



Major Research Project

Title:

Young Peoples' Experiences of Hearing Voices: A Phenomenological Study of Self and Sense-Making in First-Episode Psychosis

Submitted in partial fulfilment of the requirements of the qualification of Doctorate in Clinical Psychology from School of Psychology, University of Exeter

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¹ See Appendix 6.1 for Dissemination Plan

² See Appendix 6.2 for Author Guidelines

If you believe, as I do, that the mind wants to heal itself, and that the psyche seeks coherence not disintegration, then it isn't hard to conclude that the mind will manifest whatever is necessary to work on the job.

Jeanette Winterson, *Why be Happy when you could be Normal?*

Declaration

I certify that all material in this dissertation which is not my own work has been identified and properly attributed, and no material is included for which a degree has previously been conferred upon me.

Signed: Date:

Acknowledgements

To the young people involved in the interviews, I feel privileged to have met you and to have been entrusted with your stories. I hope I have done justice to your openness, sincerity and desire to share your experiences. I hope in telling your stories we can make a difference to others.

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Abstract

The experience of hearing voices has been theoretically construed in a number of ways. The current dominant approach is psychiatric in nature; often criticised for pathologising the experience and neglecting to explore the subjective meaning the experience holds for people who hear voices. The limited literature, which has explored voice-hearers' experiences, predominately reflects the experiences of adults, largely neglecting to represent younger peoples' experiences (i.e. 16 to 25 year olds), when psychosis is most likely to occur and when identity formation and self-development are fundamental. This study aims to explore the impact of hearing voices within first-episode psychosis on young peoples' sense of self and how they make sense of this experience. This study utilises interpretative phenomenological analysis (IPA) to reflect on experiences of eight young people who hear voices. Three themes were identified: 1). "I'm losing my mind": The shattered self; 2). "I can't say it in words": More than words; 3). "It just makes a lot of sense like, that I was a bit crazy": Trying to make sense of voices. The transitional process the experience appeared to embody for these young people is outlined in a model. Key components of the model attend to the importance of others and how crucial their response is in helping the young people make sense, but also in their perceptions of themselves and their identity.

Introduction

This research seeks to explore how young people experiencing first-episode psychosis (FEP) make sense of hearing voices (HVs)³ and how this impacts on their sense of self at a crucial time in identity formation (Adams & Marshall, 1996; Erikson, 1968). As the term ‘young people’ can refer to a broad age range, this research is specifically interested in people aged between 16 to 25 years of age.

FEP commonly occurs during late adolescence or early adulthood⁴ (Lewis *et al.*, 2002).

Within Western culture the predominant understanding of HVs is psychiatric; referred to as an ‘auditory hallucination’ and considered an indicator of psychosis or schizophrenia. Many argue that reliance upon diagnostic labels can result in a medical and pathologising understanding of HVs resulting in people feeling marginalised by society and stigmatised, which can exacerbate and hinder recovery (Rosenfield, 1997).

Adolescence is a transitional stage of physical and psychological development; Erikson (1968) proposes identity formation, the key psychosocial task, often extends into early adulthood. Different selves are rehearsed through exploring roles; becoming more autonomous, less dependent on family, developing peer networks and pursuing vocational aspirations (McGorry & Yung, 2003; Riedesser, 2004).

³ HVs is the preferred phrase in this review as it does not pathologise the experience. ‘Auditory hallucinations’ will only be used when referring to the medical description of this experience. Similarly, the term ‘schizophrenia’ will be used cautiously and in moderation to indicate reservations about its validity as a diagnostic category.

⁴ See Appendix 1.1: Extended Information about Issues of Definition in the Research Literature

Complex debates and conceptualisations characterise the study of self and identity within social psychology (Holstein, & Gubrium, 2000; Lapsley & Power, 1988). Despite this there is general agreement about the social construction of selfhood and identity (Estroff, 1989). The notion of a relational self suggests self and other are inextricably linked and self is constructed and maintained through social relations (Mead, 1967); thus, social isolation usually fosters loss of self (Charmaz, 1983). Similarly, illness may shape situations in which people learn new definitions of self and relinquish old ones (Corrigan & Watson, 2006).

FEP typically results in confusion, fear, depression, stigma, social isolation, disruption, and a sense of loss of future aspirations, in conjunction with attempts to cope with adolescence/early adulthood (Kilkku *et al.*, 2003). Fewer social contacts may limit possibilities for positive validation of self (Charmaz, 1983). Research suggests being labelled with psychiatric disorder in adolescence may shape identity affecting this stage of development (Lally, 1989).

Conceptualising psychosis as a disturbance to self is a long-standing area of interest within psychiatric literature (Laing, 1978); often described as a disruption to self, sense of boundaries between self and others, and the ability to relate meaningfully to the world (Fabrega, 1989). Many ascribe damage and loss to former characteristics of self (e.g. Birchwood *et al.*, 2002).

FEP has long been recognised as the most frightening and shattering experience when compared with subsequent episodes (Ludwig, 1971). With time, these experiences are no

longer experienced as alien suggesting psychosis becomes incorporated into sense of self. Little research has explored the impact of FEP on sense of self (Boydell *et al.*, 2010), fundamental to understanding distress and adjustment (Jackson & Iqbal, 2000), particularly as young people have no pre-existing cognitive schema to understand/guide adjustment (McGorry, 1995).

The only study comprehensively exploring the impact of FEP on young peoples' sense of self was by Geekie (2004). He found three main constructs: authoring (making sense of psychosis by telling and sharing their story with others); ontological insecurity (uncertainty about their sense of being in the world); and epistemological uncertainty (uncertainty about their ways of knowing causing them to doubt their perceptions). Based upon people aged 20 to 37, this research excluded younger people, and was not specific to voice-hearers. There is substantial need for further exploratory studies of subjective experiences of FEP pertinent to the developmental stage of this group, and the current research will adopt this focus.

Early Intervention Services (EIS) work with young people aged 14 to 34 for three years following FEP. Aiming to improve earlier recognition, access and intervention; reduce psychological distress; and promote recovery (Welsh *et al.*, 2010); the rationale for intervening early is 'duration of untreated psychosis' (DUP) has been found to negatively affect outcomes of those impacted (Johannessen *et al.*, 2007). More research is needed to increase understanding of factors precipitating and/or delaying help-seeking in FEP.

Most research utilises quantitative methods often determining useful relational links between factors and likely causes of psychosis; but often criticised for reducing meaningful

experiences to meaningless symptoms, discounting context and having little relevance to informing therapeutic interventions (Romme *et al.*, 2009).

Growing efforts to systematically study voice-hearers' subjective experiences have emerged using qualitative research (DoH, 1999; NICE, 2002). Pioneering such research, Romme and Escher (1989) found many Dutch adult voice-hearers from the general public could cope without psychiatric intervention. Explanations for voices formed two categories: voices arising from within the individual (mystical, psychodynamic/traumatic, parapsychological origins); and voices caused by external factors (biological, spiritual origins). People appeared to transition through three phases to cope with voices: 1). Startling: characterised by onset of voices, often experienced as frightening and confusing; 2). Organisation: selection and communication with voices; 3). Stabilisation: accepting voices as part of self, no longer perceived as overpowering, which appeared to facilitate coping. Based upon people with some success at coping; it is unclear if people viewing themselves as unsuccessful at coping and/or HVs for the first time would experience similar transitions. More research is needed to identify processes enabling progression through these phases; other research suggests greater complexity and a less linear process (Chin *et al.*, 2009; Fenekou & Georgaca, 2009).

Research suggests voice-hearers show a strong tendency towards spiritual and psychological explanations over biological ones (Romme *et al.*, 2009). Jones *et al.* (2003) found 20 service-users' and non-users' views about voices clustered into six factors. Seven took positive spiritual perspectives, regarding voices as a blessing; four used personal relevance relating voices to life experiences; three used resigned pessimist perspectives, troubled by voices and believing therapy would not alleviate distress; two took pragmatic perspectives, believing they could communicate with spirits; three felt passive to forces they believed caused voices

(spiritual possession, neurochemical imbalances); finally, two took mental illness perspectives believing voices need controlling with medication. This shows the diversity and complexity of beliefs about HVs, but as participants were aged between 27 and 75, experiences of young voice-hearers were not captured.

Research with young voice-hearers has primarily focused on long-term outcomes of adolescent-onset psychosis (Escher *et al.*, 2002; Hollis, 2000). One study has explored young peoples' subjective attempts to make sense of this experience. Newton *et al.* (2007) found 17 and 18 year olds' voice-hearing accounts formed two groups: agentic explanations where they felt able to exercise some agency over voices (illness, brain dysfunction, sensitivity to stress); and passive explanations without agency (other people, supernatural forces, spiritual entities). Findings are consistent with studies with adults, stressing the importance of feeling able to exert control over voices (Romme & Escher, 1989; Vaughan & Fowler, 2004); but provide little information about processes by which young people make sense of HVs.

Exclusion of young people from research is surprising given FEP commonly occurs during late adolescence/early adulthood and literature suggests difficulties may be more distressing and long-term outcomes most vulnerable in this period (Birchwood *et al.*, 1998). EIS base interventions on research carried out with adults raising questions about generalising findings to young people who hear voices (Newton *et al.*, 2007). Needs and preferences of young service-users experiencing FEP have not received the attention they warrant.

This study aims to extend this body of research using a qualitative method, specifically interpretative phenomenological analysis (IPA). Drawing upon eight young people's

experiences of HVs during their FEP, this research aims to explore the impact on their sense of self and how they understand this experience.

The extensiveness of theoretical influences and epistemological openness of IPA were seen as strengths, permitting an open-minded approach to the data (Ware & Raval, 2007). This research seeks to adopt a co-operative enquiry by involving participants in the analysis. A reflexive approach was adopted, alongside a broadly critical realist epistemology (Willig, 2001). This position allows recognition of the experience of HVs as 'real', whilst acknowledging there is no one way to understand their impact.

Method

Service-User Involvement

During design of this study extensive consultation was sought from a member of the Lived Experience Group at the University of Exeter, who expressed a positive response to the study acknowledging the limited research carried out with young voice-hearers⁵.

Participants

Eleven young people were approached by professionals to participate in the study and were given the Participant Information Sheet⁶ that included an invitation to register their willingness to engage in the research by informing the clinician involved in their care. Five young women and three young men expressed an interest, and participated in the study (see Table 1^{7,8}).

⁵ See Appendix 2.2: Extended Information about Service-User Involvement

⁶ See Appendix 4.5: Participant Information Sheet

⁷ Information presented in Table 1 aids in contextualising information presented in the findings without compromising anonymity. Each participant was given a pseudonym to be used throughout the research to ensure anonymity.

⁸ See Appendix 2.7: Information about the Participants - Extended Table

Table 1. Information about the Participants

Participant	Age	Identities of Voices	Approximate Time Since Onset of Voice-Hearing	Approximate Duration of Involvement with Early Intervention Services
Ellie	18	Multiple adult and childrens' voices; voices of spirits; men and women screaming	3 years	2 years 4 months
Rachael	22	Two or three asexual voices and boyfriend's voice	2 years 6 months	1 year
Megan	23	Multiple unidentified voices	3 years	2 years 5 months
Claire	18	Deceased Grandfather and deceased bully	2 years 6 months	2 years
Jake	24	Multiple voices: The Triad (Chinese Mafia) and FBI; familiar voices, such as friends' voices	1 year 6 months	1 year 6 months
Debbie	16	An unidentified male and a female screaming	4 months	3 months
Carl	19	An unidentified girl and male adult	3 years 6 months	2 years 8 months
Harry	18	Two unidentified male adults	3 years	2 years 6 months

Recruitment

Clinicians within EIS were approached to explain the purpose of the study, inclusion criteria and identify potential participants. As recommended with IPA, purposive sampling was used to ensure participants shared as many characteristics as possible within the inclusion criteria⁹ (Smith, *et al.*, 2009). Young people were approached if they:

- Were between 16 and 25 years old;
- Experienced their first voice-hearing experience within the last three years;
- Were receiving support from one of four EIS within the NHS in South West England;
- Were not experiencing risk, distress, mental health problems or a lack of capacity to consent in a way that would influence their ability to participate, determined in the first instance by Early Intervention workers¹⁰;
- Were able to understand and speak fluent English.

The Interviews

Clinicians from two of the four EIS approached, identified young people that met inclusion criteria¹¹. Verbal consent was initially gained by clinicians before participants were approached to discuss the potential of taking part in the study. Interviews were conducted at venues and times convenient for the young people. To promote feelings of safety and comfort participants were offered choice about the venue; seven of the eight interviews took place in

⁹ See Appendix 2.3: Extended Information About Participants

¹⁰ See Appendix 4.1: Care Co-ordinator's Suitability and Screening Tool for Potential Participants

¹¹ Only two teams identified young people meeting inclusion criteria, therefore the other two teams did not become involved with the current study.

young people's homes, one took place in a NHS mental health setting¹². Before informed written consent¹³ was sought, issues of confidentiality, anonymity, the voluntary nature of participation in the research and any outstanding questions were addressed.

Eight semi-structured interviews were conducted; this number is in keeping with methodological recommendations for IPA (Smith & Osborn, 2008). Interviews were seen as 'conversations with a purpose' (Bingham & Moore, 1959) enabling participants to tell stories about their experiences in their own words (Smith *et al.*, 2009); yet centred on a pre-determined schedule¹⁴ of broad topics for discussion. However, specific ways in which questions were asked and ordered was influenced by participants' responses and the rapport formed (Parker 2005). Interviews were audio-recorded, and transcribed verbatim.

