users with a diagnosis of schizophrenia reported that the participants appreciated the opportunity to tell their story (Haghighat, 2008; Lobban et al., 2005). It was anticipated that participants could become distressed when recounting their experience of receiving information about FEP or a diagnosis of schizophrenia or psychosis. Participants were encouraged to disclose only that which they felt comfortable discussing and were informed that they could withdraw from the interview at any stage.

Another ethical consideration arose out of the use of illustrative quotes from interview transcripts. As the plan was to disseminate the findings among professionals and other service users taking part from the same EIP Service, it was of utmost importance to ensure that no one could be identified by the information they provided. All transcripts were anonymized by changing names, places, dates and any other potentially identifying features prior to analysis.

2.5 Quality issues

Yardley (2000) proposed four criteria for the quality appraisal of qualitative research: Sensitivity to Context, Commitment and Rigour, Transparency and Coherence and Impact and Importance. These were used as a guide to ensure that the current study fulfilled these criteria for good research.

2.5.1 Sensitivity to context.

In order to become aware of the political context in which the research was taking place, the researcher conducted a thorough review of qualitative research around mental health diagnosis and became familiar with current debates around the provision of a diagnosis of Schizophrenia or Psychosis including arguments about the reliability and utility of the diagnostic label (Boyle, 2007; May, 2007; Pilgrim, 2007). In addition the social context within which the participants were located was considered. Although there was some variability in the sample, participants were all white British and mostly working class service users living in relatively deprived areas of a large city. In addition to demographic variables it was also important to consider the experience of the participants as service users; for example to be aware of the potential for participants to associate the researcher with the mental health services and the subsequent potential for a power imbalance to be perceived. The participants may have experienced other

phenomena such as stigma, being perceived as being 'ill' and having limited power which is outside the researcher's experience.   It was crucial to consider this when interpreting the interview transcripts and to be aware of the potential for misunderstanding by the researcher of language or frames of reference used by the participants (Yardley, 2000). It was also important to be aware of how these differences will have impacted on the way the participants shared their story with the female researcher, which might have been different to speaking with a fellow service user or a male researcher.

2.5.2 Commitment, rigour, transparency and coherence.

Methodological rigour and commitment to the research was enabled by the researcher transcribing all of the interviews to become immersed in the data before a thorough analysis was performed. Coherence was achieved by selecting an appropriate phenomenological methodology to explore participants' accounts to answer the research question. Supervision with a Clinical Psychologist facilitated reflection on the analysis process and acted as a form of triangulation. Disclosure of the detailed analysis methodology in this report and the use of a reflective diary enhanced the transparency of the interpretative procedure.

2.5.3 Impact and importance.

The present study is conducted in a context of ambiguity and ongoing discussion around the diagnostic labels of Schizophrenia and Psychosis discussed earlier in this paper (Bentall, 2006; Boyle, 2007) and will illuminate the current debates about the value of these labels from the perspective of the service user. It is hoped that this research will provoke further debate in this arena.

3. Analysis

The aim of this research was to explore service user accounts of receiving information about a first episode of psychosis which may include diagnosis of psychosis or schizophrenia. Although the interview transcripts yielded much interesting information, this section is focused on the themes shown in Table 2, which most closely relate to the research questions.

Table 2: Themes

Theme	Subtheme
Having an official condition	Having an official condition Diagnostic fit Feeling unable to escape
Being the patient	Subordination Taking some control
Construing identity	Being construed as dangerous Making me normal

3.1 Having an official condition.

The diagnostic process appeared to be understood by participants as making an official declaration about their experiences. This theme is made up of subthemes that address participants' different responses to this experience.

3.1.1 Having an official condition.

A diagnosis was perceived as 'Having an Official Condition'. It confirmed the presence of difficulties and named the problem. Some participants appeared to find it reassuring to have a name to describe their experiences, but this seemed to be complicated by associations with mental health or misconceptions about the predictive value of diagnosis.

Kate: Oh yeah, it was nice to know what it was. And erm I think it was upsetting as well to be told that you do have mental health problems. But, so yeah, it did have an impact. (90-92)

This is probably best understood within the context of current negative societal attitudes towards mental health and stigma, some of which are explored in more detail in the theme 'Being Construed as Dangerous'.

Some participants appeared to find diagnosis of an 'official condition' a helpful explanation for their difficulties.

Steven: There's a reason behind like some days I wake up and I'm like quite low and depressed, it's not because everything's happening or my life's not going the right way or nothing, it's just a part of the illness. (147-150)

Steven seems to use the illness model provided by his diagnosis as a strategy to understand his experiences. He appears able to reassure himself of the distinction between his feelings which he perceived as a symptom of his 'illness' and reality.

Jack appeared to view schizophrenia as an 'official condition' and struggled with what he perceived to be a predictive value of the diagnosis.

Jack: Like 'cause they don't know it's gonna happen again, I don't know it's gonna happen again, so I don't know how anybody really knows. If you've actually got like official condition that's going to make something happen again. (564-567)

Jack seemed to fear that in being given the diagnostic label of an 'official condition', he was in some way being given schizophrenia. He appeared to believe that by being diagnosed he would experience further episodes of psychosis.

In contrast David appeared to experience diagnosis as being official but irrelevant and superstitious, and that the doctors used diagnosis to make themselves feel important.

David: I suppose it felt like a lexicon factory from the doctors you know. Superstitious, trying, I suppose they felt (mumbles) to me they were trying to feel important like they could do something about stuff. (252-255)

David's example and others could suggest that the emotional impact of receiving the diagnosis is linked to participant's perception of the legitimacy and relevance of the diagnosis.

3.1.2 Diagnostic Fit.

Diagnostic fit describes how the participants made sense of their diagnosis through the way it might or might or might not fit with their existing knowledge.

Years before his diagnosis Steven had become aware of drug-induced psychosis through the media. This pre-existing knowledge provided a framework within which to interpret his diagnosis of psychosis.

Steven: And when they said that, when they said psychosis, like in my assessment, (coughs), that's the first thing that came into my head. Drug induced psychosis. 'Cause even if (.) you've stopped smoking, you can like, you can like, the damage can still be there like. And so I always thought that was the reason why I got it. And that was about it really. That was the only bit of psychosis I could like, really like think of. (485-492).

The framework provided by Steven's knowledge appeared to influence the meaning he made of his diagnosis and the way it fit with his experience. He made an

assumption that his psychosis must be the result of smoking cannabis when he was younger. This led him to believe that he had damaged himself in some way and that it was his own fault. However, information provided by the EIP service challenged these ideas and supported Steven to realise that it was not his fault.

> *Steven "but then they got me thinking like it might not have been that. It could just, it could have been stress, could have been, could have been all different kinds of things so it were like it weren't my fault. " (127-130)*

Steven later received a diagnosis of Schizophrenia, however, this time the EIP Service created a framework within which to fit the diagnosis.

> *Steven: I think it's helpful like the way they don't just (.) 'cause like they was always explaining different things to me, but then like they don't just like push it straight on you if you know what I mean. Like, they got me ready for it kind of thing. (689-693).*

> *Steven: But then like we had that meeting and like it all come out. And then he was like hold on a minute we already spoke a bit about this. So er such like, it weren't a shock to me. (726-729)*

Steven felt he was prepared for his diagnosis of schizophrenia by having things explained to him over a period of time which created a framework within which to fit his diagnosis. In the event the diagnosis fitted with Steven's expectations that this might happen and his ideas about his experiences. This mitigated the emotional impact of the diagnosis.

Where diagnosis did not fit with expectations participants felt they were not being heard, or that the issues that were most important to them were not being addressed.

Jack: But for a long time, like last year, when I was just feeling depressed I felt like they weren't addressing the real issues. 'Cause I was saying it's the depression that's my problem and it's almost like they keep referring back to the psychosis. (1116-1120)

Jack's experience was to be referred back to his psychosis diagnosis when he complained of low mood. Jack felt that his low mood was separate to and predated the psychosis and the medical model of psychosis did not answer his questions or alleviate his depression. The focus on the dominant diagnosis of psychosis appeared to be invalidating. Similarly John remarked*:*

John: my main concern was my headaches which I have. So I'm thinking why, why is that not being dealt with as opposed to erm, dealing with psychosis (83-85).

3.1.3 Feeling unable to escape.

Receiving a diagnosis for some participants was experienced as something they were unable to escape from. At the time of diagnosis, participants appeared to interpret it to be a permanent and unquestionable label imposed on them which typically negatively impacted on their thoughts about their future.

Jack: It's quite depressing to be told you have, you have something, because it's, you feel like you can't escape that, if you know what I mean? (231-233)

Participants seemed to feel low in mood in response to this presentation of inescapable fact. During the interviews, diagnosis was not generally associated with

recovery and Steven described disbelief when he received his first diagnosis of psychosis.

> *Steven: To be honest I thought well, I thought that the way I was feeling then, I thought no way is this how it's going to be like, for the rest of my life. Not being able to do anything, paranoid and stuff like that. Not being able to go to the shop or do what normal people do. (557-562)*

As a result of this interpretation of diagnostic permanence, participants seemed to experience a changed view about their future and found this aspect of diagnosis worrying.

> *Interviewer: has your experience of receiving a diagnosis of psychosis, has that changed your ideas about your future or your life ahead of you?*

> *Jessica: Um, well it did for a bit. I did get quite worried. You know I thought I'll end up having to be on benefits forever. And you know I won't get a decent job, 'cause it's quite important for me to try and find a good career. (801-808)*

One interpretation of diagnosis appeared to be that it was permanent and inescapable. Jessica perceived that she may be unable to return to work and would have to survive on benefits. There also appeared to be a fear that her diagnosis would limit her career and that she would be unable to get a "*decent job*" as a result of being labelled with psychosis.

Diagnosis impacted on Kate's ideas about her future career.

> *Interviewer: Erm, and has your diagnosis changed the way that you think about your future?*

Kate: Erm, I think so because it does, it really knocks your confidence, so I don't (.) I get worried about going back to work and stuff because it was stress from work that caused it. So it's impacted in that sort of way. (126-131)

Receiving a diagnosis of psychosis appeared to result in a loss of confidence in her ability to cope with stress. She held the belief that her psychosis was created by stress in the workplace, and this belief about her diagnosis affected her thoughts about her future. She worried about returning to work in case she became stressed and experienced psychosis again. Kate's experience is slightly different in that she believed her diagnosis provided information about the cause of her difficulties which was the basis for her concern, while Jessica, Jack and Steven reacted to the perceived permanence of the diagnosis itself.

Summary

Receiving a diagnosis was perceived as confirmation of 'Having an Official Condition'. Some participants found it helpful to have a name for their difficulties and others were able to use their diagnosis positively to make sense of their experiences. The emotional impact of this diagnosis was related to perception of mental health and also the perceived legitimacy of the label. Participants' existing knowledge about their diagnosis and the way it 'fitted' with their experiences was also influential in their response to the diagnostic process. The official nature of diagnosis felt inescapable for some participants and impacted negatively on their beliefs about their future.

3.2 Being the Patient

Being the patient describes the subordinate position participants appeared to feel they were placed in by both the people responsible for their care and by their diagnosis.

In their subordinate status, participants were expected to comply with medication and to accept the power of those in perceived authority. However some participants did forge themselves some elements of control where they felt it was possible.

3.2.1 Subordination.

Some participants had experienced involuntary hospitalisation before coming to the EIP service. This seemed to be experienced as the ultimate loss of power at the direction of someone in authority. Unsurprisingly this was a distressing and confusing period for participants during which they were prescribed medication to manage their symptoms. Participants reported that medication was given without information, explanation or choice. Expected compliance with medication was a recurrent theme throughout the transcripts.

> *Kate: Er, I just, they didn't really explain medications a lot. You had to take it, but you weren't ever told like side effects or what it was for. You were just told to take it so I think it would be more helpful if you were told why you were taking it. What it was for. (180-183)*

> *Jessica: And um, they gave me a pill, they didn't tell me what it was, I think they told my brother though. It was like a white pill. And they went right you have to take this. Um so I just took it you know, I didn't, I should have asked what it was, but I didn't I just took it. (70-74)*

Being expected to take medication without explanation appeared to confirm their subordinate status of being a patient and prevented them from asking questions or refusing the medication. It seemed they perceived that they had no choice but to take the medication, especially if they wanted to be discharged from hospital.

David: I think I started taking the meds. I wasn't very keen to before. And er I

dunno, I just er (.) washing. I didn't have a bath or anything like that when I

was at my parents.

*Interviewer: And did it feel ok to do those things at the ****unit or did you feel*

they were things you had to do.

David: Er, there was quite a lot of pressure I suppose, 'cause they were hot on

those sort of things. And there's like quite a socialisation of medication and it

was partly just to cooperate and partly to be myself you know. Er, eventually I

got, managed to get discharged. But it was horrible. It really was. Just the

desolation and the sort of tormented people you know. (107-118)

David described how he started to comply with his medication and personal hygiene while in hospital as a result of perceived pressure and culture biased towards medication. His use of the words 'horrible', 'desolation' and 'tormented people' does not describe a therapeutic environment for recovery and he was keen to do whatever it took to be discharged, even if that meant cooperating. Discharge was the decision of someone in authority based on his compliant behaviour.

Being the patient appeared to be experienced by some participants as a submissive position with no autonomy to recover by themselves. The doctors were positioned as the people who were dealing with the psychosis using medication.

Jack: Maybe almost like there's too much of a feeling of they're the people who

deal with the psychosis and you're the patient. (1148-1150)

It would appear that being positioned as the patient created dependence on others. It assumes knowledge about psychosis and its management that is only known by doctors, putting them in the position of expert with all the power.

This power relationship between doctor and patient is illustrated further in the next passage from Jessica.

Jessica: Initially they said it's psychosis. That was the first one [diagnosis]. But my doctor's note I've had things like um severe depression written on there. God what was the other one, it was something really weird like transient something psychosis. (591-594)

Jessica: I just don't think I'd have asked. 'Cause I just wanted my note really. I didn't really, 'cause I was a bit worried they wouldn't sign me off again and I was like I still need to be off for a bit. So I just wanted to get the paperwork out of the way and to just get out of there and like send the note off and then know that I have the financial security of having the benefits rather than think, thinking I'm. 'Cause I sort of thought if I ask too many questions then they might start questioning me. You know and they might be like, oh do you really need the note and are you sort of well enough to not have it you know.(640-650)

Jessica's experience raised a number of points regarding the power relationship between her and her doctor. The changing diagnoses on her sick note evidently have not been disclosed or explained to her, emphasising that her diagnosis is the doctor's opinion and he has not collaborated with her about this. She did not understand the changing diagnoses but she felt unable to ask questions. She felt that to ask questions might signal to the doctor that she was well and he may refuse to give her the documentation she needed to obtain benefits. Jessica appeared to presume the doctor

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had power over whether or not she is able to stay off work. It is also appeared that Jessica believed the doctor would decide when she was better, regardless of how she felt herself. This can be understood in terms of subordination and compliance. Other participants referenced the need to comply with authority in order to be discharged from hospital. Within this framework Jessica might perceive asking the doctor questions about her diagnosis as a challenge to his authority for which she might be punished by having her sick note removed. It also confirms the power relationship where the patients feel unable to ask questions of doctors.

3.2.2 Taking Some Control.

Maybe in response to their general experience of subordination, some participants appeared to seek out opportunities for control and autonomy. A good example of this is how Jessica sought control over her medication use. The power differential is evident as she felt unable to challenge the doctor about her prescription and feigned compliance in his presence but made a choice not to take the medication.

> *Jessica: I didn't start taking it. I weren't taking it. I'd only one in front of him when he was like you're going to have to take it now. So I took it then. Um, so I didn't start taking it till after I'd stopped seeing him. (195-198)*

Eventually Jessica's need to control her symptoms overrode her need to be in control over her medication compliance.

> *Jessica: Um it was just like basically being on a really bad trip and in the end I've thought well I've been feeling like this for months, you know and I just wanted it to stop. I thought well perhaps the medication might be a good idea. 'Cause really I decided. Then she [key worker] kept trying encourage me, like*

look you really need to take it 'cause it will make everything stop and in the end

I sort of built a trust with her and thought right I'm going to start taking it.

(217-224)

It appeared important to Jessica that taking the medication was her choice and not an act of compliance. Her choice was influenced by a trusting relationship she had built up with her EIP worker. Jessica speaks of being encouraged to take her medication, which allowed her the opportunity to make the choice for herself, rather than having to comply. Trust appears important so that she felt safe to take the medication. This aspect of autonomy and trust in the health professionals is missing in the 'Subordination' subtheme where the participants felt powerless and compliant against their wishes. It also demonstrates that given the choice, Jessica elected to take her medication. Choice appeared to be important because it gave her some control over her experience and over her psychosis.

John seems to use knowledge to exercise some control over the process of receiving his diagnosis.

John: I bought a book from University and I did some research on the internet.

Interviewer: Do you think that was important for you to be able to do that? To learn about it?

John: Yeah. Yeah. I've been doing that throughout his whole process really, just kind of it was helpful with the last doctor I saw, everything he was saying contradicted against the (mumbles) 'cause there is, I thought it was really important to do that. To argue against what they're saying really. I asked him

the reasons why he thought I had a certain condition and I argued against each

one. And without it I wouldn't have been able to do that. (209-220)

Although this did not change his diagnosis, John felt it was important to challenge the doctor. Being able to make arguments against the diagnosis seemed to help him feel less like a subordinate patient. The fact he bought the book from university rather than any other book shop would seem to suggest that legitimacy of his source of knowledge was important to allow him to position himself against the doctor.

Summary

Participants' experiences of being a patient would appear to be characterised by feelings of powerless subordination, of being compliant with medication regimes and losing their freedom. They were socialised into being subordinate through assumptions within the process, described by one participant as "socialisation of medication" whereby they felt unable to ask questions or disagree with health professionals. Participants appear to exercise control where they could, whether that was choosing to be compliant to be discharged from hospital or taking control over their medication use. Being given information and choice was one way in which the participants seemed able to readdress the power imbalance between health professional and patient.

3.3 Construing identity

The impact of diagnosis on construing identity was experienced in two ways. Participants were aware of popular representations of schizophrenia and psychosis and appeared to feel they were construed as dangerous by others because of their diagnosis. Perhaps in response to these perceptions there was a tendency to construct their experiences as normal to retain their sense of identity separate to their diagnosis.

3.3.1 Being Construed as Dangerous.

Receiving a diagnosis of schizophrenia or psychosis meant that participants were exposed to the risk of being judged by societal perceptions of these conditions. The participants in this research were aware of popular cultural representations of mental health and schizophrenia. Although there are other social constructions associated with schizophrenia and psychosis, several participants spontaneously spoke about media portrayal of people with these diagnoses being dangerous, violent and criminal.

> *Steven: And we talk about it in the papers you only hear the bad press about them, about like schizophrenic maniac stabbed so and so so many times. Or like, my boyfriend did this to me, he was schizophrenic and like, just bad press like. You never really hear like about schizophrenics or anyone with a mental issue doing good. It's always well they had this or they had that. And it's like they should never be allowed out and that was like the main thing that worried me 'cause like that's what people, that's what I think some people like who are not open-minded enough that's all they see like, the bad press about it. (317-330)*

This media discourse of schizophrenia was an emotive topic that Steven had discussed with housemates with the same diagnosis. Although there are a variety of media representations available in books, films and television, Steven focussed on news items possibly because news items are perceived as factual. He acknowledged that society is fearful of people with this diagnosis and believes they should be detained or segregated in some way to keep the population safe. Steven's main concern was that

people may share this cultural perception of schizophrenia and perceive or judge him to be dangerous.

Awareness of this negative perception of psychosis and schizophrenia created a dilemma for some participants around disclosing their diagnosis to others.

Jessica: 'Cause psychosis, they probably think she's going to go berserk one day in the office. Or, you know, come in and stab a load of people. Or, you know, they can kind of be thinking anything. But with depression they might think, you just get a bit sad, you know, have a bit of a cry now and again. (475-480)

Jessica expressed reluctance to share her diagnosis of psychosis with future colleagues and indicated that she was *"more inclined to say depression rather than psychosis" (471-472).* Jessica had successfully shared her diagnosis with friends and family but feared being judged by future colleagues who may not know her well enough to distinguish between media portrayal of psychosis and the real Jessica. Despite these fears that others might find them dangerous, there was no evidence that Jessica or Steven accepted this representation to be accurate, either about people with these diagnoses or about themselves. However, this non-acceptance was not the case for all participants as will be discussed later.

In addition to the negative media representation, sharing the diagnosis also resulted in misunderstanding. The diagnosis of psychosis was misunderstood by one participant's partner. Rather than reacting to media stereotypes of the diagnosis of psychosis, the word was misunderstood to mean psychopath.

Steven: Like my girlfriend, she heard it and she was like you're a psycho, I always knew you was a psycho. And then it's like well hold on a minute its psychosis that's completely different to psycho. I know it's got, it's got the same kind of letters in the name and that but that's where, that's like where it stops. (239-244)

This misunderstanding of the diagnosis of psychosis to mean psychopath further complicated the experience for participants disclosing a diagnosis and indicated poor awareness in society of the difference between psychosis and psychopath. A diagnosis of psychosis may leave service users open to be perceived as a dangerous psychopath. In Steven's case this misperception of him as being dangerous was influential in the breakdown of his relationship.

Further evidence of the negative construing of psychosis is experienced in the way service users may be treated by those in authority.

Jack: I think like I got, yeah I think I struggled or something, er I think, I don't know. Maybe I can't even remember what happened, but they [police] sprayed pepper spray in my eyes. Which er, I'm sure I didn't do anything that bad to get um. I think they were just treating me as a dangerous person, 'cause they just treated me like, ok this guy's psychotic he's dangerous.

Jack attributes his experience of being physically subdued by police purely to his diagnosis of psychosis rather than his conduct at the time. He doesn't question the actions of the police but rather accepts that this is the way they treat dangerous people and they perceived him as being dangerous because he was psychotic.

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Jack's experience with the police appeared to be influential in his struggle to make sense of his diagnosis within a framework of popular culture and previously held assumptions about mental health and crime. This led him to wonder if this social construction of psychosis and schizophrenia was accurate and resulted in him questioning whether he might actually be dangerous because of his diagnosis.

Jack: I think there is a slight fear behind it that, maybe, what if something happened when I was psychotic and 'cause you start to see that sometimes a lot of criminal acts they might have been psychotic at the time and then, there's a little bit of fear due to that I think. The idea that you're out of control and you could do something that you didn't. I hope to think that my basic nature wouldn't ever do anything. (950-956)

Jack's ideas about being out of control during a psychotic episode merged with his awareness of societal and media ideas about the criminally insane to produce a fear that he may not act in accordance with his values, that he may have the capacity while psychotic to do something bad. However, he balances this construing against his perception of his "basic nature" that would protect him from acting out.

3.3.2 Making me normal.

Participants appeared to reconcile their diagnosis and media representations described earlier with their sense of identity by making their diagnosis and experience appear normal. This idea was prevalent in many interview transcripts and a sense of normality was achieved in a variety of ways.

One way participants made psychosis and schizophrenia more acceptable and normal was to acknowledge it could happen to anybody.

> *John: So just having that experience yourself and knowing that actually this*
> *could happen to anyone, it's really helpful. (424-426)*

Or that it might be common.

> *Jenny: I've asked whether it was common to have it at my age and they said that*
> *it is. It's like in your twenties you get Schizophrenia. (274-276)*

> *Jessica: Um, I felt a bit better, sort of knowing that, like it was kind of, that it*
> *wasn't really too far, too weird, you know. And that it's quite common. (182-*
> *1884)*

Information received from the EIP service reassured participants that anyone can receive a diagnosis of psychosis or schizophrenia which made it feel like a more normal experience. It appeared to give participants a sense that there was there was nothing abnormal in receiving these diagnoses, or abnormal about them for having these experiences. Similarly, the ideas that these diagnoses are common at a particular age offered some reassurance. These reassurances seemed important to enable participants to retain their sense of identity and make their diagnosis more acceptable to them.