The Researcher

I am a female Trainee Clinical Psychologist, working in South West England; affiliated both to the University of Exeter where I am training and to the NHS, the institution in which I work. Epistemological foundations of IPA make explicit acknowledgment that inevitably the analytical process will involve a high degree of subjectivity as it is shaped by the researcher's interpretative framework. IPA does not seek to bracket the researcher's values and beliefs; instead viewing these as necessary in understanding and making sense of peoples' experiences¹⁵ (Shaw, 2001).

¹² See Appendix 2.8: Extended Information About the Interviews

¹³ See Appendix 4.6: Consent Form (Sample)

¹⁴ See Appendix 2.6: Interview Schedule

¹⁵ See Appendix 2.5: Reflexivity Statement

I do not have first-hand experience of HVs, but have a close friend who has experienced unusual auditory experiences. My understanding of the experience is it is often confusing and distressing for those concerned. In this study, in identifying such preconceptions and involving participants in the analysis, it was hoped this would restrain any presuppositions and limit idiosyncratic interpretations; instead remaining as close as possible to the meaning young people were attempting to convey, enhancing the validity of findings.

Ethical Considerations

Mindful of the potential emotional vulnerability of participants, and the possible impact of speaking of their experiences through involvement in the study, extensive ethical consideration ensued¹⁶ and formal ethical approval was gained from the University of Exeter Ethics Committee^{17,18} and NHS South West REC board^{19,20}.

Description of the Analytic Process

Design

The present study adopted a qualitative, phenomenological, hermeneutic, and idiographic design to enable exploration of the complexities surrounding voice-hearers' subjective experiences, which are not as easily accessible via quantitative measures (Smith & Osborn,

¹⁶ Attention was paid to professional guidance around research (BPS, 2004) and that associated specifically with the experience of HVs (Romme & Escher, 2000).

¹⁷ See Appendix 4.3: Confirmation of Ethical Approval from the University of Exeter Ethics Committee.

¹⁸ See Appendix 4.2: Confirmation of Research Sponsorship and Insurance Cover.

¹⁹ See Appendix 4.4: Confirmation of Ethical Approval from the NHS.

²⁰ Copies of the literature review, research proposal, University ethical approval and sponsorship letter and NHS ethical approval letter were made available to NHS trusts I was recruiting from and to the management and workers of EIS.

2008). This made the use of IPA appropriate as it is concerned with sense-making of people who share similar experiences (Smith, *et al.*, 2009).

Analysis

Transcripts of the eight interviews were analysed in accordance with principles of IPA^{21,22} as described by Smith and Osborn (2008). It was hoped this approach would enable young peoples' personal voice-hearing experiences to be contextualised, explored and comprehended within their lived experiences.

Transcripts were read and re-read and subject to a detailed examination to enhance familiarity with the content. A list of emerging themes was produced for each interview, and subsequently collated to create three superordinate themes and nine constituent themes²³. The themes and narrative account of the young peoples' stories were developed through my interaction with the data, as I attempted to make sense of the participants trying to make sense of their own personal and social worlds (Smith, 2004).

At each stage, care was taken to refer back to original transcripts to ensure themes were grounded in the data, attention was paid to my reflective journal²⁴, and to checking the credibility of the developing themes and analysis with others^{25,26}. Issues of plausibility, power

²¹ See Appendix 2.10: Detailed Description of the Analytic Process

²² See Appendix 2.9: Transcription Notations

²³ See Appendix 3.1: Table of Quotes

²⁴ See Appendix 2.13: Extracts from Reflective Journal

²⁵ See Appendix 2.12: Extended excerpt from Transcript (Interview 2: Rachael) Including Analytic Annotations

²⁶ See Appendix 3.1: Table of Quotes

and validity were also attended to. Established criteria were used to aid this process to ensure sensitivity to the context, commitment and rigour of the method, transparency and coherence of the analysis, as well as the impact and importance of the discussion (Yardley, 2000)²⁷.

Young Peoples' Involvement in the Analysis

Young people who hear voices represent a marginalised group who have been neglected from the research literature. I endeavoured, as far as possible, to privilege the voice of the young people; six of the eight young people contributed to the analysis²⁸. Participant validation was obtained by asking the young people to comment on a model representing the broadly sequential process the experience of HVs appeared to embody for them. Feedback was used to refine the model.

²⁷ See Appendix 2.4: Quality Considerations: Credibility, Plausibility, Power and Validity

²⁸ See Appendix 2.11: Extended Information about Young Peoples' Involvement in the Analysis

Findings

Through analysis three superordinate themes²⁹ were identified, which embodied the process of HVs that unfolded over time³⁰:

- 1). “I’m losing my mind”: The shattered self,
- 2). “I can’t say it in words”: More than words,
- 3). “It just makes a lot of sense like, that I was a bit crazy”: Trying to make sense of voices.

Table 2 details the superordinate themes with their constituent themes and indicates the number of participants contributing to each.

²⁹ Superordinate themes were grounded in and named after participants’ quotes

³⁰ See Appendix 3.2: Table showing the Development of Meaning about Voices over Time

Table 2. Summary of Analysis: Superordinate and Constituent Themes

Superordinate Themes (Number of Participants)	Constituent Themes (Number of Participants)
“I’m losing my mind”: The shattered self (8)	1.1 “I didn’t know who I was. I was even scared of myself” – Fearing, blaming, punishing self (8) 1.2 “I wasn’t going mad or anything, I don’t think?” – Loss of agency, questioning madness (8) 1.3 “I just let everything slip away” – The insidious escalation of voices (8)
“I can’t say it in words”: More than words (8)	2.1 “It’s all like some giant story or something, I don’t know what to make of it” – Struggling to understand and articulate (8) 2.2 “Because I’m taking the meds I think I’m obviously just going crazy like” – Constrained by the medical model (8) 2.3 “I don’t know how to explain what I mean” – The struggle to have a voice and fit in (8)
“It just makes a lot of sense like, that I was a bit crazy”: Trying to make sense of voices (8)	3.1 “I will make sense bout it in the minute” – The complexity of making sense (8) 3.2 “Psychosis...That’s what everyone tells me” – The dominant explanation for HVs (8) 3.3 “Everyone thinking I’m crazy” – Finding my voice, telling stories of stigma, injustice and resilience (8)

Woven through the young peoples’ stories is an overarching sense that the experience of HVs constitutes a pervasive attack on every domain of their lives. Themes were constructed in a way that reflects how their accounts were laden with tales of disruption and confusion in relation to their: sense of themselves; relationships with concepts of ‘voice-hearing’/‘psychosis’; and relationships with others.

“I’m losing my mind”: The shattered self

Intertwined through the stories is how frightening experiences compounded already unsafe lives provoking a shattering and incomprehensible loss of all they knew about themselves. Attempts to make sense of disturbing experiences were hindered by the absence of any experience that could compare to the incoherence and fear they experienced. The magnitude of their experiences shook to the core their sense of themselves in their worlds leading to a terrifying and disintegrating sense of reality.

1.1 “I didn’t know who I was. I was even scared of myself” – Fearing, blaming, punishing self

Each person’s account alluded to disruption (distressed families, bullying, loss, traumatic histories) occurring before the emergence of voices, suggesting their worlds had not felt safe prior to HVs.

“other experiences (...) when I was younger, which I don’t really want to talk about, and I think it’s to do with that.” (Rachael: 129-130)

They spoke of the confusing nature of voices developing from loud thoughts, whispers, “*a dull roar of a crowd*” (Carl: 3), and “*gibberish (...) random words*” (Rachael: 88). Difficulty discriminating voices from self-talk caused further uncertainty.

“I’ve always like heard voices in my head (...) my own voice (...) I started hearing louder voices (...) like someone had just put like a little speaker-microphone in my ear and was communicating with me” (Jake: 50-53)

For two young people their voices occasionally offered comfort and reassurance:

“it can be saying ‘it’s alright, everyone likes you like though mate’” (Jake: 312)

Yet, voices were predominantly negative. Voices became more frequent and intense, causing them to increasingly doubt their perceptions: *“I would hear someone call my name and when I looked back...no-one’s there” (Ellie: 92)*. They spoke of the profound and pervasive uncertainty it engendered:

“I didn’t know what I was, who I was, what I’m doing, why I’m like this” (Claire: 738)

Uncertainty escalated as they grappled with making sense of whether it was them or something else causing the voices.

“I thought it was a person but I thought it was just like an evil kind of voice in my head as well.” (Claire: 47)

Losing trust in others they withdrew. Fear became so pervasive they became afraid of themselves; in an attempt to withdraw they used drugs/alcohol or resorted to self-harm to take *“it out on themselves” (Claire: 196)*. *“Holding my hands to stop myself from worrying” (Harry: 56)*, creating protective people, or using aggression and violence were other ways of tolerating and/or communicating distress.

“[angel] put her hand on my shoulder.” (Ellie: 239)

“locked myself away and used drugs all the time (...) my relationship with my family deteriorated, I became quite aggressive and would smash things, argue and fight with people” (Carl: 71-73)

With a sense of resignation they described feeling the experience would never end:

“I thought I was just going to slowly lose my mind and never recover” (Carl: 393)

1.2 “I wasn’t going mad or anything, I don’t think?” – Loss of agency, questioning madness

Voices were described as relentless, menacing presences conveying “*blaming, guilt and (...) demanding statements*” (Megan: 27) and, for some, “*screaming*” (Ellie: 109).

Voices progressively became louder, more intrusive and difficult to “*tell if it’s reality or not*” (Rachael: 157); developing into discrete characters: “*a little girl with long black hair (...) a man saying: ‘Do you feel empty?’*” (Carl: 134-147), and hearing “*my boyfriend*” (Rachael: 54) or friends.

They became increasingly terrified as other distressing experiences emerged. Visions: “*seeing insects crawling on my skin*” (Carl: 299); weakened control over thoughts, as though generated from outside their intentions and inserted/broadcasted into their mind: “*I swear it’s not me thinking them*” (Jake: 185); behaviour violated, incompatible with self: “*that wasn’t me*” (Harry: 45); and persecutory beliefs others want to harm/kill them or their loved ones.

With “*no idea what was happening*” (Megan: 21) they struggled to negotiate any meaning from their experiences other than to consider the alarming prospect they were going insane.

“I just kind of thought ‘Oh I’m losing my mind.’” (Carl:50)

Voices persisted and the young people attempted to manage experiences yet failed, feeling “*weaker than ever*” (Claire: 132).

1.3 “I just let everything slip away” – The insidious escalation of voices

Young people presented narratives of escalating demands and fear. Hostile voices condemned them, often denoting threats of harm and persecution.

*“it told me to like cut myself (...) if I didn’t then people would get hurt, like my family”
(Debbie: 48-49)*

Initially commanded to do fairly harmless acts of aggression and self-harm; they struggled as demands grew to ones with potentially dangerous and damaging consequences for themselves and, at times, others. They were left feeling passive to commands, disempowered and frightened.

“I was like in the darkest moment. And, I just didn’t know what to do so I just listened to the voice” (Claire: 46)

Loss of trust in self, feeling unsafe and unable to engage in meaningful activities/roles, the young people defended against this imminent threat to selfhood by withdrawing. However, this further fragmented their social world, self and identity. Detached from others amid bizarre, distressing encounters was terrifying. This loss of connection led to hopelessness and despair. *“More alone than ever” (Claire: 61)* some alluded to considering suicide: *“you just want to give up altogether in life” (Claire: 760)*. However, reaching this point of desperation and fearing losing themselves appeared pivotal in spurring help-seeking.

“I can’t say it in words”: More than words

Each person experienced difficulty in articulating their experiences. Language felt restrictive as they struggled to express the complexity, confusion and terror of HVs. They sought to speak about their experiences in ways that made sense for both themselves, and me. Sense-making appeared further constrained in their attempts to relate unspeakable experiences to limited, often simplified, explanations available to them.

2.1 “It’s all like some giant story or something, I don’t know what to make of it” - Struggling to understand and articulate

Negotiating a way of understanding voices permeated their narratives; they sought alternatives to ‘madness’.

“you know I mentioned that I heard voices, you know when I explained why I hear voices in my head, you know the reason why I, um, (...) I’m trying to explain properly.” (Ellie: 448-451)

Confusion and difficulty articulating experiences became apparent in their fragmented language with “I don’t know” saturating their stories. It appeared ‘reality’ was experienced as distorted as they struggled to remember or make sense of events they were trying to describe, having often to concede that they could not find the words.

“I don’t know. I don’t really know what’s happened so...I don’t know what to say.” (Jake: 246)

Unable to contain their distress alone and fearing ‘madness,’ they found ways of asking for help. Few disclosed HVs: *“I eventually told my Mum that I needed to go to the doctors for*

sleep” (Harry: 102). Some approached those outside family/friends, such as “*Childline*” (Debbie; 310). Sharing their secret “*felt like a weight had been lifted*” (Megan: 116). Largely unaware of professional services they could access, others helped them make contact with services.

2.2 “Because I’m taking the meds I think I’m obviously just going crazy like” - Constrained by the medical model

In their contact with services, some spoke of feeling assigned a ‘sick role.’

“I don’t like (...) feeling ill” (Rachael: 278)

The medical conceptualisation constructs voices as a ‘symptom’ introducing the potential professionals will be able to remove it. A sense of immense disappointment saturated accounts as they spoke of their experiences persisting and how professionals led them to believe they could provide explanations/interventions that would help, but failed to take the voices away.

“they were all telling me ‘you’ll take Lorazepam...and you’ll get better’ (...) I don’t feel I’m getting better” (Carl: 465-468)

One individual described how medication “*did help the voices go away*” (Ellie: 262). Mostly, it only offered some relief³¹.