Some participants made sense of their experiences as being normal by minimising the importance and impact of their diagnosis. Jack and John appear to provide evidence of construing their diagnosis in a way that would minimise its impact on them.

> *Jack: Like a psychiatrist will see things as conditions and stuff and they were*
> *thinking of diagnosing me with schizophrenia but. 99% of the time I'm just*
> *normal, not schizophrenic. (213-216)*

John: So, where I've got [mumbles] and I know that it's mild, it's not even

concrete whether it's there or not. (344-346)

Jack minimised his potential diagnosis of schizophrenia by allocating it a

percentage, that he is normal 99% of the time, therefore schizophrenia is a very small

condition or problem. He also reduced the importance of the diagnosis by describing

the way psychiatrists like to view things as conditions, rather than reify the diagnosis.

Johns use of words like "slight" and "mild" seem to reduce the importance of his

diagnosis, and he even questioned whether he had it or not. The overall impression was

that this construing came from the participants rather than the psychiatrist. Jack and

John may have used this way of talking about their diagnosis to reassure the interviewer

that their diagnosis is minimal, and/or to reduce cognitive dissonance around the threat

their diagnosis poses to their sense of identity.

In addition to making the diagnosis normal, or minimal, participants found other

ways to makes sense of their experience. Jack seemed to find it useful to reconcile his

sense of identity by separating from his diagnosis to construe schizophrenia as a

tendency.

Jack: Like you could say you have schizophrenic tendencies. Like and then it

would be like yeah. Like ok I got schizophrenic tendency. 'Cause obviously if

you say that schizophrenic is the same word as psychosis, you've obviously had

psychosis so you can go, psychosis, schizophrenia. Erm, yeah 'cause the

tendency part means that you can feel ok 99, well not schizophrenic 99% of the

time. And then you have a tendency 1% of the time. Not even 1%, but a tendency

to, for that to happen. (732-740)

A schizophrenic tendency seemed more acceptable to Jack as it is a more fluid, abstract idea that he may have some increased risk of having a psychotic episode. This appeared less threatening to his sense of identity and allowed his psychotic episodes to exist or even reoccur without having to take on a schizophrenic identity. This statement also tells us something about Jack's perception of a hierarchy of diagnoses where psychosis was acceptable to him but schizophrenia is not. Apparently to reduce this threat he claimed that schizophrenia and psychosis were the same.

Favourable comparison against others with the same diagnosis was another way some participants seemed to reduce the impact of the diagnosis on their sense of identity.

Jack: 'Cause I did come round very quickly and they were very surprised at how, well they seemed surprised at how well I'd sort of came back to normal. And was very balanced quite quickly. 'Cause for some people I don't think it goes that quickly. (355-359)

It seemed Jack appraised his recovery as being faster than someone else experiencing psychosis, such a fast recovery that people were surprised. This would appear to be proof that he was different to 'others' with psychosis and not as severely affected by it. This seems to have the benefit of making Jack special in some way, that he doesn't fit the diagnostic criteria that other people with this diagnosis do and so he is able to maintain his sense of identity.

Interestingly, following his diagnosis of schizophrenia Steven compared himself against people with psychosis.

Steven: And then like you get some people who are like just got like normal psychosis and they're like just, just going like off it. And erm, they're coming to the end of like being with the early intervention team. And they're like well, I'm only on like 2mg of this, what you on ((laughs)) and you tell them your medication and they're like cor. (405-411)

Steven confirms the diagnostic hierarchy where schizophrenia is perceived as more serious than psychosis. It appeared that receiving a diagnosis of schizophrenia moved his parameters of normal to include 'normal psychosis', perhaps to diminish the severity of schizophrenia. Steven seemed to be proud of his diagnosis of schizophrenia and medication status compared to those with "normal psychosis", almost like a badge of honour to impress them with. It seems that, possibly as a result of cognitive dissonance, Steven has rejected the idea of being normal and instead had created an identity more in line with his ideas about schizophrenia. This is directly opposed to the efforts of other participants to be seen as normal.

Summary

In summary, participants were aware of cultural and media perceptions of schizophrenia and psychosis and as a result some participants experienced being construed as dangerous because of their diagnosis. In response to this, many participants made efforts to normalise their diagnosis through believing it was common, by minimising the impact or by comparing themselves favourably against others with the same diagnosis. This allowed them to retain a positive sense of identity against the backdrop of stark and condemning cultural discourses regarding their diagnosis.

4. Discussion

There is a paucity of research about service users' experiences of receiving information about FEP. This research aimed to answer the research question 'What are service user experiences of receiving information about their psychotic experience?' Interpretative Phenomenological Analysis of seven interview transcripts resulted in three super-ordinate themes: 'Having an Official Condition', 'Being the Patient' and 'Construing Identity'. These themes are discussed with regard to the current literature and the research question. Clinical and research implications of these findings are considered.

4.1 Having an official condition

When asked about information received from the EIP service, most participants spoke about receiving a diagnosis. That is not to suggest that they did not receive other information, but rather that their diagnosis was the most salient aspect of their experience. The focus on diagnosis is surprising given the importance of diagnostic uncertainty and deferred diagnosis in EIP services (DOH 2001; IRIS). All the participants had been given a diagnosis at the time of the interview but there was variability within the sample around diagnosis provision and some participants had received a diagnosis prior to entering the EIP service.

The theme 'Having an Official Condition' is original to this research and indicates the official and formal way that the diagnostic process was experienced. Some participants felt that diagnosis was helpful as it confirmed and named their difficulties, which concurs with previous research (Delmas et al., 2011; Pitt et al., 2009; Young et al., 2008). This study and previous research also describe how initial relief was offset by distress about the mental health aspect of the diagnosis (Mauritz & van Meijel,

2009; Pitt et al., 2009). Accounts in this research support criticism of the diagnostic process which suggests that diagnosis is presented as a fact rather than one interpretation of service user experiences (Pilgrim, 2007).

The perception of diagnosis as a factual and permanent 'Official Condition' meant that some felt that their diagnosis would be detrimental to their future which has been reported in previous research (Gallagher et al., 2010; Wittman & Keshaven, 2007). One participant spoke about a loss of confidence in her future ability to manage stressful situations at work following information about the reason for her diagnosis.

Participants appeared to make sense of their diagnosis through a process of 'Diagnostic Fit' using their existing knowledge or ideas about their experiences. Information provided by the EIP service was important to support one participant to relinquish the self blame adopted as a result of this diagnostic fit.

Information from the EIP service was also important to prepare participants to receive a diagnosis. This study provides new information about how information presented gradually supported participants to slowly come to understand without feeling overwhelmed. This approach was reported in preparation for a second diagnosis and may indicate the difficulty of preparing service users for an initial diagnosis when it is given early, possibly in order to satisfy obligations to cluster service users. This offers more support for use of diagnostic uncertainty not only until symptoms have become stable but also until the service user has been sufficiently prepared to receive a diagnosis.

Some participants felt that information provided by the EIP service was biased towards a dominant diagnosis of psychosis or schizophrenia and felt their other concerns were invalidated by being referred back to this diagnosis as an explanation for

their experiences. This indicates that focus on a diagnostic framework may not allow service users' concerns to be heard. The focus on diagnosis in this theme is contrary to, and offers support for, the principles of EIP services which advocate diagnostic uncertainty, deferred diagnosis and symptom specific interventions (IRIS).

4.2 *Being the patient*

'Being the patient' described the power relationship between the participants in this research and health professionals. Previous research has also reported the disempowerment of service users created by health professionals' ability to diagnose and treat service users which can promote dependency (Harrison & Gill, 2010; Henderson, 2003; Hickey & Kipping, 1998).

Participants felt subordinate and expected to comply with medication without explanation or information. Lack of information has been found to be disempowering for service users in other research (Pitt et al., 2009). In the current research this lack of information was experienced as having no choice. Hickey and Kipping (1998) reported that health professionals expect service user compliance as they believe they know what is best for service users. This idea supports the experience of 'socialisation of medication' and also may explain why participants in this research made assumptions about being unable to question their treatment or ask for information.

Participants' interpretations suggested that diagnosis was experienced as a one-way process and did not feel collaborative. Participants felt unable to ask questions about their diagnosis, medication, or to challenge the psychiatrist. Knowledge has been found to be a currency of power in this study and previous research where withholding information from service users placed health professionals in a position of powerful expert (Horn, Johnstone & Brooke, 2007). Having information and knowledge has been

found to be a source of power for service users (Horn et al., 2007) and empowered a participant in this research to challenge his diagnosis.

Engagement with service users in EIP services is prioritised (Lester et al., 2009) and this research found that information provided as part of a trusting relationship with EIP Service professionals was important for one participant to feel able to make a choice to take her medication. Being allowed to make a choice readdressed the power dynamic for this participant and restored some sense of control and autonomy.

4.3 Construing Identity

The Impact of diagnosis on identity has been cited in previous research (Haghighat, 2008; Wittman & Keshaven, 2007). The current study emphasises the influence of participants' awareness of popular social representations of psychosis and schizophrenia on the impact of diagnosis. Participants felt they were construed as dangerous by others because of their diagnosis which is original to this research.

This perception is supported by research into attitudes towards mental health by the Royal College of Psychiatrists who found that people associated schizophrenia with being a danger to others (Crisp, Gelder, Goddard & Meltzer, 2005). Negative attitudes were most prevalent in the age group 16-19, and 20-24 years (Crisp et al., 2005), which match the ages of the participants in this research and may influence their perception of this construing. Other research has indicated that service users may struggle with their own prejudices about their diagnosis (Knight et al., 2003).

As a result of societal construing of people with schizophrenia as dangerous, participants' experienced a dilemma about sharing their diagnosis with others. One participant considered lying about her diagnosis to future colleagues, a view echoed in

research by Schulze, Matthias and Angermeyer (2003). Participants in several other studies also worried about disclosing their diagnosis and said they would censor the information they shared for fear of stigma (Delmas et al., 2011; Gallagher et al., 2010; Pitt et al., 2009).

Despite feeling construed as dangerous by others most participants did not accept this idea themselves but one participant did question whether he could be dangerous because of media links between criminality and his diagnosis.

Perhaps by way of a challenge to the societal construing of their diagnosis, participants in the current research appeared to normalise their diagnosis and experiences as described in the theme 'Making me normal'. Some participants reduced the impact of their diagnosis by minimising it or construing it to be mild. Information from the EIP Service was important for participants in making their diagnosis feel normal by emphasising the frequency of these diagnoses in the general community, or that it could happen to anyone. This minimisation of diagnostic importance by the participants is original to this research and has not been found in other studies.

Schizophrenia has been described as an "*I am illness that may overtake and redefine the identity of the person*" (Estroff, 1989, p.189). Estroff also suggested that there is an aspect of the self that exists over time and is more than the diagnosis or illness. Participants' attempts at normalising in this research appeared to be related to retaining this sense of identity.

Cognitive dissonance (Festinger, 1957 cited in Colman, 2001) or psychological discomfort which occurs when two beliefs are opposing, appeared to be apparent in this study, for example, the belief that 'I am normal' is opposed to beliefs about the diagnosis 'Psychosis/Schizophrenia'. By making the diagnosis feel more 'normal' the

psychological discomfort is reduced. Alternatively and/or additionally, participants may have been trying to reassure the researcher that their diagnosis was minimal or normal. Normalising has been suggested as part of Cognitive Behavioural Therapy (CBT) for service users with schizophrenia to assert a continuum of experience rather than normal versus abnormal experiences (Warman & Beck, 2003). This fits with current guidance from the National Institute for Health and Clinical Excellence (NICE, 2009) on the treatment of schizophrenia.

4.4   Clinical Implications

Findings from this research identify some areas around information provision to consider when supporting service users experiencing a first episode of psychosis.

i.   Providing accessible information.

This study and previous research has found that participants appreciated being provided with information over time before a diagnosis which mediated the emotional impact. This has been found to be empowering for service users and addresses some of the perceived power imbalance. Services could consider providing participants with accessible information, about their medication for example, repeatedly and to check their understanding.

ii.   Consider timing and presentation of diagnosis.

Both this study and previous research would suggest that delaying diagnosis until a trusting therapeutic relationship is established would be helpful. This might counter some of the subordination participants in this research perceived. Delaying diagnosis would also allow more time for information to be provided and understood. Services may wish to consider to what extent diagnosis should be given

with a level of certainty and how to include other explanations for service users'

experiences such as psychological formulation.

iii.   Challenge negative societal constructions of diagnosis.

Participants in this research felt they were construed as dangerous as a result of

their diagnosis. Information from the EIP service about the frequency of these

diagnoses was important in helping service users to feel normal and to retain their sense

of identity separate to their diagnosis. Information could also be provided more broadly

within the media and local institutions such as further education organisations, to

challenge negative societal and cultural discourses at a broader level.

4.5 Methodological Critique

The sample size of seven participants is within guidelines for an IPA study, and

the participants were well mixed in terms of their sex, diagnosis and length of time

in service. However, due to recruitment difficulties all of the participants were

recruited from the same EIP service, rather than three services as planned,

providing the possibility that service users in other services have different

experiences.

All participants in this research were white British which is another limitation of

the findings. Other ethnic groups might have different experiences and

interpretations which are not represented here.

The rationale behind interviewing service users who had been in the EIP service

between six and 24 months was to access experiences that were fairly recent. That

the participants were recruited via a service that they were still receiving support

from, and were interviewed by a trainee clinical psychologist, might have limited

the information they felt able to share. To mitigate this, participants were assured of confidentiality and anonymity.

The approach to recruitment via team members meant that the participants in this research were all engaged with the EIP service and possibly would provide positive accounts of their experience. Future research might benefit from finding a more independent route to recruitment, such as service user groups which might facilitate access to individuals who have disengaged from EIP service, although, this could generate its own difficulties in terms of homogeneity and participant safety.

IPA was an appropriate methodology for this research which was focussed on service users' experiences and generated some strong themes to explain the experience of receiving information or a diagnosis within an EIP service. The use of only one analyst is a potential weakness; to counter this, supervision was utilised during the analysis procedure to aid reflection and strengthens the analysis process.

4.6 Research Implications

There were several original topics uncovered in this research that warrant further investigation. More research is needed to understand how the perception of factual presentation of diagnosis affects the impact on service users compared to alternative explanations such as formulation. The relationship between service users' awareness of societal representations of their diagnosis and the impact on their identity was also original and could be further explored. Finally, further research could explore the way participants minimised the importance of their diagnosis and the possible role played by cognitive dissonance around this.

Future research would benefit from recruiting from several services to explore the experiences of service users receiving different approaches. It would also be prudent to explore the experiences of service users who have disengaged from the service following diagnosis. The experiences of ethnic groups other that white British also need to explored and represented.

4.7. Conclusion

This research found that diagnosis was perceived as the most salient form of information received by the participants. This was experienced as an official and formal process which participants felt unable to challenge or question. Unequal power relationships between health professionals and participants were found to be particularly linked with the provision of information and perception of choice. Interpretations of information and impact of diagnosis were complicated by participants' existing ideas and societal representations of the diagnosis.

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Critical Appraisal

Critical Appraisal

1. Overview

In this section I will outline my research journey. This will cover how I chose this particular project, the difficulties I faced with recruitment and the challenges of analysis and writing up my research. I will also consider the strengths and limitations of my research and suggest areas to consider for future research.

2. Selecting a Project

I completed my undergraduate dissertation on the experience of anaesthetic awareness and had an interest in conducting further research in this area. My undergraduate research had used Interpretative Phenomenological Analysis, which was a methodology that I felt fitted well with me conceptually and my interest in experiential research. When selecting a project for my doctoral thesis I was faced with choosing between quantitative research in anaesthetic awareness or to choose a qualitative project with a methodology that was congruent with my style in an area that was less familiar to me.

An opportunity was presented to conduct qualitative research with service users in an Early Intervention in Psychosis (EIP) service. This is an area of psychology that I knew little about as I had no experience of working with this client group or EIP services. However, it is an area that I find personally fascinating and I was keen to learn about service users' perceptions and experiences of receiving care from an EIP service. I hoped that being involved in this research would be an opportunity to meet and learn about service users with experiences of psychosis and to gain a better understanding of

EIP services. It was also an opportunity to explore the process of receiving a mental health diagnosis.

3. Research Design

Although the idea for this project was suggested by my supervisor, designing the research was a collaborative process. We already had a client group in mind but we needed to identify a specific research question. I completed searches of the relevant literature and read around the subject area to build up an understanding of current research and the political context which were then discussed in supervision. A gap was found in the literature to explore service users' experiences of receiving a diagnosis of psychosis or schizophrenia. In the spirit of diagnostic uncertainty we extended this to include information about a First Episode of Psychosis (FEP) which may include a diagnosis. IPA was selected as an appropriate methodology as we were interested in how service users made sense of their experiences. This is also a methodology that I had used before and felt confident in using for this research.

4. Recruitment

4.1 Process

I gained ethical approval from Nottingham Research Ethics Committee (REC) to conduct research in three EIP services across the Midlands (Appendix E). This included obtaining approval from three separate Research and Development (R&D) Departments as the services were in different NHS trusts. Following approval I presented my research proposal at five team meetings across the three trusts in order to generate recruitment of participants. My protocol outlined that team members would identify service users that matched the inclusion criteria for the research and make the

first approach on my behalf. They were supplied with participant information sheets to hand out to interested service users and to request their permission for me to make contact with them.

4.2 Difficulties

I kept in regular contact with all three teams but recruitment was difficult. In October 2011 my supervisor and I discussed the difficulty with recruitment and decided to offer to interview participants in their own homes, if that was where the early intervention team visited them, as it was proving difficult to source convenient NHS locations to meet. We also agreed to increase the maximum inclusion criteria of 18 months to accommodate service users that had been with a service for up to two years. Two R&D departments approved the amendments immediately but the third R&D department requested that I seek permission from the REC for these amendments. As a result I was required to submit an ethics form and amended protocol to the REC and received approval for the amendments in December 2011 (Appendix E).

Recruitment was further hampered when my contact in one EIP service left the service for a new post. This left me to identify and forge relationships with a new contact, who was starting a new role and was less able to commit time to the project.

I sought feedback from the two services about the difficulties in identifying and recruiting suitable participants for the research. One of my contacts was new to the service and cited this as a difficulty as her case load did not yet meet my criteria of a minimum of six months in the service. She also disclosed that my project clashed with another piece of research recruiting from the same service and she felt that team members were confused by this. The largest factor was that the service was overstretched, team members had large case loads and service users who met my

criteria of being stable for three months were often not seen regularly unless there was a crisis, in which case they no longer met my criteria. I received similar feedback from the other service that was unable to recruit to my research, that staff shortages had pushed my research down the list of priorities for the team. I found this all very frustrating as I had invested a considerable amount of time and effort gaining R&D approval for all three sites and had travelled extensively across the Midlands to present my research to the teams prior to recruitment. Waiting for participants to be identified from the other two services also delayed my data collection resulting in an extension to my hand in deadline.

In the end all of my participants were sourced through one EIP service which suggests the possibility that their experiences will be similar. However, each participant had contact with different psychiatrists and team members, which creates some variability in the information and approach they experienced. I will consider this further in my critique.

5. Interviews

I enjoyed interviewing the participants and felt humbled by their experiences and their honest bravery in recounting them to me as a complete stranger.

Having conducted interviews for my undergraduate research and a recent service evaluation I felt confident about interviewing participants for this research. However, in practice I found it difficult to bracket off my clinical skills and just actively listen and encourage participants to talk. I found myself thinking therapeutically during the interaction in my early interviews rather than focussing on exploring the participant's experience. I used supervision to reflect on this.

I found the second interview particularly difficult. The participant answered all of my questions but she gave no details and I felt concerned about upsetting her. This resulted in a short interview that was lacking in richness. I reflected that this could be understood as transference of the participant's fears of becoming ill again if she became upset. I used supervision to think about this and received support and advice from my supervisor for future interviews.

A further problem was encountered during a particularly emotive interview where the participant became upset recounting her experience. The Dictaphone stopped working but this was not noticed until the interview was over. I was faced with an ethical dilemma, as the participant had shared her story I felt an ethical duty to represent her experience in my research, however, that would mean re-interviewing her, which I believed would cause her distress again. My decision was to use the section of the interview that had been recorded and not to ask her to repeat the interview. This was disappointing as she shared some valuable experiences which would have added to the richness of my dataset. Upon reflection an alternative would have been to offer her the choice whether or not to be re-interviewed.

One participant asked me for information about schizophrenia during the interview. I felt uncomfortable that I could not answer her questions and instead referred her to her key worker at the EIP service. I also requested her permission to let the team know that she wanted to talk to someone about her diagnosis. Upon reflection, although I found it frustrating not being unable to answer her question at the time, referring her to the team was the appropriate course of action. I was present as a researcher and in maintaining my boundaries I was also able to maintain my position as an interested party rather than an expert.

Overall, my interviewing skills improved with each interview and I was pleased with the information that was elicited during my contacts with participants.

I was conscious of reflexivity during the interviews. Although I stated clearly at the outset that I was not affiliated with the EIP service I perceived an eagerness to please me from some participants. There was lots of positive information about the EIP service and particularly about the Psychologist on the team. I wondered if my declared position as a Trainee Clinical Psychologist had influenced this representation, or if it was a spontaneous and genuine report. Further influence of my position as a Trainee Clinical Psychologist was uncovered when a participant reflected that talking to me had been like talking to the Psychologist in the EIP service. It was good to know that he felt he had benefitted from the opportunity to reflect on his experience but I also wondered how this perception had shaped his interview and how it might be different if I had been a Nurse, or a Psychiatrist.

6. Transcribing

I decided to do all the transcribing for this research myself. This is a lengthy and arduous task but was made manageable by the protracted data collection period. Interviews were conducted weeks apart from one another and I transcribed the interviews within days of recording. My decision to transcribe all of the interviews was in part to help me become immersed in the data. It has been suggested that transcription is itself an interpretative activity (Smith, Flowers & Larkin, 2009) and during transcription I would notice details of the interview that I hadn't been conscious of during the meeting.

7. Analysis

Having previous experience of IPA I was looking forward to the analysis experience. I found the analysis in this project at times very rewarding and overwhelming at other times. My previous research had utilised a case study approach with two participants. Analysing the seven lengthy interview transcripts in this study was a very different experience. I followed guidance by Smith, Flowers and Larkin (2009) to start with the most engaging transcript, which was also the longest transcript at that time. I analysed each transcript individually, bracketing ideas from previous transcripts rather than looking for evidence of themes to support them.

Once all the transcripts had been individually explored, I looked for shared themes across interviews. To do this I printed out the themes, with illustrative quotes, for each transcript and lay them all out over the floor. This is a method I have employed successfully before in IPA and Thematic Analysis. However, there were such a large number of themes and supporting data that I felt a little overwhelmed by it and the resulting anxiety distracted me from the task in hand. Eventually I was able to look for shared themes by reflecting on my previous notes about the interviews and looking for evidence I had previously noticed across the studies. I then took the remaining themes and was able to find shared themes. Some themes were dropped, which I found a difficult but necessary decision to make as I could not be all-inclusive.

In the end I was satisfied that the themes identified described the participants' experiences with regard to the research question.

8. Write up

Initially I wrote up all of the themes and subthemes that I had found in the analysis. However, it quickly became apparent that I could not write about each one in sufficient detail to adequately represent the theme within the word count for my thesis. Therefore I decided to focus on those themes that were most directly related to the research questions. This resulted in some themes being amalgamated into others, and yet more were dropped. I found it difficult to abandon themes, particularly when I had found them personally interesting. There was a desire to accurately reflect the experience of the participants and I was worried that some of their experience would be lost.