³¹ Medication was described as helping improve sleep and reduce the frequency and intensity of their experiences.

“it allows me to live a normal life (...) to get on with it...rather than actually like remove my symptoms” (Carl: 421-423)

For many it was too unbearable to relinquish the hope medication would get “rid of voices” (Rachael: 182) eventually.

There was greater emphasis on ‘symptoms’ and side-effects of medication than attempts to understand their subjective experience.

“he [Psychiatrist] just says ‘what are you experiencing?’ (...) ‘ok we’ll continue this dosage’” (Carl: 412-416)

Few were asked how they understood their experiences or were supported with sense-making. Over time they developed tentative initial explanations for their voices: supernatural forces; “schizophrenia” (Rachael, 172); implanted “speaker-microphone” (Jake: 97); symbolising “something special” (Ellie: 83); “taking too many drugs” (Carl: 27); and “people (...) pumping drugs into the water” (Harry: 16).

Yet, the power of ‘expert’ opinion, biomedical explanations and treatments suggested to some that their entire account of their experience was a confabulation, leaving them feeling undermined and uncertain.

“because I’m taking meds I think (...) ‘oh I’m just going crazy, they’re just voices like, it’s just some big made up story like’ which is why I keep taking my meds like. I’m obviously making it all up.” (Jake: 134-138)

2.3 “I don’t know how to explain what I mean” - The struggle to have a voice and fit in

Finding words to encapsulate the intensity of voices bordered on ineffable; keeping them distanced from others and further removed from the world. It became painfully apparent how little any explanation, including psychiatric explanations, could help them speak about their experiences because *“they don’t understand”* (Rachael: 242), cannot *“relate to it”* (Carl: 325) and *“they’ll just think I’m weird”* (Debbie: 259).

Even if they could find the courage and words to share experiences they remained unsure who their disclosures may be imparted to. Voice-hearing was construed as a shaming, isolating experience. Many used humour to defensively minimise distress and humiliation evoked in recounting their experiences.

“They’d probably just think I was crazy or something [laughs]” (Rachael: 248)

Aware of *“the whole stigma of having mental health problems”* (Megan: 113), their accounts were infused with fear of judgement and discrimination. Experiences frequently remained unspoken, difference and distress concealed: *“I don’t really like telling people”* (Debbie: 333) because *“they’d be like ‘well this guy’s nuts’”* (Carl: 368).

Some hid distress to protect others; the inner struggle invisible yet consuming them and increasing alienation.

“[Mum] thinks I’m better than I am I think. I like it like that because she worries and gets stressed. As long as I’m not really, really bad she doesn’t know about it.” (Carl: 333-334)

They increasingly questioned their ability to conceal experiences and voiced growing concern about how others perceived their behaviour as *“a bit odd sometimes”* (Debbie: 261). They spoke of longing to *“fit in”* (Harry: 83); HVs, being diagnosed with psychosis and becoming a psychiatric patient tainted their identity: *“I call myself loopy”* (Carl: 366); insufferable at a time in their lives when peer acceptance was so important.

“I just wanted to be a normal teenager (...) go to school without hearing any voices, self-harming (...) getting bullied, having family problems.” (Claire: 557-558)

Somehow succeeding in finding words to capture the disorienting experience, they shared experiences to re-engage and feel *“understood more”* (Rachael: 244). Most spoke emotively of feeling others *“won’t believe me”* (Debbie: 251) or feeling *“misunderstood because they probably thought there was something wrong with me”* (Ellie: 332). Shame and hopelessness caused further withdrawal and emotional detachment, suspending efforts to express themselves to avoid being dismissed as *“daft”* or *“insane”* (Harry: 43).

For some, disclosures were eventually supported as others *“tried to understand”* (Megan: 112), did not *“treat me differently just cos I hear voices”* (Claire: 353), and facilitated their sense-making.

“It just makes a lot of sense like, that I was a bit crazy”: Trying to make sense of voices

These young people faced many challenges in trying to make sense of experiences that defied any simple explanation. Making sense seemed to be a, more or less, elusive process that would, if attainable, involve reaching comfortable understandings of: who they were, what

the voices were in relation to them, and who they are in relation to others in their worlds. Permeating their accounts was their need to develop personally meaningful understandings, which could be validated by others. Importantly, they negotiated these challenges in the context of physical, emotional and social upheaval of transitioning from adolescence to adulthood.

3.1 “I will make sense bout it in the minute” - The complexity of making sense

Young people grappled for months and years to make sense of an array of terrifying phenomena; attempting to negotiate explanations offered by others³² into incomplete and fragmented narratives of their own lives and selves. Impersonal explanations were rejected; whilst explanations making personal sense were accepted or refined.

“she [family friend] told me to tell them to cross over, she thought I was seeing dead people...I was terrified, but honestly thought it was a load of rubbish.” (Megan: 96-98)

For some, sense-making had barely begun: *“helpful for me to someday figure out why” (Ellie: 314)*. When they *“didn’t know who to turn to” (Claire: 60)* this slowed meaning-making, thus those with greater support appeared to make sense earlier. Social isolation, loss of self, safety and ongoing fear interrupted the process of integrating their experiences into a narrative. Confusion was compounded by disappointment that others were unable to offer meaningful explanations.

“the Psychiatrist said (...) I wasn’t like letting kind of my anxiety out (...) but I don’t know” (Debbie: 111-114)

³² Supernatural encounters, low self-esteem, anxiety and psychosis were explanations offered by others to account for their voices.

Some were able to occupy more than one perspective on their experience: *“I reckon it’s just to do with genetics and environmental stuff”* (Rachael: 123-126). Deliberations between opposing perspectives reflected ambivalence or attempts to make explanations personally significant.

Poignantly some came to view voices *“as just being me”* (Claire: 511); understanding voices as disowned selves and realising *“they are a part of me (...) I am the one that controls them (...) I do not need to be scared of myself”* (Megan: 61-68.) This involved developing an understanding of what elicits and intensifies voices: *“rationalising and understanding what I am anxious about”* (Megan: 64); a process that took place over time. Voices became understood as emotional reactions, a part of themselves, endowing them with a sense of agency. Fear subsided as voices no longer represented an uncontrollable, external, malevolent entity.

Some were able to begin to recognise how they had struggled to cope with past traumatic events and stress. Emotional development also contributed to increased awareness exposing them, for the first time in their lives, to pain they had sought to evade. Over time, they were able to link this to the emergence of ‘psychosis.’

“I seemed to become more emotionally aware (...) I had never really accepted or shown any emotion, it was all bottled up from my childhood (...) slowly leaking into my conscious memory” (Megan: 40-45)

Continuing to relate to painful experiences whilst trying to make sense of their self, identity and relationships; some reflected on wanting to respond differently to avoid concealing or

isolating themselves, things that could compromise important relationships. Yet, most remained uncertain about how to do this successfully.

*“I need to stop being paranoid (...) I’m going to push people away who I love the most”
(Claire: 599-601)*

“after we’d been together for a while I said ‘there’s probably something you should know about me’” (Carl: 336)

3.2 “Psychosis...That’s what everyone tells me” - The dominant explanation for HVs

Professional opinions were highly influential to their sense-making due to assumptions about the ‘knowledge’ these experts must hold.

“I just accept that [diagnosis of psychosis] and think well they’re obviously right.” (Jake: 209)

Psychosis was the prevailing explanation for HVs, but how they negotiated their relationship to this differed. For some, medical and psychological models validated and expanded their understanding, but these created further confusion for those who began sense-making in the absence of biomedical knowledge and for whom these concepts were too dissimilar to their understanding.

“now I think ‘oh shit am I having a psychotic episode a bit’ and then I sometimes still think ‘oh shit I’m on a wire.’” (Jake: 301-302)

Biomedical explanations (i.e. drug, fatigue or stress-induced) were more likely to be validated by others than alternative beliefs, thus these individuals appeared to make sense earlier. One person spoke of how all explanations offered have *“always been drug-related”* (Carl: 86), whilst others spoke of how spiritual or persecutory beliefs were dismissed: *“told*

my Dad about it but he just thought I was insane” (Harry: 43). Yet, those with biomedical understandings, which were external to self, appeared to struggle with having a sense of agency over voices, instead relying on medical interventions, which left many feeling passive to psychiatric treatment.

Psychological and psychiatric models offered by services included: anxiety, “*memories*” (*Ellie: 162*), stress-vulnerability, fatigue and drug-induced psychosis. Subjective experiences received less emphasis in many of these stories; instead psychosis (as medically and psychologically defined illness) became the dominant story often neglecting traumatic histories whereby ‘symptoms’ can be seen as profoundly meaningful attempts to endure overwhelming and distressing life events.

“I believe that everything I hallucinate, everything I hear has, like I’ve picked up from somewhere” (Carl: 291)

“seeing a Psychiatrist (...) didn’t really help my understanding (...) he’d be like ‘right I’ll give you Lorazepine’” (Carl: 410-413)

Young people were not content with a solely medicalised conception of psychosis as ‘illness,’ evident as they spoke of tentatively linking past distressing experiences to voices. Some developed sophisticated ways of understanding experiences as meaningful in the context of their life, often integrating parts of different explanations.

“a little bit might be genetic (...) I have experimented with drugs, I think it might be that as well (...) other experiences (...) when I was younger” (Rachael: 128-130)

Inadequate explanations of psychosis amplified confusion: *“hearing a voice in my head (...) I don’t really get how that’s psychosis. I thought that was just normal really” (Jake: 217-229).*

Some used the internet for *“understanding what psychosis was (...) knowing other people experience it, it wasn’t just me”* (Carl: 454).

Over time, they developed ways of coping: ignoring or muting voices. They used medication, *“a joint”* (Carl: 190), sleep, *“meditation”* (Jake: 184), humming, listening to music, *“painting to (...) let everything out”* (Debbie: 70), *“write poems”* (Claire: 96), *“being with friends”* (Claire: 336), managing anxiety: *“I write stuff down now if I need to remember, I don’t tell it over in my head”* (Harry: 114), and reassuring themselves *“I’m just having a psychotic episode”* (Jake: 334) as opposed to other disturbing beliefs about voices.

Some developed confidence to cope: *“I cope with them a lot better (...) forget they are there”* (Megan: 77); but for others it remained intolerable to consider it returning: *“I never want it to happen again”* (Harry: 209).

3.3 “Everyone thinking I’m crazy” - Finding my voice, telling stories of stigma, injustice and resilience

The most prevalent difficulty was stigma. Many feared being further abandoned to the ‘illness’ and pleaded for others to not lose sight of them.

“I’m not a complete and utter weirdo just cos that happens, I’m still me, like it doesn’t make me any different.” (Debbie: 336)

Some spoke of gathering broken pieces to try and put themselves back together, of strengthening their sense of self and agency; involving integrating adverse experience into a more coherent narrative of who they are and what they have been through.

“things that I’ve been through have made me stronger in myself (...) they can judge me all they like, they don’t know me. I only know myself.” (Claire: 738-757)

Often contributions from mental health services helped: feeling understood, validated and normalised when *“I didn’t think anyone would understand” (Carl: 393)*; developing trusting relationships; regular support and ways of coping; facilitating sense-making; *“genuinely interested” (Megan: 143)* in wellbeing beyond ‘psychosis’; and assistance with getting *“benefits sorted” (Jake: 442)*, *“off drugs (...) into a routine (...) to go back to college” (Carl: 399-403)*.

Some reported disempowering experiences of services: *“Sectioning me” (Jake: 438)*; finding questions *“intrusive” (Jake: 403)*; not *“understanding what psychosis was” (Carl: 454)*; asked *“the same questions”* and given *“the same explanations” (Ellie: 360)* leaving them feeling *“they don’t believe me” (Ellie: 395)* and unsupported in endeavours to make sense.

Young people avidly expressed how other voice-hearers should not be silenced, stigmatised and isolated by their experiences and others’ reactions to them; to not renounce hope *“as there is always someone out there (...) willing to listen...you are not the only one, so many people hear voices but suffer in silence, the sooner you talk about it the better” (Megan: 153-155)*; *“you’re not alone” (Harry: 220)*.