A first draft was completed and shown to my supervisor. Following feedback I realised that I had been too top-down and had imposed my ideas onto my analysis and selected quotes to support this, rather than allowing the data to tell the story.

I started the analysis write up again from the beginning. This time I allowed the story to be built from the data, which felt more natural and rewarding. The themes became more grounded and representative of the participants experience.

9. Bracketing

Bracketing is the process used by researchers in the identification and suspending of factors that could influence both the collection and analysis of data in qualitative research such as previous experience, interests and assumptions (Fischer, 2009). The goal of bracketing is to be aware of these influences and to check for their influence in the research.

During the research process I took part in bracketing interviews with my supervisor. This allocated time allowed me an opportunity to reflect on my experiences and to explore my thoughts and ideas about my research journey. I found this very helpful to help me identify and consider my stereotyped ideas of a service user with psychosis. I was struck at how eloquent, reflective and intelligent my participants had been and reflected how this did not match with my prior expectations of this group. I reflected that I may have been perceived as patronising in the early stages of my first interview and how this had the potential to affect the way the participant related to me and subsequently influence the interview content. Reading the transcript of the interview I feel I modified my approach sufficiently during the interview to avoid any negative effects.

This was a learning opportunity for me to consider how I had prejudged participants by their diagnosis and cultural discourses related to this. It was also important to consider that this had happened despite my best intentions to be open-minded. Reflecting on this allowed me to understand how these service users are judged in this way by others, some of whom may not have the best intention of being open-minded. I also reflected on how this experience might be reflected in their accounts, most notably in the theme 'Being Construed as Dangerous'.

10. Critique and limitations of research

Initially this project planned to recruit service user participants from three EIP services across the Midlands. However, due to issues with recruitment described earlier, all of the participants were recruited from the same EIP service. This was limiting in the extent that it was an exploration of the experiences of service users receiving a diagnosis or information in one service, rather than across several services.

Each service may have individual policies and procedures for disclosing a diagnosis or providing information which may influence the experience of the service user. It was hoped that differing experience would add richness to the data and facilitate some discussion about different approaches across sites. Unfortunately it was not possible to explore this in this project. Despite this, a strength of this study is that each participant had been supported by different team members and there was evidence within the interview transcripts that participants experienced different approaches from individual team members involved in their care. This created a variety of experiences and provides richness and complexity to the dataset. Further, IPA is not concerned with identifying a truth or reality that can be generalised across a population but rather to access participants' thoughts and cognitions about their experience through their account obtained during interview, which was successfully achieved in this project.

It could be argued that there was the opportunity for a sample bias in this research. All participants that took part in interviews were those service users who were able to engage with the research process, which excluded service users who might have difficulty with this process. Also, requesting team members to select and approach appropriate service users also presents a risk of bias in the sample if they only approach those service users who they believed would provide a positive response about their involvement in the EIP service. However, participants provided a range of positive and negative views about their experiences so it hoped that this concern is unfounded.

The sample consisted of white British service users, so experiences of service users from other ethnic groups are not represented in this study. This may have been influenced by the need for participants in this research to speak fluent English. This is certainly an area for future research.

There is a criticism to be made about recruiting service users that are still engaged with the EIP service and that the experiences of service users who disengage from services following diagnosis might be different to those views represented in this research. It may prove difficult to access this population via the service they have disengaged from, but this may be a consideration for future research.

The methodology for this research was appropriate as the goal of IPA is to explore how participants make sense of or interpret their experiences, which fits with the research aims of exploring how service users make sense of diagnosis or information about psychosis. Semi-structured interviews were also a suitable technique and successfully collected rich data for analysis. One potential weakness in the methodology was the use of only one analyst. To overcome this, supervision was used to explore the analysis and feedback from my supervisor was used to inform further analysis following my first draft, which strengthened the analysis process.

In conclusion, although there were difficulties with the sample as discussed, this research produced rich detailed accounts of service users' experiences of receiving information including diagnosis from EIP services.

11. Quality Appraisal and Publication

As described in the method section of the research project, a strength of this research is that I adhered to quality criteria for qualitative research proposed by Lucy Yardley (2000). It was important to me to produce a piece of work that was credible, and part of this was to ensure it met minimum quality guidelines.

I also intend to publish a paper on this research and therefore this stringent quality control will strengthen my paper for acceptance by a journal. As service users

had given me their time and generously shared their story with me I felt it was important to publish their experiences for the benefit of professionals working with this service user group and for other service users with similar experiences.

In addition to publishing my study for a wider audience, I will meet with the EIP services who were involved in this research to feedback my findings. An accessible summary will be created for distribution among the service users who participated.

12. Future research

Several original topics emerged during analysis of the interview transcripts which could be explored in future research. Participants perceived diagnosis as an 'Official Condition' and factual. This presentation of diagnosis has been criticised elsewhere (Pilgrim, 1997). More research is needed to explore and understand how this interpretation of diagnosis impacts on service users compared to alternative explanations of their experiences such as formulation.

Participants in this research described being construed as dangerous because of societal representations of their diagnosis. This awareness had an impact on their identity and the need to retain a sense of normalcy in response to this construing. One participant had internalised this construing and feared he may become dangerous despite the absence of any evidence. This relationship between awareness of societal representations and impact on identity require further investigation. A related area for further research is to explore the possible role played by cognitive dissonance in participants' minimisation of the importance of their diagnosis.

Future research would benefit from being successfully carried out across different services to explore the experiences of service users receiving different approaches as

originally planned in this research. This would allow diversity in protocol around information provision and diagnosis between services to be explored and service user experience of that diversity to be evaluated.

Service users that have disengaged from the service following diagnosis are also an important population to address. Exploration of their experiences and their reasons for disengagement may be helpful to assist service to support service users in the future, particularly as engagement is so important in EIP services.

The participants in this research were all White British. It is important to consider the experiences of different ethnic groups receiving support in EIP services which also need to explored and represented.

13. Conclusion

To conclude, I have found the research process rewarding, interesting and personally enriching, and at times exhausting, overwhelming and frustrating. Having pursued approval from three R&D departments I would very much have liked more time to be able to recruit service users from all three services. However, there had to be boundaries on the time allocated to achieve my degree. Also, I think that even with extra time, recruitment would still be problematic for reasons beyond my control and influence as discussed. I am pleased that the end product represents the views and experiences of the service users accessing support from an EIP service that I interviewed and hope that this will inform practice and further improve experience for future service users.

References

Fischer, C. T. (2009). Bracketing in qualitative research: Conceptual and practical
   matters. *Psychotherapy Research, 19*, 583-590.

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological
   Analysis: Theory, Method and Research.* London: Sage.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health,
15,* 215-228.

Appendix A

Critical Appraisal Skills Programme Screening Table

Critical Appraisal Skills Programme Screening table.

Paper	Pitt, L., Kilbride, M., Welford, M., Northard, S & Morrison, A. (2009). *Impact of a diagnosis of psychosis: A user led qualitative study.*	Horn, N., Johnstone, L., & Brooke, S. (2007). *Some service user perspectives on the diagnosis of Borderline Personality Disorder.*	Hayne, Y. (2003). *Experiencing psychiatric diagnosis: Client perspectives on being named mentally ill.*	Delmas, K., Proudfoot, J., Parker, G & Maniscacasagar, V. (2011). *Recoding past experiences. A qualitative study of how patients and family members adjust to the diagnosis of bipolar disorder.*
Clear statement of aims?	Yes	Yes	Yes	Yes
Appropriate methodology?	Yes	Yes	Yes	Yes
Appropriate research design?	Yes. Service users led the study and decided on the topics for the interview. Questions reflected the aim of the study.	Yes. Semi structured interview allowed participants to talk about the topic in their own way.	Yes. Good information about why the methodology was selected.	Yes, semi structured interviews and thematic analysis
Appropriate recruitment strategy?	Yes. Convenience sample drawn from mental health groups was used.	Yes. Good description of recruitment. Diagnosis of BPD and contact with mental health services.	Limited information about sample demographics other than they had a mental health diagnosis and understanding of it.	Unclear, purposive sample recruited through institutions related to mental health.
Appropriate data collection?	Yes. Semi structured interviews conducted by service users.	Yes. Semi structured interview	Yes. Semi structured interviews plus researcher reflections.	Yes, Semi Structured interviews.
Relationship between researcher and participants considered?	Some consideration of the researcher's involvement in the analysis and so agreement was sought with others.	Relationship between researcher and research process explored.	Yes, this is stated from the outset and the potential for bias was discussed within the research team	Not reported
Ethical considerations?	Not reported	Not reported	Yes, state clearance given	Not reported
Rigorous data analysis?	2 service users initially coded the data using IPA. Team and service users agreed themes.	Use of external moderator on analysis and then consultation with 3 participants	Good description of analysis procedure	Use of second author to check the themes and discuss areas of disagreement.
Clear statement of findings?	Themes are identified and explored and conclusions drawn from the findings in relation to experiencing a mental health diagnosis.	Findings presented clearly and in good detail.	Four themes are described in detail with interpretations to support them.	Themes are laid out clearly but little supporting data from transcripts to evidence or illustrate themes.
Value of research	Little research in this area, also service user led and of interest to service users.	Provides a good insight into the experiences of the participants.	Implications for practice are discussed.	Helps to understand how diagnosis is experienced and what might facilitate acceptance
Include in review	Yes	Yes	yes	Yes

Paper	Derksen, E., Dassen, M., Gillisen, F., Rikkert, M. & Scheltens, P. (2006) *Impact of diagnostic disclosure in dementia on patients and carers. Qualitative case series analysis.*	Young, S., Bramham, J., Gray, K & Rose, E. (2008) *The experience of receiving a diagnosis and treatment of ADHD in adulthood. A qualitative study of clinically referred patients using interpretative phenomenological analysis.*	Gallagher, A., Arber, A., Chaplin, R. & Quirk, A. (2010) *Service users' experience of receiving bad news about their mental health.*	Rose, D., & Thornicroft, G. (2010). *Service user perspectives on the impact of a mental illness diagnosis.*
Clear statement of aims?	Yes	Yes	Yes	Yes
Appropriate methodology?	Yes	Yes	Yes	Yes
Appropriate research design	Yes, topics for interview agreed with 4 experts in dementia and research.	Good discussion about choice of IPA and interview techniques.	Yes, semi structured interviews. Pilot interviews used to choose questions	Unclear design.
Appropriate recruitment strategy?	Purposive sampling of patients and partners from a memory clinic, all diagnosed with dementia.	First 8 people to respond to invitation. Recruited from ADHD service.	Yes. 10 service users	No information about sample.
Appropriate data collection?	Semi Structured Interviews at 2 and 12 weeks post discharged. Videoed to allow for non verbal communication to be analysed.	Semi Structured interviews	Yes, Semi Structured interviews	No information about how data was collected other than a literature search which yielded one article.
Relationship between researcher and participants considered?	Not discussed. The interviewer was an experienced health professional.	Yes, reported researcher's exposure to literature may affect the analysis. Reflections on differing construing between researcher and participants.	Not mentioned	No
Ethical considerations considered?	Informed consent taken.	Not reported	Informed consent	Not reported
Rigorous data analysis?	Yes, analysed separately by 2 researchers who then agreed themes.	Good description of data analysis. Examples from the data support the themes.	Research team involved in coding analysis.	Not reported
Clear statement of findings?	Good description of themes and quotes to illustrate/evidence	Clearly stated themes with quotes to illustrate/evidence.	Description of findings but themes unclear.	Findings stated but no indication of where information is from.
Value of research	Importance of identifying patient/partner awareness/beliefs before disclosure.	Identified areas to support patients receiving a diagnosis of ADHD; considered emotional impact and risk of suicide.		Not very helpful
Include in review	Yes	Yes	Yes	No

Appendix B

Data Extraction Table for Selected Papers

(Meyrick, 2006)

Data extraction of selected papers (Meyrick, 2006)