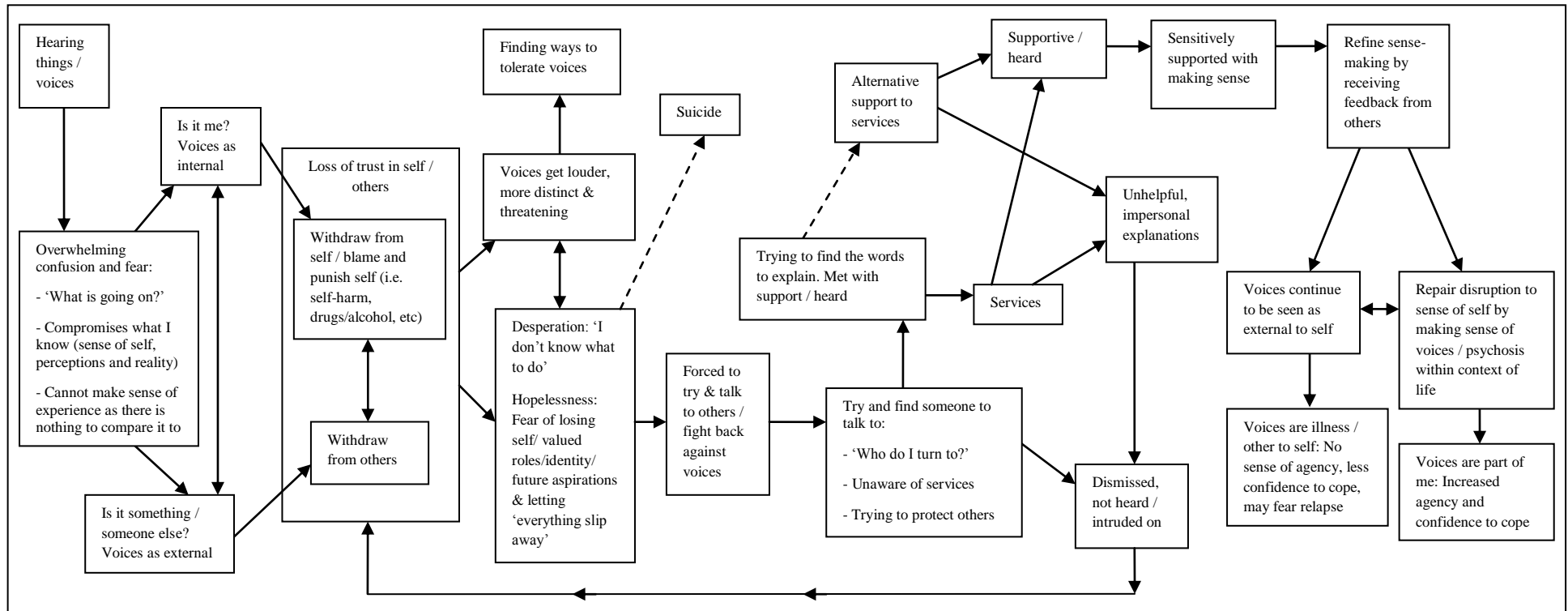
Seven of the eight young people continued to hear voices. For most, it continued to terrify and disrupt their lives. Some had adapted to living with the experience, but most longed to be free of voices.

The young people were at various stages, but described similar distressing experiences causing a disturbance to their sense of self; the importance of how others reacted to their disclosures; and the need for others to help them make sense to develop an understanding of voices as part of or separate to their sense of self. Those who spoke of being more able to cope with their voices had heard voices for a longer period of time; received support in making sense to be able to understand their voices in a personally meaningful way; and described changes over time in their relationship with voices enabling them to become more accepting of their experiences, which facilitated coping.

“I used to think I was going mad, but with help (...) I am more informed of what they are, which made me come to the conclusion that they are due to anxiety, I think once I understood it that was when my perception changed (...) I can't really imagine life without them.”
” (Megan: 67-75)

Figure 1 summarises this transitional process. Derived from, and grounded in the young people's accounts; all the young people involved in the analysis validated the model as an accurate representation of their personal experience of adapting to HVs during FEP and one minor refinement was made on the basis of feedback.

Figure 1. Diagrammatical representation of the experience of making sense of HVs



- - - - -> Possible routes
 —————> The process of making sense

Discussion

The aim of this research has been to capture the impact of HVs on young peoples' sense of self and how they made sense of the experience by looking in detail at young peoples' accounts and employing, as far as possible, their own descriptions of the process. In my attempt to provide a narrative account of eight young people's experiences of HVs, it was not my intention to suggest a simple linear process of making sense of the experience as suggested in research with adults (i.e. Romme & Escher, 1989). In contrast, the stories I heard were suffused with confusion as young people attempted to make sense of terrifying experiences that had a profound impact on their sense of self and lives. Many continue to struggle with understanding their experiences; yet others gradually found a way of making some sense. I attempted to conceptualise this journey in Figure 1, using each of the young peoples' accounts to delineate this process. Experiences appeared to be embedded within a series of vulnerable periods, which led to a stronger sense of self and resilience if they could be overcome.

HVs caused such pervasive fear and uncertainty young people retreated; lonely and isolated, voices increasingly dominated their young lives. Relationships became a source of mistrust and confusion as they attempted to decipher whether voices were caused by others or came from within themselves. When they were able to share their experiences, they often felt undermined, disbelieved or dismissed. These crushing, often stigmatising, encounters were experienced as denunciation at a time of great need. They experienced support offered from services as expert-led and symptom-focused, with little exploration of their subjective experiences.

The Young People's Experiences of Themselves

The findings in relation to these young peoples' voice-hearing experiences are important in extending the literature on the meaning of a disturbance to self in psychosis; presenting alterations in sense of self as a consequence of HVs and isolating oneself rather than as a causal factor in the emergence of psychosis/voices as earlier models have suggested (e.g. Harrop & Trower, 2003; Laing, 1978).

Participants in other studies have provided coherent accounts offering sophisticated reflections of their experiences and causal attributions (Geekie, 2004; Roe & Davidson, 2005). In contrast, young people in this study spoke of tremendous confusion shattering their sense of self, apparent in their struggle to find words. Three core features contributed to a disruption to their sense of self: first, HVs compromised all they knew about themselves and their worlds causing them to doubt the perceptions they rely on to ground them in 'reality.' This lack of trust in self was intensely distressing and others suggest it is a prime cause of suffering in psychosis (Geekie, 2004; Stone, 2006). Second, they had no other experience to compare to the chaos and fear of HVs. Lastly, they withdrew from others, compromising their social functioning and identity.

These findings corroborate existing research in many ways. HVs in adolescence/early adulthood involves the dichotomy of adjusting to FEP whilst developing a sense of identity, negotiating individualisation and relationships with peers, separating from parents, striving for autonomy and, for some, moving away from home for the first time (Braehler & Schwannauer, 2012). Uncertainty of where to seek help, worry about stigma and labelling

obstructed access to support for some young people (Perkins *et al.*, 1999). Young people kept difficulties to themselves and actively sought to conceal unusual behaviour from others (Judge *et al.*, 2008). Some alluded to suicidal ideation symbolising a pivotal moment in help-seeking (Addington *et al.*, 2002); for others disclosure only occurred when ‘symptoms’ became debilitating (Boydell *et al.*, 2006).

The Young People’s Experiences of Voices/Psychosis

Experiences of HVs resulted in their contact with psychiatric services. Some struggled to understand how ‘psychosis’ could explain their voices. For others, psychiatric input contributed to a ‘sick’ identity, medication confirming their sense of being ‘crazy’ resonating with previous findings (Estroff, 1981).

Young people perceived voices as coming from internal or external sources; relating to other research (e.g. Romme & Escher, 1989; Newton *et al.*, 2007) showing that having a sense of agency enhances coping. This was more apparent in those viewing voices as integral to self. Viewing voices as other to self (i.e. an ‘illness’) made developing a sense of agency more difficult as it affected subjective appraisals of control (i.e. greater emphasis on the belief that medication controlled voices increased fear of voices as they were viewed as uncontrollable when medication was unsuccessful at removing voices). This links to wider psychological literature into processes of adjustment to chronic health conditions, such as tinnitus (Sirois *et al.*, 2006), whereby developing a sense of control (i.e. active distraction strategies) can reduce feelings of helplessness and distress. This is specifically reminiscent of research into locus of control (Rotter, 1954; Watson *et al.*, 1990), whereby shifting the meaning of a health

condition from something uncontrollable to something conceivably more manageable means individuals are often able to adjust to their condition. Moreover, often dissatisfied with sole medical conceptualisations of HVs (Larsen, 2004); many integrated notions of illness with adverse life experiences³³. These findings are consistent with McGlashan *et al.*'s (1975) recovery styles. An 'integrative' style, characterised by flexible thinking, enables psychosis to be understood as a product of adverse life experiences, and accommodated into their life context in a similar way to having an internal locus of control. Conversely, people who 'seal over' have fixed, usually negative, views of psychosis, treating it as separate to self, often not striving to understand their psychotic experiences within their life experiences and continuing to fear relapse (i.e. an external locus of control).

The Young People's Experiences of Others

Seeking meaning and constructing personal explanations for voices was of vital significance to the young people; consistent with Geekie's (2004) notion of 'authoring.' Sharing their story and receiving validation helped them make sense of their experiences; acquire a sense of personal agency and more integral sense of self. Hammack (2008) proposes we construct our identity through telling our stories and the reactions of others to those stories. This finding supports theoretical propositions that one's sense of self is mutually interdependent on one's sense of other (Mead, 1968); that the centrality of others and their views can help reclaim a sense of self and rebuild broken identities (Ridgeway, 2001; Stone, 2006).

³³ For example, some viewed traumatic, stressful events as factors creating a vulnerability to developing psychosis and constructed explanations incorporating biopsychosocial factors to create more meaningful explanations.

Feeling dismissed, silenced or intruded upon when sharing voice-hearing explanations was damaging (Geekie, 2004). These findings extend existing research by suggesting invalidation can cause the person to withdraw, delay help-seeking and slow sense-making.

Critical Evaluation

It has been argued that phenomenological research attends to the appearance of phenomena with little regard to the cause or origin, which may limit our understanding of why such experiences occur (Willig, 2001). I attempted to consider the young people's experiences in the broadest sense taking into account their histories, experiences of HVs, relationships and the impact these experiences had on their sense of self.

Attempts to recognise the inherent subjectivity that has contributed to the construction of meaning throughout this research have been made; whilst acknowledging the impossibility of remaining outside the subject matter (Willig, 2001). However, this research is an attempt to provide as accurate a representation of eight young voice-hearers experiences as possible to help inform understanding in this area.

One may question how representative or generalisable findings are. IPA ultimately aims to achieve theoretical, rather than empirical generalisability (Smith *et al.*, 2009). While no attempt is made to elicit 'universal truth,' findings may be linked to professional experience and to the extant literature (Smith & Osborn, 2008). As findings are not broadly generalisable, results may have minimal impact on provision of services; yet can direct

further quantitative research, which can have this impact. Furthermore, the findings can influence clinicians working in the field (Marshall & Rossman, 2006).

Participant validation was used as a credibility check; young people commented on a model grounded in themes from the analysis (Silverman, 1993). Such approaches have been criticised for resulting in claims which disguise the inequalities present (Potter & Wetherell, 1995). Inviting young people to comment on the analysis inevitably created a disparity in power. I endeavoured to make this inequality transparent by acknowledging they may struggle to question/disagree with findings, but encouraged them to do so to increase the richness of the data. Those providing feedback expressed how they felt the model provided an accurate conceptualisation of their experiences. One participant made a suggestion resulting in a minor refinement; the others struggled to identify any aspect of their experience that was neglected, but spoke in detail about how their subjective experiences mapped onto the model. I therefore feel their involvement strengthened both my argument and the ethical integrity of the research by ensuring their views were not misrepresented.

Clinical Implications

When coming into contact with EIS, young voice-hearers in this study had lost trust in themselves and others. The value of simply ‘being with’ young people when they are distressed should be emphasised to help professionals^{34,35} build trusting relationships, affirming their emotional distress and alleviating pressure to ask “*intrusive*” (Jake:403) questions too early (May, 2004).

³⁴ See Appendix 6.1 for Dissemination Plan

³⁵ See Appendix 6.2 for Author Guidelines for Publication

Findings suggest more attention needs to be paid to the subjective experience of HVs through respectfully inquiring about young peoples' beliefs about their voices, validating and supporting attempts to make sense. Research has shown voice-hearers can find it beneficial to discuss their voices in a safe, supportive, non-judgemental environment (Coffey & Hewitt, 2008; Lakeman, 2000). Professionals need to be aware of the risks of invalidating clients' efforts at authoring (Geekie, 2012; particularly as diagnosis could be experienced as invalidating if this is not consistent with beliefs about voices, potentially leading to disengagement from services. Findings suggest discussing and negotiating meaning within a context recognising the plurality of ways of making sense of HVs and presenting diagnosis as one way of understanding the experience may help people have a sense of agency in this process reducing risk of invalidation.

Young people reported receiving insufficient information about the concept of 'psychosis,' thus it is important diagnosis is explained coherently. Kilkku *et al.* (2003) demonstrated the key role information plays in making sense of psychotic experiences. Providing information at the beginning of care can provide relief, become a tool for crisis management, help with integrating and accepting experiences and may help young individuals feel they are being cared for.

The young people wanted the devastating experience of HVs to be removed. One clinical implication may be to consider how clinicians can sensitively and honestly explain limitations of medical interventions in reducing voices. A way of supporting this may be to make recovery more visible in services. Involving peer-mentors in services/groups and

making recovery narratives available to young people could provide hope showing it is possible to lead a fulfilling life whilst continuing to have unusual experiences.

Feelings of shame, difference and isolation resulted from young people's experiences.

Groups could reduce isolation, providing safe spaces where experiences can be shared and explored with other young voice-hearers. Research has found this helps normalise young people's feelings, support integrative processes (Mackrell & Lavender, 2004; Newton *et al.*, 2007), and may help with beginning to differentiate identity from the pervasive negativity of voices, instead working towards other valued identities (i.e. someone able to cope with voices), thus developing a stronger sense of self (Chadwick, 2006; Dillon & Longden, 2012). Crucially such interventions are based upon engaging with peers, an underlying developmental process typical of young adults.

Wider social change is needed to help combat stigma, which made HVs an isolating experience for the young people. Brief educational courses have reduced stigmatising attitudes (Pinfold *et al.*, 2003). EIS aim to support mental health anti-stigma campaigns directed at young people (Bertolote & McGorry, 2005); interventions in schools could be effective in initiating social change, particularly if people shared their experiences of HVs/psychosis to help normalise the experience and raise awareness (Rüsch *et al.*, 2005).

Future Directions

The young people I spoke to were service-users aged between 16 and 23. EIS work with young people aged 14 to 35; further research may want to attend to the experiences of people within this age range and those who have not engaged with services.

Subsequent empirical research could further test, elaborate and refine this model, and evaluate it quantitatively; a refined model of early adaptation to HVs could be a helpful clinical and service tool.

Further research could pursue a discursive investigation of young peoples' experiences of HVs³⁶; exploring professional language they adopt as the types of discourses available tend to restrict and shape how the self is constructed (Burr, 1995).

Conclusion

Current findings confirm young people who hear voices experience profound fear, isolation and uncertainty compromising their sense of self and hindering sense-making. Regaining social contact, sharing experiences/understandings and receiving validation and support with sense-making, enabled young people to reclaim a more coherent self. Integrating voices into their sense of self appeared to facilitate a greater sense of agency and ability to cope than those adopting an understanding of voices as external to self, even construed as illness.

³⁶ See Appendix 5.1: Future Directions for Further Research

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Appendix 1. Extensions to the Introduction

1.1 Extended Information about Issues of Definition in the Research Literature

Literature

In addition to the difficulties inherent to diagnosis-led approaches to research, often involving heterogeneous samples of people with different experiences, but the same diagnosis, further variation exists in definitions of age, and in concepts of ‘self’ and identity.’

Issues with Defining Young People, Adolescence and Early Adulthood

Adolescence is considered to indicate a transitional period commencing at the onset of puberty, progressing through a number of developmental milestones and culminating in adulthood (Arnett, 2000). A number of factors make adolescence difficult to define. Firstly, individuals experience this phase differently depending upon physical, emotional and cognitive maturation. Reference to the onset of puberty, which might be seen as a clear line of demarcation between childhood and adolescence, cannot resolve the difficulty of definition as puberty occurs at different points for girls and boys, and for different individuals of the same sex. Secondly, the end of adolescence/beginning of adulthood is largely debatable, but is increasingly seen by many researchers to take place sometime in the early twenties (Burt *et al.*, 1998); recognised by Erikson (1963) as ‘prolonged adolescence’ (Côté, 2009). During adolescence, issues of identity formation, as first theorised by Erikson (1968), and increasing emphasis on relationships, both with peers and romantic relationships, become important (Larsen & Richards, 1991).

Some have argued a sub-division of adolescence into early: ages 10-14 years, and late: ages 15-19 years, would result in greater homogeneity, particularly given the physical and neurological development occurring in early adolescence and the gulf in experience separating younger adolescents from older adolescents (UNICEF, 2011). In addition, Arnett (2000) argues for a theory of development with a focus on 18-25 years, the period he coins 'emerging adulthood,' which he argues is theoretically and empirically distinct from both adolescence and young adulthood. He argues young people in industrialised societies increasingly spend their late-teens through to their mid-twenties in self-focused exploration. Thus, identity formation can occur at variable rates depending on circumstances and opportunities (for example, if young people are able or choose to go to university).

The literature suggests all young people go through a similar 'adolescent' period where school, college and other opportunities are available (Erikson, 1963). Yet, this may not always be the case and the experience of psychosis at this time could cause this period to be experienced very differently, and possibly as a loss (Tarrier *et al.*, 2007).

Issues with Defining Identity and Self

A major difficulty in the study of identity and self has been definitional (Côté, 2009); both concepts are multi-dimensional and have no single or simple definitions and different domains of psychology and sociology can diverge greatly on the meaning of these terms and difficulties arise in this area when different researchers sometimes using the same terminology to refer to different phenomena (Côté & Levine, 2002). Within social psychology theories discriminate between personal identity and social identity. Personal

identity is based on continuity of the person's psychological functioning, interpersonal behaviour, and commitments to roles, values and beliefs; whereas social identity is defined more in terms of the person's sense of who they are based more upon group memberships and social relations (McLeod, 2008) and can take into consideration reflective awareness and self-regulation in how we behave in social contexts. Moreover, Thorne and Nam (2007) argue that one's sense of self is located in the context of our communities, and although personal identity is unique it is influenced by cultural values and by those to whom we tell our stories. Thus, this relates to how discourse or giving voice can be considered equivalent to identity and thus self and identity should be considered relational concepts (Mead, 1967; Sands, 1996).

Appendix 2: Extensions to the Method

2.1 Theoretical and Methodological Considerations

A number of factors influenced the decision to use IPA. Firstly, it was selected as the most appropriate methodology due to its compatibility with the epistemology of the research question. Secondly, given the historical and political context of the treatment of those who hear voices, I wanted an idiographic method allowing detailed exploration of individuals' accounts to remain true to their experience. Thirdly, I sought an inductive approach, allowing ideas and themes to emerge from the personal accounts as I did not want to impose a predetermined theory, but rather to hear the young peoples' stories in order to capture and explore the meanings they assign to their experiences. This opens up possibilities yet to be considered; 'unexplored territory' where a theoretical pretext may be lacking and can provide meaningful and unexpected analysis of psychosocial issues (Reid *et al.*, 2005).

A phenomenological methodology reflects my belief that while it is not possible to directly access others' experiences, and discourse attempting to elucidate such experience can complicate this process, things of significance about the person and their experience can be drawn out through conversation and subsequent analysis. In substantiating this, I will consider my position, and that of this research, in relation to the three theoretical underpinnings of IPA: phenomenology, hermeneutics and idiography.

In attending to the unique and diverse accounts of these young people (idiography), I had to reflect on the extent to which I felt it was possible to reach the essential meaning of their experiences (phenomenology), whilst considering the potential implications of my own and

their interpretations (hermeneutics) when attempting to capture the quality and texture of their individual experience and unravel the meaning within the account. Reflecting upon my position within this provided clarity about what I believed I could access in dialogue with the young people and then subsequently analyse, and what conclusions and recommendations might then be reasonably drawn from such findings.

Phenomenology

This study is phenomenological in that it attends to the experiences of others, viewing and recruiting participants as experts on their own experiences who can offer an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words (Reid *et al.*, 2005). Yet, I contend there are two fundamental reasons that I was unable to directly access the experiences of the young people in my conversations with them. First, interviews provide retrospective accounts of experiences and the distance in time means they cannot be recalled precisely as they were, as the act of reflecting upon oneself and experiences in the present necessarily eludes the experience. Furthermore, the experience has been made sense of by the participant, and subsequently by me; a succession of inevitable happenings termed ‘the interpretative gap’ (Parker, 1999). Second, experiences are largely beyond recounting, in that they cannot be described as they are or were because so much of experience, for example emotions and thoughts, cannot be brought into being through language as often the complexity escapes words. As Nightingale and Cromby (1999, p222) elegantly put it: ‘our lives are so much more than we can say.’

Hermeneutics

Hermeneutics, the study of interpretation (Smith *et al.*, 2009), was incorporated into the study. I attempted to reflect on the nature of interpretation and the ways of making sense that were occurring throughout the analysis, not only to the area of HVs, but also to the context of the study itself. The method relies on individuals being able to explain their experiences verbally and some experiences, particularly those linked to trauma, for example, often lead to lost or fragmented memories which may colour the interpretative process (Herman, 2001). However, care was taken in construction of the Interview Schedule to facilitate the young people in articulating their experience (for example, additional prompts were added to the schedule for use if required).

I deem the data, which was subject to analysis, to be interpretive accounts of the young peoples' experiences and sense-making that was shaped by my encounter with the young people and created in dialogue between them and myself (Parker, 2005). My analysis attends not simply to accounts of their experiences, but goes beyond this to consider the narratives created about those experiences, and why they may have taken the forms they did (i.e. how my presence may have influenced the young peoples' accounts). My impact on the study was inevitable (Nightingale & Cromby, 1999), though I have attempted, in so far as I was able, to recognise this impact, and draw the reader's attention to what I believe could be considered mine and what was that of the participants, as well as to relate my interpretation to theory. To acknowledge my involvement, I have referred to myself, throughout the text, in the first person.

Idiography

The final major influence is concerned with investigating detail and thus understanding how particular lived experiences have been understood from the perspective of a small group of specific people, in a specific context (Smith *et al.*, 2009). IPA is an idiographic mode of inquiry as opposed to the nomothetic approach which has long dominated psychology (Smith, *et al.*, 2009). As such, a good IPA study should allow something to be learnt of generic themes in the analysis but to also provide information about the narrative world of the particular participants who have told their stories (Smith & Eatough, 2007). This study is idiographic in that each young person's account was analysed individually before attempts to combine the derived themes were made. However, a limitation is that what I learned from previous interviews remained with me as I was unable to forget the themes I encountered in earlier accounts.

How I would like this Work to be Judged

This thesis presents accounts and interpretations of young people's experiences of HVs and how they attempt to make sense of this phenomenon. I have attempted to provide an account that reflects the stories I was told by the young people.

I am aware that some consider 'each act of interpretation does violence to the lived experience of the other' (Gubrium & Silverman, 1989, p. 59). However, it is unavoidable to understand, interpret and report the stories of others without my influence helping to construct those accounts. Rather, in sharing my analysis with the young people, I hoped to reduce the ferocity at which my interpretations differed from the meaning they intended to

convey. My aim was to produce a thought-provoking piece of research incorporating in-depth analysis and relating findings to analysis, and I hope I have provided sufficient detail about the process of this research to ensure the integrity of the work.

I am mindful that another researcher may have constructed a very different account of the young people's experiences; therefore, I hope the quality of my analysis, and the work as a whole, be evaluated on its entirety (Madill *et al.*, 2000) taking into consideration the criteria I have adhered to (Elliott *et al.*, 1999; Yardley, 2000).

2.2 Extended Information about Service-User Involvement

Prior to conducting interviews, extensive consultation took place with my Field Collaborator and Early Intervention workers from the different localities recruited from. Additionally, consultation was sought from a member of the Lived Experiences Group at the University of Exeter. Feedback was given about the relevance of the study and during the planning and design of research materials, namely the Participant Information Sheet and Interview Schedule. This consultation indicated a positive response: the study was felt to be important and relevant to young people's experiences of HIVs, an area previously neglected within the literature. Few concerns were expressed about the proposed Interview Schedule other than it may benefit from reducing the initial, rather lengthy set of interview questions, into more succinct broad open areas of questioning with the addition of extra prompts if needed, to help ensure the interview was more fluid and less guided by the researcher's line of inquiry. Our correspondence also prompted refinement to some of the information provided in the Participant Information Sheet so as to clarify participants' involvement in the research

process. This ensured both the language used and the overall approach to participant recruitment and data collection was clear, sensitive and respectful and that themes covered within the study appeared relevant to a young voice-hearing community.

2.3 Extended Information about Participants

Initially a homogenous sample was sought; a group of young people who shared a number of demographic similarities (i.e. a closely defined age group of 14 to 18 years of age). Yet it became apparent that few 14 year olds had contact with EIS and moreover such a sample could create a potential gender bias as onset of psychosis tends to occur earlier in males than females (Leung & Chue, 2000). Despite recruiting individuals whose experience of voice-hearing had occurred within the last three years, the young people exhibited a number of differences, for example: in the experience of HVs they recounted; if and/or how they were able to make sense of these experiences; and how they coped with voices. I acknowledge the sample reflected those willing to speak of their experiences (Smith, 2003). However, more significantly I feel, this reflects the nature of the experience of HVs as something that is not openly discussed and is not amenable to simplistic definitions or descriptions; and the complexity of experiences is something that IPA analysis is able to draw out for consideration (Chapman & Smith, 2002).

2.4 Quality Considerations: Credibility, Plausibility and Power, and Validity

Increasingly, the value and quality of qualitative research needs to be argued for and justified against established criteria that are quite distinct from quantitative research. Without this, qualitative researchers lay themselves open to criticism from those of the positivist

persuasion who regard qualitative research as “‘merely’ subjective assertion supported by unscientific method” (Ballinger, 2006, p. 235).

Good qualitative research is that which engages “with the messiness and complexity of data interpretation in ways that...reflect the lives of...participants” (Savin-Baden and Fisher, 2002, p.191). Thus, an overall aim of this study was the intention to draw attention to the complexity, ambiguity and ambivalence of young people’s experiences of HVs, which in itself can be considered a reflection of quality. In doing so I draw on Keen’s (1975) four criteria, which assess quality of descriptive accounts in phenomenological analysis: vividness (I hope to draw the reader in creating a feeling of authenticity), accuracy (depicting the young peoples’ experiences clearly), richness (deepening the description and enabling the reader to access the emotional qualities of the young peoples’ experiences), and elegance (disclosing the essence of the phenomena of HVs in accessible language).

Throughout the analysis process an array of established procedures and criteria, outlined below, were employed to ensure the integrity of the final interpretations (Mays & Pope, 2000; Yardley, 2000).

Credibility

Establishing credibility relies on involving others during the analysis procedure to make comparisons and check interpretations (Willig, 2001). Two colleagues completed checks of the analysis by attending to anonymised copies of transcripts and engaging in subsequent discussions about identified themes. The value of presenting and discussing the data and

analysis, was not to merely seek concordance over themes, but to engage in a process of challenging and clarifying notions and assumptions, exploring the content of disagreements, furnishing alternative explanations, and examining the insights that discussion provided for refining and clarifying developing themes (Barbour, 2001). This ensured the integrity of interpretations, encouraging critical thoughtfulness and thoroughness, both in interrogating the data but also in providing an account of how the analysis was developed. Additionally, I engaged in discussions about the analysis with my research supervisors who commented on and contributed to the development of themes.

There are multiple perspectives of the world that are created and constructed in the research process (Lincoln, 1985). Parker (2005) reflects on how 'knowledge is different for the powerful than it is for the oppressed' (p.2) as those with power are often unable to see mechanisms that privilege their own standpoint over others (Hartsock, 1987). The views and experiences of the oppressed group are often obscured by the researcher who will unavoidably be working to an agenda. Therefore, many advocate that participant validation is one of the most robust techniques for checking the credibility of qualitative research (Lincoln & Guba, 1985; Hammersley & Atkinson, 1995; Silverman, 1993). This involves imparting the developing analysis to participants so they are able to comment on the accuracy and truth of their story as it is portrayed by another. This process hopes to capture the richness, diversity and complexity of lived experience and to ensure the views of participants are not misrepresented. In this study, each participant was invited to comment on the findings developed through the analysis and presented in a model.