Paper	Pitt, L., Kilbride, M., Welford, M., Northard, S & Morrison, A. (2009). *Impact of a diagnosis of psychosis: A user led qualitative study.*	Horn, N., Johnstone, L., & Brooke, S. (2007). *Some service user perspectives on the diagnosis of Borderline Personality Disorder.*	Hayne, Y. (2003). *Experiencing psychiatric diagnosis: Client perspectives on being named mentally ill.*	Delmas, K., Proudfoot, J., Parker, G & Maniscacasagar, V. (2011). *Recoding past experiences. A qualitative study of how patients and family members adjust to the diagnosis of bipolar disorder.*	Deksen, E., Dassen, M., Gillisen, F., Rikkert, M. & Scheltens, P. (2006). *Impact of diagnostic disclosure in dementia on patients and carers. Qualitative case series analysis.*	Young, S., Bramham, J., Gray, K & Rose, E. (2008). *The experience of receiving a diagnosis and treatment of ADHD in adulthood. A qualitative study of clinically referred patients using interpretative phenomenological analysis.*	Gallagher, A., Arber, A., Chaplin, R. & Quirk, A. (2010). *Service users' experience of receiving bad news about their mental health.*
Epistemological and Theoretical Stance	Phenomenological	Phenomenological	Phenomenological Explicitly stated	Phenomenological	Phenomenological	Phenomenological	Phenomenological /Constructionist
Aims	To explore the impact of a diagnosis of psychosis from a service user perspective.	Explore service user understanding and experience of BPD diagnosis	Exploration of mental health diagnosis as an aspect of mental illness.	Explore adjustment to Bipolar diagnosis.	Describe the experience of receiving a dementia diagnosis	Evaluate the impact of receipt of diagnosis of ADHD in adults	To understand service users experiences of receiving news about mental health
Methods	IPA	IPA	Phenomenological thematic analysis	Phenomenology and Lived Experiences Framework	Grounded Theory	IPA	Grounded Theory
Sample	Convenience sample from mental health groups 8 service user participants	Purposive sample 5 service user participants	Purposive sample. 14 participants	Purposive sample. 17 Patients and 9 family members	Purposive sample. 18 patients and 18 partners	Purposive Sample 8 service user participants	Purposive sample 10 service user participants

Data Collection	Semi structured Interviews with service users. 20-60minutes. Audio taped, transcribed verbatim.	Semi Structured Interviews plus reflective notes taken during interview	Audio recorded interviews with prompt questions plus clippings, memos, drawings of researcher during analysis.	2 points in time Semi structured interviews Screened with Mood swings survey	2 points in time. Semi structured interviews video recorded to include non verbal data.	Semi structured interviews	Semi structured interviews.
Analysis	Initially 2 service user researchers, then Steering group and supervisors involved in analysis	External moderator and 3 participants involved in analysis	Bracketing interviews.	First and second authors involved in analysis	2 analysts separately.	1 analyst	Team agree codes
Results and Conclusions	Contradictory impact. Positive and negative experiences of diagnosis. Naming the problem vs being labelled. Diagnosis as a means of access v disempowering.	A social constructionist approach found to be helpful. Diagnosis helpful if it led to support.	Diagnosis as indisputable knowledge that changes sense of self but can be positive in getting support, especially if disclosed sensitively.	Diagnosis as relief; disturbing and anxiety provoking; recommends support and information for patients	Confirmation; shock; increased quality of life.	Review of past process towards acceptance; anxiety, move from internal to external attributions.	Diagnosis seen as significant news. Comparison to physical illness not always helpful. Culture/religion important.
Ethics	Consent to record interview	Not reported	Ethical permission mentioned	Informed consent	Informed Consent	Not reported	Informed consent

Key

IPA = Interpretative Phenomenological Analysis   BPD = Borderline Personality Disorder

Appendix C

Tabulation of Data for Primary Synthesis

Tabulation of data for Primary Synthesis

Reference	Study type	Population	Themes
Pitt, L., Kilbride, M., Welford, M., Northard, S & Morrison, A. (2009). *Impact of a diagnosis of psychosis: A user led qualitative study.*	Semi structured interviews IPA Steering group and supervisors involved in agreeing themes	8 Range of diagnosis (bipolar, schizophrenia, schizoaffective disorder, personality disorder, some multiple diagnosis)	Diagnosis as a means of access (to meds/support/understanding). Cause of disempowerment (lack of information) Naming the problem Labelling the person Cause of social exclusion (stigma) Achieving social inclusion (new social networks, voluntary work)
Gallagher, A., Arber, A., Chaplin, R. & Quirk, A. (2010). *Service users' experience of receiving bad news about their mental health.*	Semi structured interviews Grounded theory (team agree codes)	10 Range of diagnosis- not stated	Uncertainty and lack of understanding, Anxiety about stigma Extreme emotional reactions Importance of information
Hayne, Y. (2003). *Experiencing psychiatric diagnosis: Client perspectives on being named mentally ill.*	Semi structured interviews, records of impressions and insights Hermeneutic phenomenology (thematic)	14 Have a mental health diagnosis and understanding of it.	A knowledge that knows (a knowing that cannot be challenged; no longer knowing who I am) Destructive [gift] of difference (contrary forces) Making visible the invisible (healing though diagnosis, knowing what is wrong) Knowledge made knowledgeable (diagnosis transmitted in a way so SU feels knowledgeable.)
Horn, N., Johnstone, L., & Brooke, S. (2007). *Some service user perspectives on the diagnosis of Borderline Personality Disorder.*	Semi structured interview (good detailed procedure). IPA Analysis checked with a second person and three participants.	5 Diagnosis of Borderline Personality Disorder, in contact with services >6months and >2years previously.	Knowledge as power (containing but also power of expert) Uncertainty about what diagnosis meant (doesn't explain experience) Diagnosis as rejection (by services) Diagnosis is about not fitting, Hope and possibility of change

Reference	Study type	Population	Themes
Young, S., Bramham, J., Gray, K & Rose, E. (2008). *The experience of receiving a diagnosis and treatment of ADHD in adulthood. A qualitative study of clinically referred patients using interpretative phenomenological analysis.*	Semi Structured interviews IPA.	8 Met DSM-IV criteria for ADHD.	Review of the past(feeling different from others) The emotional impact of diagnosis (relief and elation, followed by reframe of past experiences, anger and sadness) Rumination about the future (stigma, disclosure, acceptance).
Delmas, K., Proudfoot, J., Parker, G & Maniscacasagar, V. (2011). *Recoding past experiences. A qualitative study of how patients and family members adjust to the diagnosis of bipolar disorder.*	Semi structured interview Sample until saturation. Analysed using the Phenomenology and Lived Experiences Framework.	Purposive sample. Diagnosis of bipolar OR family member. (17 bipolar) (9 family members – not caregivers)	Misdiagnosis and Growing Awareness.(increasing awareness of problem, misdiagnosis by professionals, feeling defective and guilty) Accepting the diagnosis [1. initial reaction to the diagnosis; 2. Adjusting to the diagnosis]. Factors that may have facilitated an earlier acceptance. (Importance of information in acceptance).
Derksen, E., Dassen, M., Gillisen, F., Rikkert, M. & Scheltens, P. (2006). *Impact of diagnostic disclosure in dementia on patients and carers. Qualitative case series analysis.*	Semi structured interview videoed at 2 and 12 weeks post diagnosis Grounded theory. Interviewed until saturation.	Purposive sample. Diagnosis of dementia or partner. 18 pairs of patients and partners. (80% patients male, mean age 71.)	Awareness of dementia: awareness of cognitive problems, diagnosis expected, confusion, feelings of loss and grief, coping behaviour. Partnership: reliance on partner, notion of partners' burden, changed relationship, positive experiences. Social relationships: support given by children, relatives or friends; change of social relationships, future (care) planning.

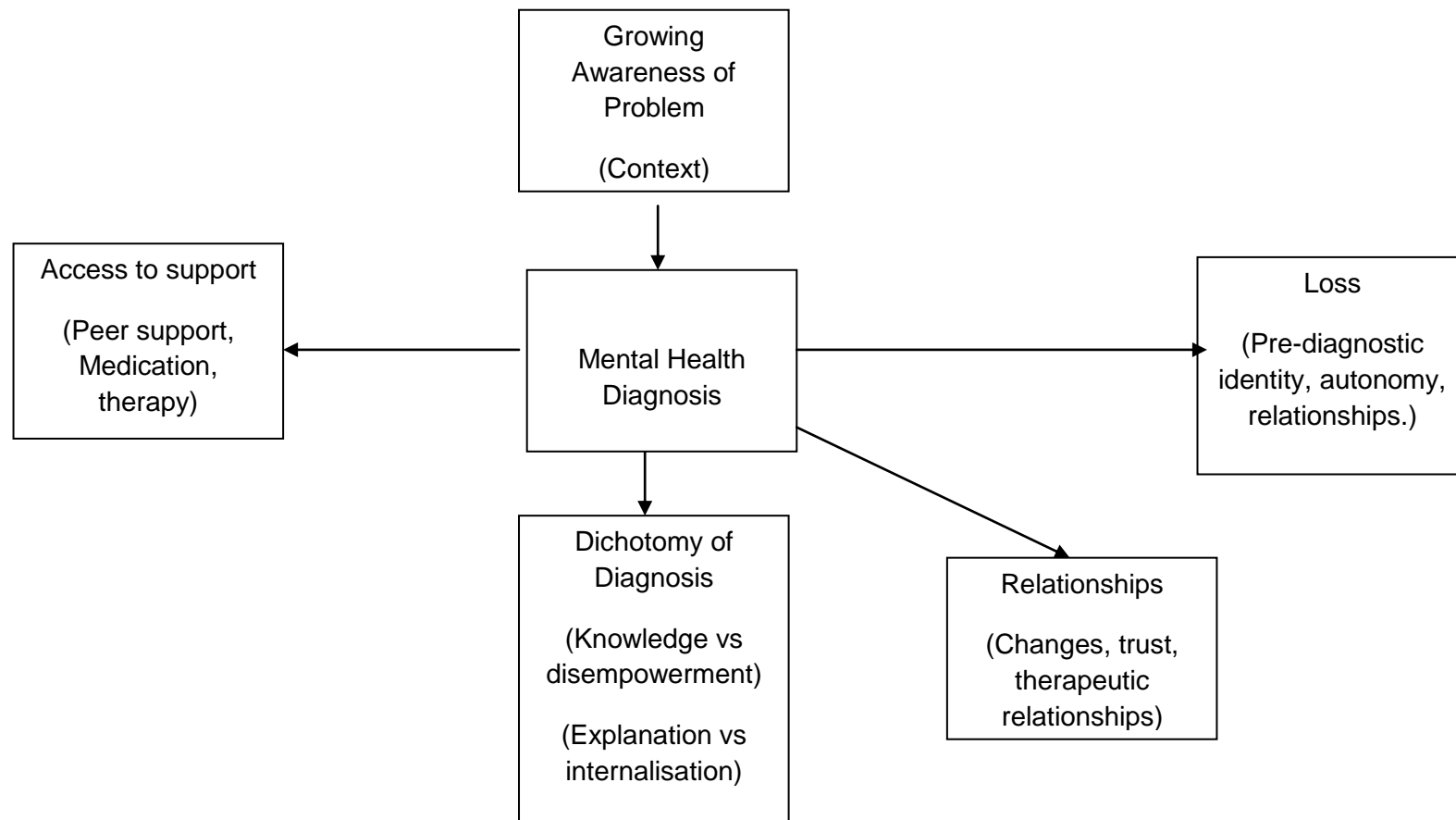Appendix D

Preliminary Synthesis Table

Preliminary synthesis – table showing clusters of original themes from reviewed papers.