Triangulation was not used as a means of establishing credibility as it was considered questionable as it assumes any weakness in one method will be compensated for by strengths in another (Mays & Pope, 2000) and moreover no means of doing so could be identified.

Plausibility and Power

There is usually considerable emphasis on the need to establish the ‘trustworthiness’ (Lincoln & Guba, 1999) or ‘plausibility’ of qualitative research rather than the ‘truth’ or ‘validity’ often associated with positivist approaches. For research to be ‘trustworthy,’ Hammersley, (1992) argues it should demonstrate both rigour (process) and relevance (contributing something significant and novel to the literature). The rigour and commitment with which the researcher engages with the topic can be demonstrated by means of the competence and skill with which the method used is applied, and by the ability to go beyond superficial description of data and conduct a thorough analysis.

Lincoln and Guba (1999) propose four criteria to formalise rigour in qualitative research, which I have adhered to: credibility (use of participant validation and prolonged engagement with the field); transferability (providing a detailed portrait of the setting in which the research is conducted to afford readers enough information for them to judge the applicability of the findings to other settings), dependability (providing an audit trail, thus documenting data, methods and decisions about the research, which can be laid open to external scrutiny), and confirmability (auditing as a means to demonstrate quality, for example, researchers providing critical reflexive accounts and involving others in the process of checking the findings).

When discussing the power of the analysis, Smith and Osborn (2008) refer to how IPA can elicit theoretical rather than empirical generalisability. This refers to the extent to which readers are able to make links between the findings of the study, their own professional and personal experience, and the claims in the extant literature. Thus, the power of the study is determined by its ability to shed light within this broader context.

Validity

Validity in qualitative research can be understood as the researcher's understanding and ability to represent other peoples' meanings (Bannister *et al.*, 1994). Validity, therefore, does not relate to the assumptions of reliability and objectivity as it might in more positivist research. Alternatively, it acknowledges that a researcher is not independent of what is researched and inevitably bring their own experiences and understandings to each stage of the research process.

On one level, validity in qualitative research may be seen to adopt a pragmatic approach, where validity may be measured in relation to the extent that findings of a study may further an intended objective (Aguinaldo, 2004). Moreover, this relates to how I remain hopeful that the knowledge I derived from the final analysis may be effective in facilitating change and improving provision of mental health services for those young people I have researched and for others in similar positions. Yet, I am also aware that this interpretation is not beyond scrutiny and criticism (Aguinaldo, 2004). Consequently, I have considered validity in this study to be based upon its and my trustworthiness (Lincoln & Guba, 1985). By contextualising my position in the following reflexivity statement I hope to enhance

transparency making it easier to evaluate the work, and in doing so make myself more accountable.

2.5 Reflexivity Statement

Here I hope to meaningfully demonstrate to the reader the position I have taken as well as my approach and relationship to the work. I draw on the work of Parker (2005) to facilitate this reflection.

I am personally influenced by the notion that our understandings and experiences of ourselves and the world are largely socially constructed (Burr, 2003). Yet, I continue to negotiate my position within the broad sphere of social constructionist approaches. I am drawn to critical realist ideas, which recognise the subjective, constructive element in knowledge production (Willig, 1999). For instance, I believe that things such as psychosis, in any of its manifestations, occur in real senses, though argue that experiences of psychosis, and the recounting of those experiences are crafted by societal understandings and pressures, the limitations of language, and the uniqueness of the lives and contexts in which they occur. However, despite being attracted to epistemological constructionist positioning, I do not stray into the territory of discursive psychology where the use of language becomes the primary source of knowledge. Such a positioning cannot be evaluated in terms of its relationship with the broader context and neglects questions about subjectivity and self (Willig, 1999). Similarly, I stop short of realist's epistemological stance of regarding a pre-existing external reality (Nightingale & Pope, 1999). Thus, critical realism transcends the segregation between discourse and reality, instead attempting to capture something of a 'real' story whilst

acknowledging its partial, tentative status and how it is brought into being ‘by the interaction of the researcher and of what is researched’ (Pujol & Montenegro, 1999, p. 15).

Five of the young people informed me that they had found the opportunity to speak about their experiences in the research interviews helpful, and all conveyed the hope that this research may in some way help other young people with similar experiences through making their own experiences visible. This was both an affirmation of the work for me, but also constituted a degree of pressure to do them justice and make the research worthy of their efforts.

In line with IPA, and my belief that our experience of the world is profoundly influenced by our assumptions, intentions and actions, I have adopted a reflexive stance in a sincere attempt to ameliorate the potential of unduly privileging my knowledge and interests over the voice of the young people (Parker, 2005). In doing so I hope it becomes evident to the reader the impact that reflexive thinking had on each stage of this research. Borrowing from feminist psychology, I was aware of how such approaches attend to how power is reproduced moment-by-moment as part of the interview’s process (Gergen & Gergen, 2008). As a white, middle class academic woman I was mindful of how dominant gender norms and issues of sameness and difference between myself and the participants may have implications for dimensions of power (Parker, 2005). Aware the research contributed to my professional training in Clinical Psychology and their past experiences with professionals may have had implications about what was said and was not said by the young people in the interviews. I was also influenced by the feminist standpoint epistemology and notion of ‘giving voice’ to marginalised people (Mauthner & Doucet, 2003), such as young voice-hearers, and my desire

to react against the traditionally and often still dominant research tradition of disregarding the views of those who could be seen as ‘mad’ and deluded (Boyle, 2002).

I was very aware of my influence, of what I did and did not say, in the interviews. I grappled with the role of a researcher, rather than clinician, and with how my primary objective was not to help ameliorate distress or facilitate sense-making, but simply to hear and capture what they tried to convey to me. I feel, at times, my confusion around my role as a researcher may have constrained how able I felt to ask questions around the most emotive parts of their accounts. Reflection has permitted me to consider that much of the restraint I experienced also reflected my desire to respectfully allow them to determine how much to disclose to a stranger and to avoid intrusion into painful private material (Parker, 2005).

The decisions I made in relation to the analytical process of interpreting and identifying themes was often challenging as I feared misrepresenting these young people. In conversations with colleagues it became apparent that I was desperately seeking a ‘happy ending’ for these young people as it was difficult to consider their prolonged distress. Therefore, I had to be mindful of this during analysis to ensure that I also held onto the nuances, those for whom the confusion and fear persists, and to not only report the more positive outcomes. Moreover, I had an assumption that the young people would have some way of making sense of their experience; an assumption I feel arose from discussions with my Field Collaborator, and also from my knowledge of the extant literature. Yet, some of the young people clearly lacked any coherent way of making sense of what was happening to them. The opportunity to reflect on these issues was helpful in contextualising my own assumptions in relation to their accounts.

I was aware that having no personal experience of HVs may well influence my interpretation of the young peoples' accounts and limit my understanding of aspects of their stories. Yet, I feel these limitations were lessened by involving participants in the analysis and drawing on their insights of HVs and inviting them into a reflexive discourse about the findings (Finlay, 2002). Furthermore, it was important for me to give voice to these young people, who have often been marginalised, invalidated and silenced. A model summarising the findings of the analysis was therefore taken back to these young people as a way of credibility checking, offering them the opportunity to discuss my findings and to ensure my interpretation of their stories was an accurate reflection of their experience. Moreover, I will also be sending them a summary of the work on its completion.

2.6 Interview Schedule



INTERVIEW SCHEDULE

Introduction of Interviewer

- Trainee Clinical Psychologist at the University of Exeter.

Overview of Research

- Research for thesis as part of Doctorate in Clinical Psychology.
- Research focusing on young people's experiences of hearing voices for the first time – little existing research in this area.

Overview of Interview Structure

- Interview to last about one hour – can stop at any time.
- Will ask about how you explain and understand your experience of hearing voices and whether this has changed over time.

Participant Information Sheet

- Have you read the participant information sheet about your role in this research? (Take time if needed).

Do you have any questions?

Consent Form to be completed

Important Information

- Are you likely to hear voices during the interview? If so, what should we do about that?

Onset of Voices

1. Can you tell me about your first experience of hearing voices?

Prompts:

- How old were you when you first heard the voice(s)?
- How did the voice(s) start?
- Number, identity (was the voice(s) familiar/unfamiliar?), content, duration, location, source (internal/external)
- What was that like? How did you feel?
- What did you think was happening/caused the voice(s)?
- What did the voice(s) say? What did you do? What would happen if you did/didn't do what the voice(s) said?
- How did you manage hearing the voice(s)? How effective was that for managing the voice(s)?
- What was happening in your life around that time? Work/school situation, family and friends, any big changes in your life? Why do you think it happened then?

2. Can you name all the reasons you think you might hear voices?

Prompts:

- What are the explanations that others offer? What do you think is the best explanation?

Evolution of the Voices over Time

3. Since the first time you heard voices can you tell me about any other experiences of hearing voices?

Prompts:

- When? Most recent? How many times/how often?
- Can you describe how these later experiences were similar or different to the first time? Has the voice(s) changed in any way?
- Has the way you feel about hearing the voice(s) changed in any way? If so, why do you think that is?
- Have your ideas about what causes the voice(s) changed? If so, why do you think this is?
- Has the way you cope with the voice(s) changed in any way? If so, why do you think this is?
- Can you describe times when the voices have been more frequent or intense? Why do you think this is?

4. Have there been any changes to your beliefs about the voices over time? If so, why do you think this is?

Prompts:

- Originally you thought the voice(s) were caused by..... do you still think this?
- Some people think the voices they hear are caused by spiritual experiences, using drugs or alcohol, an illness, a result of personal life experiences....do you agree with any of these explanations?
- Does having an explanation for what causes the voice(s) help? How?

Other People's Perceptions/Reactions

5. What do other people think about your experience of hearing voices?

Prompts:

- Who have you told about the voices you hear?
- What was their reaction? Was their reaction what you expected? How did this make you feel?
- What do they think causes your voices? Do you agree?
- Are there some people you haven't told? If so, why?

Help and support

7. Can you tell me about the help and support you have received?

Prompts:

- Who from? How did you feel after meeting with the STEP Team?
- Has there been anything positive/negative about the help or support you have received?
- How did this help and support compare with your understanding of the voices? Do you agree with what they said?
- Did professionals want to hear about your understanding of the voices you hear? How did that make you feel?
- What type of help and support would you have liked to have received? Was there anything that wasn't helpful?
- Have you found any other helpful sources of support and help?

Concluding remarks

8. If you had one thing you wanted to tell me today, what would it be?

9. If you had one thing you wanted to tell other voice-hearers, what would it be?

10. If you had one thing you wanted to communicate to the general public about the voice(s) you hear, what would it be?

Thank you for taking part in the research → Wind up, provide information sheet with additional sources of support and retail voucher

2.7 Information about the Participants – Extended Table

Pseudonym	Age	Summary of Voices / History	Approximate Time Since Onset of Voice-Hearing	Duration of Involvement with EIS (approximate duration reported by participants)	Current Education / Employment
Ellie	18	Multiple children's voices informing her about bullying, repeating bullying messages others have said; men and women screaming	3 years	2 years 4 months	College
Rachael	22	Several asexual voices; her boyfriend's voice	2 years 6 months	1 year	University studying Textiles (3 rd year)
Megan	23	Multiple unrecognisable voices; "surround sound"	3 years	2 years 5 months	University studying Psychology (2 nd year)
Claire	18	Voice of her deceased Grandfather and a deceased school bully	2 years 6 months	2 years	College
Jake	24	Multiple voices from members of the Triad and the FBI; familiar voices, such as those of friends	1 year 6 months	1 year 6 months	Unemployed
Debbie	16	Unidentified male voice; a female screaming	4 months	3 months	College
Carl	19	An unidentified female child and male adult	3 years 6 months	2 years 8 months	University studying Chemistry (1 st year)
Harry	18	Two unidentified male voices	3 years	2 years 6 months	College

2.8 Extended Information about the Interviews

As the interviewer I wanted to ensure the young people felt as safe and comfortable as possible, which supported my decision to offer choice about where the interviews would be held. Furthermore, offering participants' choice over the venue is also a strategy used in ethnographic research. This approach accentuates the importance of an 'internal frame of reference' for the interviewee, in that the context in which the interview is held will have some prior engagement with the lifeworld of the young people, which may provide information about the context in which they live and pertinent events that have occurred (Parker, 2005).

I sought to create opportunities to try and enter, as far as possible, the psychological and social world of the young people. Subsequently, I endeavoured to allow the young people to shape the direction the interview took, allowing them to introduce ideas or notions I had not considered; therefore, providing the greatest opportunity for them to tell their own story without being restricted by a predetermined schedule of questions. This allowed engagement in a dialogue where initial questions were modified in light of participants' responses allowing freedom to explore interesting and important areas as they arose (Smith & Osborn, 2008). Furthermore, interviews, each lasting between 35 and 70 minutes, varied in duration depending on how much the young people wanted to share with me.

I deliberately kept research questions broad as I endeavoured to make room for the young people to determine what they felt it was important to tell me. Interestingly, at the outset, I had little expectation that a relational model of self/identity would apply to the young people

experiencing psychosis. A question on the interview schedule asked about what others thought of the young people's explanation for the voices they heard, but the young people brought the topic of relationships with others into the interview by talking extensively about issues of relation, connection and difference.