Knowledge as disempowerment	Knowledge as power	Rejection/Stigma	Uncertainty	Diagnosis for access to support	Hope	Reactions (emotional)	Information	Relationships
Cause of disempowerment. A knowledge that knows [a knowing that cannot be challenged, no longer knowing who I am]. Destructive [gift] of difference.	Knowledge made knowledgeable [diagnosis transmitted in a way so service user feels knowledgeable]. Knowledge as power [containing for service user, power of expert].	Labelling the person. Anxiety about stigma. Cause of social exclusion. Diagnosis is about not fitting. Review of the past (feeling different from others). Rumination about the future. Diagnosis as a rejection [by services].	Misdiagnosis and growing awareness (increasing awareness of problem, misdiagnosis by professionals, feeling defective and guilty). Awareness of cognitive problems. Naming the problem. Uncertainty and lack of understanding of diagnosis.	Diagnosis as a means of access (to medication, support, understanding). Achieving social inclusion (new social networks, voluntary work).	Hope and possibility of change. Making visible the invisible [healing through diagnosis, knowing what is wrong].	Accepting the diagnosis [1. Initial reaction to the diagnosis: 2. Adjusting to the diagnosis]. The emotional impact of diagnosis [relief and elation, followed by reframe of past experiences, anger and sadness]. Extreme emotional reactions.	Factors that may have facilitated an earlier acceptance.	Social relationships [support given by children, relatives or friends: change of social relationships. Future (care) planning]. Partnership [reliance on partner, notion of partners burden, changed relationship, positive experiences].

Appendix E

Thematic Map of Diagnosis Experience

Thematic Map of Diagnosis Experience

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                        ┌─────────────────┐
                        │    Growing      │
                        │  Awareness of   │
                        │    Problem      │
                        │                 │
                        │   (Context)     │
                        └────────┬────────┘
                                 │
                                 ▼
┌─────────────────┐     ┌─────────────────┐     ┌─────────────────┐
│ Access to support│◄───│                 │───►│      Loss       │
│                 │     │  Mental Health  │     │                 │
│ (Peer support,  │     │   Diagnosis     │     │ (Pre-diagnostic │
│  Medication,    │     │                 │     │ identity, autonomy,│
│   therapy)      │     │                 │     │  relationships.)│
└─────────────────┘     └────┬───────┬────┘     └─────────────────┘
                             │       │
                             ▼        ╲
                  ┌─────────────────┐  ╲ ┌─────────────────┐
                  │  Dichotomy of   │   ►│  Relationships  │
                  │   Diagnosis     │    │                 │
                  │                 │    │ (Changes, trust,│
                  │ (Knowledge vs   │    │   therapeutic   │
                  │ disempowerment) │    │  relationships) │
                  │                 │    └─────────────────┘
                  │ (Explanation vs │
                  │ internalisation)│
                  └─────────────────┘
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Appendix F

Statement of Epistemological Position

Statement of Epistemological Position

The researcher adopted a contextual constructionist epistemological stance for this research (Madill, Jordan & Shirley, 2000). This position is not interested in a true reality, but rather the way that participants and the researcher interpret events and experiences. It acknowledges that data collected during an interview between a particular researcher and a particular participant at a particular location and point in time will generate a unique account that would differ if any variable was changed (Madill et al., 2000). In order to ensure representation of the participant's perspective analysis is grounded in the interview data (Madill et al., 2000) through the use of illustrative quotes for each theme identified.

This position emphasises the importance of the characteristics of the researcher as these will help the reader to understand the influence on the data collection and analysis. In this case the researcher was a white female in her mid thirties from a different geographical area to where the research was carried out. She had no prior experience with service users in Early Intervention in Psychosis Services, or anyone who had experienced a first episode of psychosis or had a diagnosis of either psychosis or schizophrenia. However, she did have lay knowledge about these diagnoses and had received some teaching about them during her training. Further, the researcher position as a Trainee Clinical Psychologist was also important in her interactions with the participants and it is possible that they perceived her as a clinician, which would influence the information they shared during their interview.
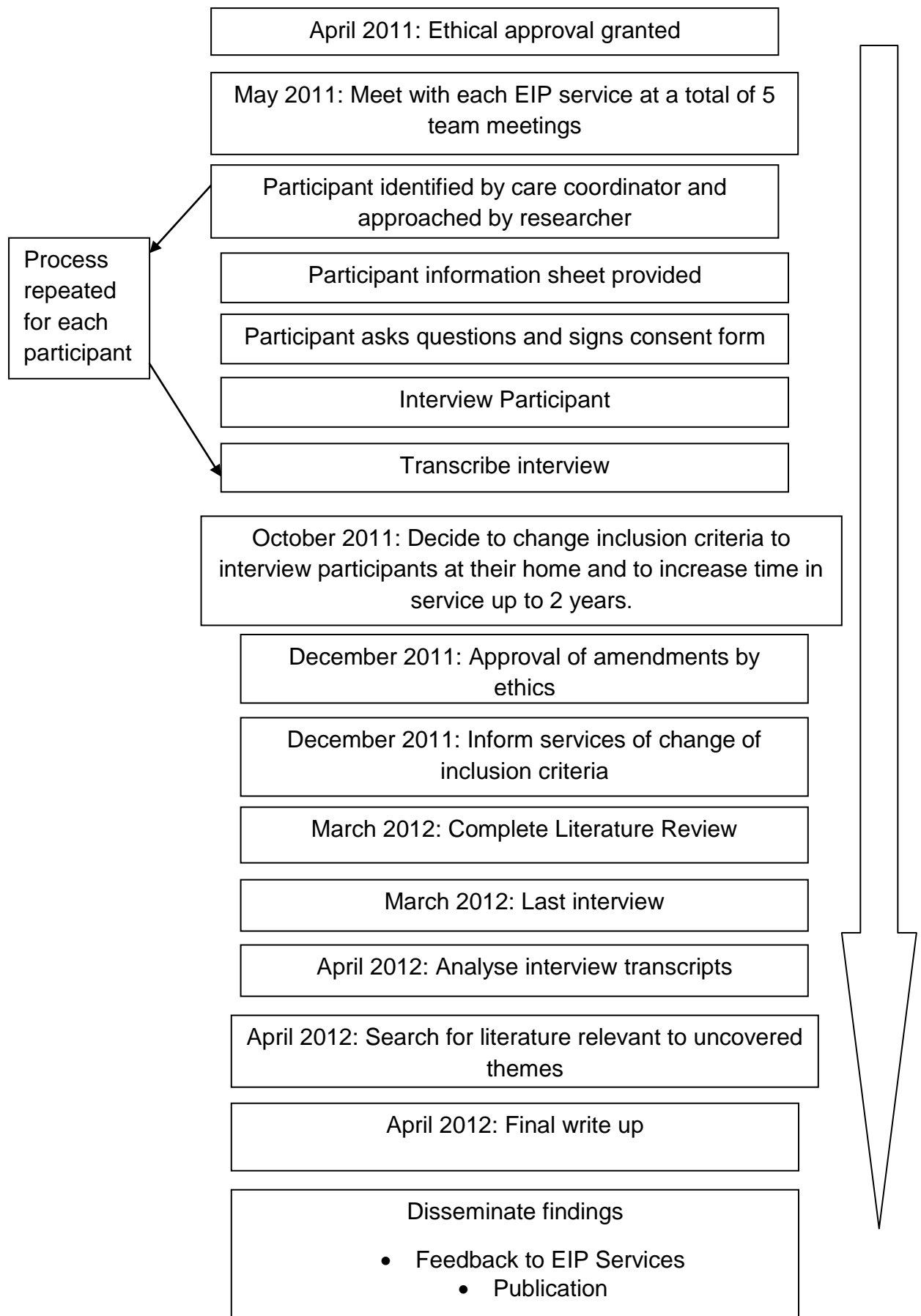
References

Madill, A., Jordan, A. & Shirley, C. (2000). Objectivity and reliability in qualitative

analysis: Realist, contextualist and radical constructionist epistemologies. *British*

Journal of Psychology, 91, 1-20.

Appendix G

Chronology of Research Process

Chronology of Research Process

April 2011: Ethical approval granted

May 2011: Meet with each EIP service at a total of 5 team meetings

Participant identified by care coordinator and approached by researcher

Participant information sheet provided

Participant asks questions and signs consent form

Interview Participant

Transcribe interview

Process repeated for each participant

October 2011: Decide to change inclusion criteria to interview participants at their home and to increase time in service up to 2 years.

December 2011: Approval of amendments by ethics

December 2011: Inform services of change of inclusion criteria

March 2012: Complete Literature Review

March 2012: Last interview

April 2012: Analyse interview transcripts

April 2012: Search for literature relevant to uncovered themes

April 2012: Final write up

Disseminate findings

- Feedback to EIP Services
  - Publication

Appendix H

Interview Schedule & Documents for Participants

<center>**Participant Information Sheet**</center>

Project Title: An Interpretative Phenomenological Analysis of Service Users' Experiences of Receiving Information about 'Psychosis' Following a First Episode.

I would like to invite you to take part in my research study. To help you decide whether or not to take part please read this information sheet. You may wish to talk about the study with other people you trust before you make a decision.

What is the study for?

The purpose of the study is to find out about service users' experiences of entering the Early Intervention in Psychosis Service, what information they are given and how this information affects them. We hope that the findings from this research will be useful to help mental health professionals understand the impact of the information they provide for service users.

What is an Interpretative Phenomenological Analysis?

Interpretative phenomenological analysis is a method which allows the researcher to look for themes across a number of interviews with service users. These themes help the researcher to understand the experience of receiving information about psychosis from a service user perspective.

Why have I been invited to take part?

You have been invited to take part because you have been involved with the Early Intervention in Psychosis Service for between six months and two years. Participation is voluntary and it is entirely up to you to decide whether or not to take part. Your decision will not affect the standard of care you receive.

Should you who wish to take part in the study you will be given the opportunity to share your experiences with a researcher during a private interview lasting less than one hour. If at any point during or straight after the interview you decide you no longer wish to take part in the study any information about you will be destroyed.

If I take part, what will happen?

Interviews will take place in private at an agreed location. Although the researcher will have questions you are encouraged to speak about the issues that you feel were most important to you. You will not be expected to talk about subjects that cause you to feel distressed. Should you feel upset during the interview you will be able to stop the interview. The interviews will be recorded by the researcher who will later type up the conversation for analysis. The researcher will look at interviews from a number of participants to see if there are any shared experiences or ideas.

Will my information be confidential?

All information provided will be kept safe and confidential. However, should you disclose information to the researcher that causes them to be concerned for your safety or the safety of others then this will have to be passed on to your key worker.

Only the researcher will know your name and your name will not be kept with your interview material. Any information that might be recognisable to others such as names, places and dates, will be changed to make sure the material is anonymous. Only the researcher and the research supervisor will see the full interview transcripts, however some examples from the interview material will appear in the final report. The report will be made available to the Early Intervention in Psychosis Service and to people who have taken part in the study. A copy of the report will also be kept in the library in the Clinical Psychology Department of Leicester University. It is hoped that the research will be published in a psychology journal to make the findings known more publicly.

How can I find out more?

You can contact the researcher directly if you have any further questions about the research or taking part.

Contact details

Researcher: Emma Nicholas

Mobile: 07983 280 939

E-mail: en46@le.ac.uk

Can I complain?

If you are unhappy with the conduct of the researcher you may address complaints in writing to:

Professor Mike Wang

School of Psychology,

104 Regent Road,

Leicester

LE1 7LT

Semi Structured Interview Schedule.

Information/Diagnosis Received

- Could you briefly describe how you came to be seen by the Early Intervention in Psychosis Service?
    Prompt (referral route, presenting problems)
- What did you know about the service before you came?
- How long have you been in the service for?
- What were you told about your experiences *(hallucinations, delusions etc)*
    Prompt (when were you told? How consistent was the information? How were they explained to you?)
- Have you been given a diagnosis/label to describe your experience?
- Who/how many people have talked to you about this? How many times?
- How did you feel that you were supported (or not) in the receiving of this information?
- What questions did you have about this? And did you feel able to ask them?
- Was anybody with you (partner, friend, relative) when you received this information?
- Did anybody check that you understood what you had been told?
- Have you been given alternative explanations for your experience?

Influences

- What did you understand about what was said to you about your experiences?
- What did you know about this diagnosis/psychosis at the time?
- What effect did that have on how you made sense of the information you were given?