2.9 Transcription Notations

(break) long pause

... short pause/trailing dialogue

Bold emphasis

(inaudible) inaudible dialogue, could not be transcribed

[gesture] comments by me on an event that occurred in the room during the interview,
or details of an identifying feature that has been anonymised

(...) abbreviated quote

Punctuation was used in transcripts of the interviews to aid the reader with the structure of conversations, to appreciate the way language was used and constructed whilst remaining as loyal as possible to the phrasing used.

2.10 Detailed Description of the Analytic Process

The process of analysis began following the first interview when I recorded my initial thoughts and impressions in my reflective journal. Following transcription, the interview was read a number of times to enable me to gain as much familiarity with the participant's account as possible. Line by line coding ensued, key phrases, preliminary interpretations and any apparent associations, commonality, contradictions or other notable features were recorded in the left hand margin. The right hand margin was used to note developing themes, which constituted significant words or short phrases that succinctly captured the initial codes and meaning of passages of the data.

Questioning the data, using both an empathetic hermeneutic and a critical hermeneutic (Ricoeur, 1970), sought to explore different interpretations, and aid in sustaining a detailed, rich qualitative inquiry (Smith & Eatough, 2007). An empathetic hermeneutic was employed in an attempt to understand what the experiences described in the accounts were like from the position and perspective of the participant. Yet, to facilitate a detailed analysis I also employed a critical hermeneutic to enable curious and critical exploration, for example to question why stories were told in particular ways and to establish a sense of whether additional information was unintentionally conveyed through the narratives.

Taking all the initial codes and subsequent identified themes from the first transcript, these were recorded in a table electronically along with corresponding passages of text. This enabled similarities, connections and contradictions within the account to be more easily identified. Next themes were collated and meaningfully clustered together. At this stage of

analysis I referred back to the selected quotes and original transcript to check and ensure themes remained consistent with the participant's account. As a result of this process, a table of themes was produced for the first transcript. This process was repeated for the subsequent seven interviews, and themes were developed within each individual transcript until a coherent and organised account of each transcript was made. Yet, the process was inevitably and essentially influenced by knowledge and experience gained through analysis of earlier interviews. Thus, the identification of themes from earlier analysis was considered in relation to the information conveyed in subsequent interviews. Although commonalities across themes began to emerge, repeated reading and thorough analysis of each individual transcript ensured each participant's account was endowed appropriate and particular attention so that care was taken to acknowledge differences and new concepts developing within the accounts (Smith & Osborne, 2008).

Themes developed from each of the eight transcripts were then compared allowing analysis of commonalities and divergence between the themes. This involved a continual and complex process, of integrating and collating themes for the group of participants across all eight transcripts, which finally enabled the identification of constituent and superordinate themes. These themes were compiled on post-it notes and paper and this acted as a visual aid for validity checking. Each superordinate theme was connected to underlying themes, which in turn, were connected to the original annotations and extracts from participants, thus throughout this process themes were consistently checked to ensure they were grounded within the transcripts. A table of superordinate and constituent themes was produced. This aided with identifying interconnections between themes, which made it possible to understand individual accounts within the context of experiences shared across participants. Themes were then ordered so they could be translated into a coherent narrative account,

which captured the essence of the young people's experience of HVs, illustrated with verbatim extracts from the participants. The analytic process continued throughout the process of writing up the research and themes that no longer fitted as fluidly with the structure of the narrative, or were less well supported by the data were discarded. A reflective journal was kept and used throughout the analysis process to continually record notes and help develop a continual awareness of my involvement in the analysis.

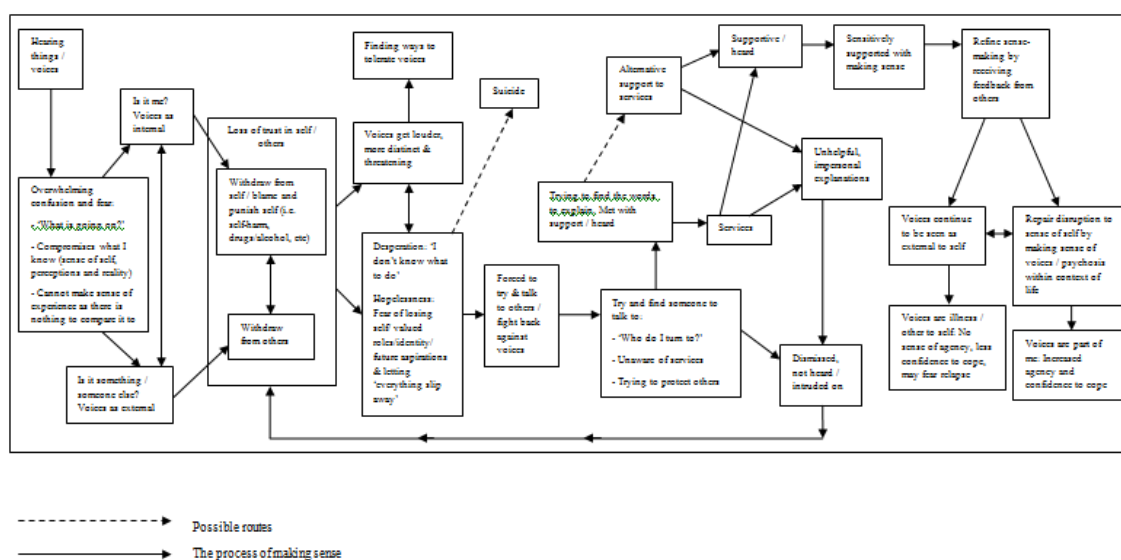
Appendix 2.11: Extended Information about the Young People's Involvement in the Analysis

It was not feasible in all cases for the young people to contribute to the analysis (Yardley, 2008) due to pragmatic issues such as having academic pressures to meet. However, six of the eight young people accepted offers to be involved in this process.

The analysis went beyond simple descriptions of the stories told by the young people and highlighted contradictions/differences between participants' perspectives, and the suppressed meanings and functions of talk. Theories such interpretations were dependent upon may be difficult for young people to comprehend; therefore, it was important to consider what parts of the analysis young people would be able to relate to. I felt asking young people to review lengthy transcripts would be unlikely to add much value to the analysis and would place considerable demands on their time (Barbour, 1998). I was also aware that reviewing these transcripts on a different day in a different context could cause them to question aspects of the accounts they provided in their interaction with me. The model (see Figure 1), which was derived from, and grounded in the young people's accounts, depicted an overview of the

broadly sequential process they described in adapting to their experiences of HVs. I felt this would be the most helpful aspect of the analysis to share guiding broad discussion about this process rather than focusing on the specific experiences of each participant . Furthermore, the model was deemed to have relevant clinical implications. As Lincoln and Guba (1985) highlight, I hoped the young people ‘may be able to agree that reconstructions are fair even if they are not in total agreement with them’ (p. 315). But if not, I felt responsible to note any incongruity between my interpretation and that of the young people, and in doing so increase the transparency of the analysis.

Figure 1. Diagrammatic representation of the experience of making sense of HVs



When sharing the model with the young people we spent time exploring if their subjective experiences mapped onto the model. All the young people were in agreement with the transitional process the model depicted. One young person suggested a minor refinement to the model. Describing how the experience of HVs impacted on her ability to focus on her studies, she explained how the threat of losing something she valued that contributed to her identity and was connected to her future aspirations led her to seek help; rather than the

pivotal point in help-seeking relating to suicidal ideation as it had for most of the young people. Although this fitted within the broad category of ‘Hopelessness: Fear of losing self and ‘letting everything slip away’ I felt this area needed refining. Thus, ‘Fear of losing valued roles/identity and future aspirations’ was incorporated into this category on the model to contribute to enriching the analysis and ensuring all the young peoples’ experiences were captured to as great an extent as possible (Smith, 1994).

2.12 Extended Excerpt from Transcript (Interview 2: Rachael) Including Analytic

Notations

speaking to people I just like think it's just like a chemical reac...I don't think it's anything like you know else apart from a chemical reaction in my brain or yeah...

P2: Ok that's great. Some people might think that voices are caused by lots of different things like spiritual experiences, or using drugs or alcohol, illness, a result of life experiences, um do you agree with any of those?

P2: Yeah I think it's probably an illness slash using drugs and slash um life experiences as well.

I: So not so much a spiritual experience?

P2: No.

I: Ok, that's fine. Do you think having the explanation you've got for your voices, so thinking it's a combination of different factors, do you think that's quite helpful to um help with understanding what's happening?

P2: Yeah, I don't think it possibly could have been just one factor though.

I: No, I guess lots of people have lots of ideas don't they.

P2: Um yeah.

I: So has that been helpful to make sense of it?

P2: Yeah cos I really don't think it, well unless you did maybe a really stupid amount of drugs and stuff then yeah but I don't think it could just be genetic or I don't think it is like that. I think with mental health it must be like enviro...I don't know like in my head I just think it must be environmental the experiences and stuff, yeah.

I: Yeah sure.

P2: But it's like um, I sort this like, my Psychologist explained to me like some people um have like um what is it, like higher sort of tolerance to stress than other people and like your tolerance to stress sprt of like goes up and down according to your life experiences, your, maybe like your genes and stuff, hes showed me this um, I can't remember what it is, this chart.

I: Ok.

P2: Which like really helped, it made a lot of sense really and he said that obviously because of my life experiences um like my genetics, like my mum and stuff, that basically I have to keep my stress levels down and alcohol like increases it, and that means like I will be less...is this making sense at all? I can picture it.

I: Was it the stress-vulnerability model?

P2: Yeah, yeah yeah.

I: Ok.

P2: Yeah I think that helped a lot cos it made me understand it a lot more.

Contradiction - discarded integrative explanation - for chemical imbalance perspective - minimising experience.

- from speaking to ppl now believes voices are due to a chemical reaction in her brain.
- integrative explanatory framework - unless drugs & life experiences

Integrative explanatory framework

Resistance to adhering to 1 explanation - expressing complexity of exp.

- helpful to have an explanation that combines different factors

"In my head..." mind/rationalising vs body/soul/feeling?
Sense of being understood as model fitted to subjective understanding

- environmental experiential explanation.

Validating

Model helped that was consistent in her integrative understanding of why she was HV/exp psych

- explanation offered by P2 really helpful - made sense - stress/vulnerability model - tolerance to stress influenced by life exps, genetics, alcohol, etc - need to keep stress levels down to help control psychosis/stay well.

Sense of control given back in this explanation - i.e. keep stress & wellbeing/wellness ↑.

- helpful explanation that ↑ understanding.

Added to personal explanation - validated it.

- model maps onto her understanding of voices - enters different factors she felt influenced her voices
 - only told small no. of ppl about voices
 - reaction expected by others - didn't expect them to understand
 - wishes she felt more understood - feels they'd think she's crazy if she spoke to them about voices in more detail / if she was having a bad day - disclosed VHL exps to friends, but minimally - no exploration of exp pattern to help her understand
 - only told a few ppl about exps for fear of being judged
 - contact in services on fortnightly basis - keep track of how she's feeling

I: And it combines all those different factors you spoke about and puts it all into one model I guess.

P2: Yeah.

I: Ok so that was helpful. And the people you've spoken to about your experience of hearing voices what's their reaction been like?

P2: Um, I haven't really...well I told my um housemate. My other housemate didn't, wasn't really bothered about it cos she experiences stuff like that, and the others, I dunno they just, I think they were a bit shocked but they just didn't really say anything much. Um I told one of my best friends down here and um I just said that I'm sorry I can't drink cos I've got medication and I hallucinate and stuff and she I dunno she didn't really say much.

Lack of responsiveness when sharing VHL exps in others.

I: No, ok. Was that the reaction you expected?

P2: Yeah, cos I don't, they don't understand so they're not likely to say much about it I don't think.

Alienated/misunderstood - Disappointed

I: Ok sure. How did that make you feel?

P2: Ummm, I don't know. I just wished it was, I dunno that I feel understood more. I can't, I don't feel like I really talk to, like I can talk to my friends about everything apart from this one thing like if I was having a bad day or if I was a bit stressed, but I can't say to them, talk to them about it cos they just don't, I don't think they'd understand. They'd probably just think I was crazy or something [laughs], I dunno.

Unable to share exps in peers.

Unable to talk to friends - isolating stigma

I: Ok, and has anybody else, you said your mum mentioned a reason that you might hear voices...

P2: Yeah.

I: ...did any of your friends offer any ideas?

P2: No, cos we didn't really go into an in-depth conversation it was just "I'm experiencing this..." and then that was the end of it, yeah.

Uncomfortable exps of sharing her VHL exps - unlikely to do this again?

I: Yeah sure, and so the people you haven't told why do you think that is?

P2: Cos I don't want them to judge me [laughs].

Judgement, prejudice, stigma prevents her sharing her exps
Shame of disclosure.
Fear of judgement.

I: Right, you feel you'd get judged?

P2: Yeah.

I: Yeah ok. There's just like a few more questions now, but...could you just tell me a bit about the help and support you've received?

P2: Um, like in [redacted], cos obviously I'm like at uni in [redacted] um I, there's like a crisis team, like they, I think it's a crisis team, they come like every, I have an appointment every 2 weeks and sort of talk about how I'm doing and stuff and it's like the same here. I see a Psychologist every 2 weeks just to sort of keep track of how I'm feeling and stuff.

Support in 2 localities fortnightly.
Opportunity to talk about feelings

I: Yeah.