Meaning /Effect of information

- What did the information mean to you (about you?) at the time?
    Prompt (A load of rubbish? A good explanation? Good/bad news)
- Has the meaning changed for you since that initial time?
- How did you feel/react when you were told?
- Does what you were told fit with your ideas/meaning about your experiences?
- Did it impact on your life? If so, how?
    Did you speak to anyone about it at the time? Or now? Are there people you would/wouldn't talk to?
- Has your experience/diagnosis affected your employment?
    Prompt (what did you tell your employer?)

Future

- What has been your response to this information and your experience?
- Has what you were told changed your view/ideas about your future at all? If so how? If not, what not?

Consent Form

Title of Project: An Interpretative Phenomenological Analysis of Service Users' Experience of Receiving Information about 'Psychosis' Following a First Episode.

Researcher: Emma Nicholas

Please initial box if you agree with the statement

Please initial box to agree

1. I confirm that I have read and understood the information sheet for this study. I have been given the opportunity to ask questions and have them answered.

2. I understand that my participation in this research is voluntary and that I may withdraw from the study without my medical care being affected.

3. I understand that the interview will be recorded and typed up by the researcher but that my name will not be kept with this material and that any identifying details such as names, dates or places will be altered to ensure anonymity.

4. I understand that examples from my interview might be featured in the final report that will be shared with the Early Intervention Service and other service users taking part in the study.

5. I understand that a copy of the final report will be kept in the library of the Clinical Psychology Department at Leicester University and that findings from the final report may be published in a professional journal.

6. I understand that data collected during the study may be looked at by individuals from University of Leicester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information.

7. I understand that if I disclose information during the interview that causes the researcher concern for my safety or the safety of others that this information will be shared with my key worker.

8. I agree to take part in this study.

Name of person   Date   Signature

Name of person taking consent   Date   Signature

Appendix I

Example of initial analysis

Example of initial analysis

Themes	Text	Initial Ideas
Psychiatric conditions Accepting schizophrenic tendencies Fixed/Permanent Condition	Jack: And it seems sometimes the psychiatrists come along and they want to give everybody a condition. Where it isn't necessarily as easily defined as that. Cause, life has so many ins and outs and ups and downs, that it isn't um. But I do agree that maybe I could have, I mean I do, obviously I have like a psychotic tendency at certain points, or schizophrenic tendency. Like I don't, I don't disagree, I'm not like fighting the idea that I have something. It's more, it's more the idea of a fixed condition that you are locked into.	Psychiatrists want to give everybody a condition. Accepting I have something. Prefers use of tendencies. Locked into fixed condition. Not fighting Scared of permanent diagnosis.

Appendix J

Letters to and from Research Ethics committee

16 March 2011

Mrs Emma Nicholas

Dear Mrs Nicholas

Study Title:	Interpretative Phenomenological Analysis of Service Users Experiences of Receiving Information about First Episode Psychosis
REC reference number:	11/EM/0050

The Research Ethics Committee reviewed the above application at the meeting held on 8 March 2011. Thank you for attending to discuss the study.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
REC application	68565/189843/1/861	24 January 2011
Participant Information Sheet	1	16 February 2011
Investigator CV	1	16 February 2011
Investigator CV	1	16 February 2011
Participant Consent Form	1	16 February 2011
Protocol	4	16 February 2011
Interview Schedules/Topic Guides	1	16 February 2011

Discussion

- The Committee asked you what ethical issues you envisage when talking about first episode psychosis with individuals. You stated that approval will be given by the keyworker that a potential participant is suitable. Therefore, you will be led by the service. The Committee asked whether participants talking about their first episode of psychosis, is likely to cause any distress to them. You confirmed that this has been addressed in the application. Also, you have found from experience with other patients that they have found it helpful.

- The Committee asked you what measures are in place whilst working alone in the various sites. You stated that as yet you do not know where the interviews will

take place. However, this will be dealt with in conjunction with the service prior to the interviews.

- You were informed that 'IPA' should be defined/clarified in the Participant Information Sheet.

- The Committee informed you that there should be a mechanism for complaints identified in the Participant Information Sheet. You asked who would be a suitable point of contact and the Committee stated that this could be someone either from within the Trust e.g. Patient, Advice and Liaison Service (PALS), or alternatively, a contact at the University. However, the contact should not be connected with the research in any way.

- The Committee informed you that data storage would normally be for more than 5 years, and is usually 7 years for the University.

- The Committee informed you that there should be a mechanism identified in the Participant Information Sheet to report anything untoward e.g. disclosure etc. You also stated that you would include provision in the Consent Form to enable a participant to consent to this should anything be identified.

- You stated that you wish to look at differences across the geographical areas i.e. Leicester, Northampton and Nottingham. The Committee asked whether you were wanting a similar number of participants from each area. You confirmed that as the study uses an IPA approach, it does not matter how many you have from each area – it could be 7 from 1 area and 1 from another – you will still be gaining experiences.

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

Further information or clarification required

1. There should be a statement above the 'initial boxes' in the Consent Form stating 'Please initial box'

2. The Participant Information Sheet mentions IPA. However, this is not defined. It should clearly define what IPA is in simple terms.

3. There should be a mechanism for complaints identified in the Participant Information Sheet. This should be a department at the Trust or University that is not involved in the research.

4. The Committee request assurance that data will be stored in line with University policy.

5. There should be a mechanism identified in the Participant Information Sheet to report anything untoward e.g. disclosure. It should make clear who this will be referred to etc. There should also be provision made in the Consent Form to enable a participant to consent to any disclosure being referred, should it be

identified etc.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 14 July 2011.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

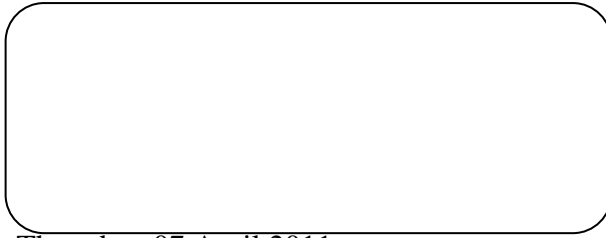| 11/EM/0050	Please quote this number on all correspondence

Yours sincerely

P. Wheel

pp **Mr Robert Johnson**
Chair

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy to:

Emma Nicholas
Trainee Clinical Psychologist

Thursday, 07 April 2011

Dear Mr

Study Title: Interpretative Phenomenological Analysis of Service Users Experiences of Receiving Information about First Episode Psychosis

REC reference number: 11/EM/0050

Thank you for your letter dated 16th March 2011 regarding the above application to the ethics committee. Following your recommendations I have made the following adjustments to my documents enclosed and highlighted:

1. A statement above the initial boxes on the consent form stating "Please initial box to agree" (version 2)

2. Brief lay description of IPA in the participant information sheet (version 2)

3. Complaints procedure in the participant information sheet (version 2)

4. I have confirmed with the University of Leicester (Doctorate in Clinical Psychology Department) that data will be stored securely for a period of 7 years.

5. Advice that disclosure of material during interviews that causes concern to the researcher about the safety of the participant or others will be passed on to the participants key worker in the participants information sheet (version 2) and in the consent form (version 2)

I hope that these adjustments meet the committee requirements set out in your letter. However, should you require further adjustment please do not hesitate to contact me. I look forward to hearing from you with regard to the opinion on my proposed research.

Yours Sincerely,
Emma Nicholas
Trainee Clinical Psychologist

National Research Ethics Service

NHS

NRES Committee

20 April 2011

Mrs Emma Nicholas

Dear Mrs Nicholas

Study title:	**Interpretative Phenomenological Analysis of Service Users Experiences of Receiving Information about First Episode Psychosis**
REC reference:	**11/EM/0050**

Thank you for your letter of 07 April 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

## Ethical review of research sites

NHS sites

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

Conditions of the favourable opinion

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

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

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

1370

148
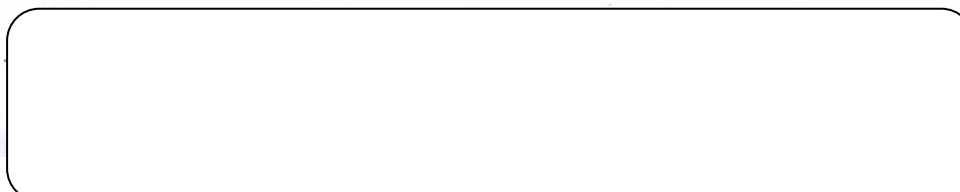
Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

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

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

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

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

Approved documents

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

Document	Version	Date
Protocol	4	16 February 2011
Response to Request for Further Information		07 April 2011
Investigator CV	1	16 February 2011
Investigator CV	1	16 February 2011
Participant Information Sheet	2	07 April 2011
Interview Schedules/Topic Guides	1	16 February 2011
REC application	68565/189843/1/861	24 January 2011
Participant Consent Form	2	07 April 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

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

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

We would also like to inform you that we consult regularly with stakeholders to improve our
service. If you would like to join our Reference Group please email
referencegroup@nres.npsa.nhs.uk.

| 11/EM/0050 | Please quote this number on all correspondence |

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

Yours sincerely

Enclosures: "After ethical review – guidance for researchers"

Copy to:

NRES Committee

22 November 2011

Mrs Emma Nicholas

Dear Mrs Nicholas

Study title: **Interpretative Phenomenological Analysis of Service Users Experiences of Receiving Information about First Episode Psychosis**
REC reference: **11/EM/0050**
Protocol number: **N/A**
Amendment number: **1**
Amendment date: **08 November 2011**

Thank you for submitting the above amendment, which was received on 08 November 2011. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

Documents received

The documents to be reviewed are as follows:

Document	Version	Date
Protocol	5	06 November 2011
Notice of Substantial Amendment (non-CTIMPs)	1	08 November 2011
Covering Letter		08 November 2011

Notification of the Committee's decision

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

11/EM/0050:	Please quote this number on all correspondence

Yours sincerely

NHS

Health Research Authority

NRES Committee

02 December 2011

Mrs Emma Nicholas

Study title:	Interpretative Phenomenological Analysis of Service Users Experiences of Receiving Information about First Episode Psychosis
REC reference:	11/EM/0050
Amendment number:	1
Amendment date:	08 November 2011

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	5	06 November 2011
Notice of Substantial Amendment (non-CTIMPs)	1	08 November 2011
Covering Letter		08 November 2011

Please note: the reference to participants being involved with the Early Intervention Service for between six months and two years (as requested in the amendment) should be amended in the Participant Information Sheet, as it still refers to 'one year' under the heading 'Why have I been invited to take part?'.

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Re-issued to amend incorrect address 18.04.2012

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

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

11/EM/0050:	Please quote this number on all correspondence

Yours sincerely

Appendix K

Author Guidelines for Literature Review

Author Guidelines

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

• Papers reporting original empirical investigations

• Theoretical papers, provided that these are sufficiently related to the empirical data

• Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications

• Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Submission and reviewing

All manuscripts must be submitted via http://www.editorialmanager.com/bjcp/. The Journal operates a policy of anonymous peer review. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.
4. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.
• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.

• All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

• All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading 'Practitioner Points'.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

6. Supporting Information

BJC is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at http://authorservices.wiley.com/bauthor/suppmat.asp

7. Copyright

Authors will be required to assign copyright to The British Psychological Society. Copyright assignment is a condition of publication and papers will not be passed to the publisher for production unless copyright has been assigned. To assist authors an appropriate copyright assignment form will be supplied by the editorial office and is also available on the journal's website athttp://www.blackwellpublishing.com/pdf/CTA_BPS.pdf. Government employees in both the US and the UK need to complete the Author Warranty sections, although copyright in such cases does not need to be assigned.

8. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded here.

9. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found athttp://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

10. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. For the full list of terms and conditions, seehttp://wileyonlinelibrary.com/onlineopen#OnlineOpen_Terms

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form available from our website at:https://onlinelibrary.wiley.com/onlineOpenOrder

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

11. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript.

Visit http://authorservices.wiley.com/bauthor/ for more details on online production

tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site:http://www.adobe.com/products/acrobat/readstep2.html.
This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Hard copy proofs will be posted if no e-mail address is available. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Clinical Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. *Human Rights Journal*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x
Further information about the process of peer review and production can be found in this document: What happens to my paper?