2.13 Extracts from Reflective Journal

In order to maintain awareness, and continually monitor, my impact upon the research process (Nightingale & Cromby, 1999), a reflective journal was kept throughout the research process. This not only recorded the challenges of the key stages of the research, but also provided a record of my initial impressions, thoughts, doubts and concerns throughout. The analysis was guided by research exploring quality in qualitative research (e.g. Ellis *et al.*, 1999; Mays & Pope, 2000; Yardley, 2000) and monitored regularly through supervision and discussion with my Research Supervisor and Field Collaborator, who provided feedback on the development of analytical ideas.

16th December 2012 - Following Interview Six

I met with a 16 year old girl who only started HVs within the last four months. She seemed utterly confused by the whole experience and had no way of making sense of the voices. She described her experiences as being distressing, confusing and frightening. The voices tell her to hurt or kill herself or otherwise threatens to harm her family.

I noticed I struggled with my role as a researcher in this interview. I found myself wanting to help her spend time exploring her experiences and begin to make some sense of the chaos. She spoke of painting as a creative outlet for the intense fear she experienced and talked about how helpful she finds this.

She explained her Psychiatrist had offered an explanation for the voices she hears; suggesting they may be a manifestation of anxiety, which has built up because she is managing her OCD differently as a result of getting professional support. She spoke of how she feels better to think of voices as just being anxiety, yet she seemed unable to accept this explanation offered to her as she continued to convey her confusion and ambivalence.

I can't begin to imagine what it must be like to be 16 and have such disturbing and frightening experiences on top of all the stresses and difficulties inherent to being an adolescent. Again I noticed I just wanted to validate her feelings and fears, and so I again felt restricted by this researcher position, which felt unnatural given the distress she spoke of.

5th January 2012 – Following Interview Seven

I am struck by how few people have heard about this young man's experiences of HVs. This has made me reflect on my position as a researcher and how fundamentally as a stranger I am one of the very few who has heard of his troubling and disturbing experiences and been allowed access to his world. This is similar to a lot of the other young people I have spoken with. The stigma and embarrassment, which appears to increase their isolation, means that professionals can often be some of the only people they can confide in; I feel sad - what a lonely place.

7th February 2012 – During Analysis, following a conversation with a colleague about reflexivity

I'm sat in the computer room surrounded by papers about reflexivity and am confused about attempting to negotiate my position in relation to the young people involved in my research – thinking about my ability “to mark where ...[my] self ends and another begins” (Pillow, 2003). I am also aware of how enormous and overwhelming all the data generated from the interviews feels. I'm afraid I will never be able to make sense of it all or that I will miss something crucial. The information from the young people's stories feels completely overpowering, confusing and quite anxiety-provoking as I don't know where to start to make sense of it all. This has made me reflect on the apparent parallel process between how I am attempting to make sense of the young people's attempts to make sense of their experiences.

I am aware of the difficulty of using language to capture and secure both the meaning and 'truth' of these young people's stories. Similarly, I felt during interviews and subsequent transcribing that language would simply fall apart when participant's attempted to voice the complexity of their experiences. I'm longing to find a different way of making sense of the experiences I heard, but feel unable to adequately capture this, thus I feel as though I'm engaged in a similar, but no doubt lesser, struggle to capture the experience and articulate it just as the young people are....

Appendix 3. Extensions to the Findings

3.1 Table of Quotes

This abbreviated table of quotes is provided to facilitate the reader’s understanding and appreciation of the analysis. I felt the full table of quotes reflected too much of the young people’s stories for inclusion in this work.

<p><u>Superordinate Theme 1.0</u> “I’m losing my mind”: The Shattered Self</p>	<p>Theme 1.1: “I didn’t know who I was. I was even scared of myself”: Fearing, blaming, punishing self</p>
	<p><u>Emotional Distress Preceding Voices</u></p>
	<p>“I was really stressed at university and then I started getting like panic attacks...I started getting like thoughts, but it still came across as thoughts then it eventually like started, yeah, as voices.” (Rachael: 19-22)</p> <p>“Round about a month after I started having panic attacks, one evening late at night I heard one voice which sounded as if it was coming from the corner of my bedroom along with a hallucination. (...)” (Megan: 8-10)</p> <p>“I wasn’t feeling particularly good maybe that kind of like started it off. (...) felt depressed a lot and I have OCD as well” (Debbie: 96-100)</p>
	<p><u>Initial auditory experiences: What was that?</u></p>
	<p>“It sort of started of like loud thoughts, well like loud thoughts and then that developed into hearing voices.” (Rachael: 16-17)</p> <p>“I’ve always liked heard voices in my head like, but um...yeah that was just my own voice, but about a year, year and a half ago I ...started hearing louder voices it seemed like and it felt like someone had just put like a little speaker-microphone or something in my ear and was communicating with me, broadcasting to me.” (Jake: 50-53)</p>

	<p>“I used to kind of like sometimes hear like people whispering, but just like saying my name and stuff” (Debbie: 49-50)</p> <p>“it started more as like a dull roar of a crowd (...) like I was surrounded by lots of people.” (Carl: 3)</p> <p>“Apart from the voices that I used to hear, I used to hear screaming (...) they were screaming from hell” (Ellie: 109-112)</p>
	<p><u>Profound, Overwhelming Confusion</u></p> <p>“I just didn’t really understand what was happening like in my brain, I just didn’t have any explanation cos I just didn’t know what was going on” (Rachael: 197-198)</p> <p>“I don’t know, I’ve got a feeling I got beaten up or something over the summer, but I don’t know, maybe I was just taking too many drugs or something. I don’t know if someone got me hooked on crack or something.” (Jake: 153-157)</p> <p>“I don’t really remember. I don’t think so, I just kind of accepted it really, I don’t know [laughs].” (Debbie: 35-36)</p> <p>“I didn’t know what, I just didn’t know what was going on really.” (Harry: 29-30)</p> <p>“I don’t know. I don’t know. I don’t really know what’s happened so...I don’t know what to say.” (Jake: 246)</p>
	<p><u>Distressing and Disturbing Experiences Unlike Any Other</u></p> <p>“my actual first vision (...) was these two men crouching down in the woods and it was dark (...) They were saying evil things (...)</p> <p>because they were trying to plan murder.” (Ellie: 288-302)</p> <p>“To me it was real, there was actually a man in my room, was so scared, paralysed with fear just wanted to shout down to Mum but I just couldn’t.” (Megan: 17-18)</p>

	<p>“sometimes it tells me that some friends of mine were killed by um the triads. And, yeah that it was somehow my fault.” (Jake: 315-318)</p> <p><u>Fragmentation of Self: Me versus Not Me</u></p> <p>“My head was sort of like, different sides just, like one part of the brain was thinking loads of other things and the other side of the brain was like just thinking a whole load of other things and my mind just needed rest and I just couldn’t have rest, I was so stressed.” (Claire: 277-279)</p> <p>“It was the voice and me.” (Claire: 80)</p> <p>“mostly what I hear is like people I think work for the FBI . (...) I think they like pretend that I’m not on a wire if you know what I mean” (Jake: 36-39)</p> <p><u>Fearing and Blaming Self</u></p> <p>“I didn’t know who I was. I was even scared of myself” (Claire: 129)</p> <p>“I was just all upset and angry and I just wanted to take my anger out on somebody, but because I’m too caring, too caring person, I took it out on myself and not on anybody else.” (Claire: 309-311)</p> <p>I’m obviously making it all up.” (Jake: 138)</p> <p><u>Finding ways to Protect Myself from Intolerable Experiences</u></p> <p>“the same angel, came towards me and I had my head down cos I was being ashamed of myself and she put her hand on my shoulder. And the reason why I was ashamed of myself was because I felt put down...because people bully me.” (Ellie: 239-241)</p> <p>“I held my hands to stop myself from worrying and stuff. (...) it was comforting and it helps me like shut off for a bit sometimes.” (Harry: 56-59)</p> <p>“Usually just got more fucked...sorry excuse my language. (...) initially it did take the edge of it and I found I didn’t really care about it too much at the time if I was using.” (Carl: 52-58)</p>
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	<p>Theme 1.2: “I wasn’t going mad or anything, I don’t think?” – Loss of agency, questioning madness</p> <p><u>Relentless Menacing Presence</u></p> <p>“I thought it was a person but I thought it was just like an evil kind of voice in my head as well.” (Claire: 67)</p> <p>“Quite scary, erm like someone looking down on you. (...) I thought something bad was going to happen. I didn’t know what, I just didn’t know what was going on really.” (Harry: 27-30)</p> <p>“Um I’d hear it everytime I was like in a dark moment or just down and depressed and it was quite often I’d hear it cos at the time I was feeling down, and you know it wouldn’t go away and I just didn’t know what to do.” (Claire: 50-52)</p> <p><u>Disempowered, Judged and Blamed</u></p> <p>“at times of severe stress it just seemed easier to listen and do what they said. If I didn’t do what they said they would just get louder and more aggressive, until I calmed myself down.” (Megan: 27-29)</p> <p>“It was telling me to like do stuff, um, do stuff to myself that I shouldn’t have done cos I was like in the darkest moment. And, I just didn’t know what to do so I just listened to the voice and let everything slip away.” (Claire: 42-46)</p> <p>“Throughout my experience of having the voices they were ones of blaming, guilt and generally demanding statements.” (Megan: 25-27)</p> <p><u>Questioning Madness</u></p> <p>“I had no idea what was happening, but knew it wasn’t right so convinced myself I was going crazy.” (Megan: 21-22)</p> <p>“It made me go a bit mad really cos I was completely convinced I was on a wire at one point, I was just going mental thinking about, thinking all this stuff had happened like, and it was somehow in the papers and all that, it made me go proper like crazy like.” (Jake: 131-133)</p>
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	<p>“So I’d be seeing stuff that wasn’t there and hearing a crowd and I just kind of thought ‘Oh I’m losing my mind.’” (Carl: 49-50)</p> <p><u>Seeking Source of Voices: Who am I and what is Real?</u></p> <p>“Sometimes I would hear someone call my name and when I looked back to see who had called my name no-one’s there.” (Ellie: 92-93)</p> <p>“most of the time I can [<i>distinguish between voices in head and people talking</i>] but I did have this one experience where I could hear people whispering, I’d had a bit of a weird day, and I couldn’t yeah I had to look around to, it sounded really realistic and I did get really scared.” (Rachael: 160-162)</p> <p>“I would sort of turn around expecting to see lots of people and there’d be no-one there.” (Carl: 25)</p> <p><u>Development of Distinct Voices</u></p> <p>“it didn’t make any sense, it would be sort of like jibberish, like it didn’t...just random words. And, like lately it’s just really random things it tells me like all the... just like orders, but I just ignore it.” (Rachael: 88-90)</p> <p>“I heard crowds for maybe a month and then it went from crowds to like voices...I noticed that the voices got more and more clearer in my head as well as time went on” (Carl: 125-128)</p> <p>“She knows one word, my name. (...) I always pictured it as a little girl with long black hair, um but yeah she just whinges at me and it really really irritates me. She’s young, 6 or 7. (...) Erm, a man saying: “Do you feel empty?” And that’s quite annoying. And with that one, I don’t know why but the name Mark comes to mind, I’m not really sure why or where that’s come from, but, erm, I’d say middle-aged, something like that. (...) I recognise, I know I know the girl’s voice from somewhere” (Carl: 134-146)</p> <p>“they’re more distinct now, they’re louder, they sort of penetrate through if that makes sense (...) They’re much more, rather than the dull roar of a crowd (...) it sounds like they’re right there in my head.” (Carl: 211-216)</p> <p><u>Other Distressing Experiences</u></p> <p>“I think like when I was on the er triad’s wire I did think they were like speaking to me in my sleep more and like using sleep-hypnosis.” (Jake: 71-73)</p>
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	<p>“I almost like try and meditate sort of thing to try and clear my own thoughts and see if that helps (...) “right I’m not thinking anything” and then I’m still hearing things (...) they seem to be trying to pretend like they are me, it’s just I’m like “yeah but I’m not making those thoughts, I’m not thinking those things.” (Jake: 184-189)</p> <p>“I knew it was just the same as me thinking aloud in my head, but I wasn’t actually thinking anything (...) someone was putting them inside my head.” (Carl: 156-169)</p> <p>“insects crawling on my skin was initially one of the most distressing things” (Carl: 301)</p> <p>Theme 1.3: “I just let everything slip away” - The insidious escalation of voices</p>
	<p><u>Fear of Harm (to self and others)</u></p> <p>“Well pretty scary at the time like, I thought I was going to get gunned down or something like.” (Jake: 66)</p> <p>“sometimes it told me to like cut myself or hurt myself. Um, and then like if I didn’t then people would get hurt, like my family and stuff.” (Debbie: 48-49)</p> <p>“Erm, er get punished, something like that. (...) he’ll come after me or something.” (Harry: 50-52)</p> <p>“it said something about that I should kill myself that there’s like no point me being here and stuff and kind of kept on saying that (...) Just that I’m kind of worthless and there’s no point me being alive and just things like that.” (Debbie: 137-143)</p>
	<p><u>Battling for Control</u></p> <p>“At first I couldn’t manage the voices, I can remember just sitting and listening to them for hours on end, until I just ran out of energy and fell asleep, they were always worse at night.” (Megan: 32-34)</p> <p>“sleeping a lot is quite good cos it can’t make you do anything. I’d just lie in bed all day like. Yeah I can’t really control it very well, it can control you though cos that means it’s controlled you just lying in bed all day.” (Jake: 146-148)</p>

	<p>“It was all just like going subliminally in the background and stuff like it controlling me without me really realising like and then they sort of turned it up loud so it was a whisper rather than so quiet and that’s when I started hearing it and realised “shit I’m on a wire” and started going crazy like.” (Jake: 278-281)</p>
	<p><u>Isolating Experience</u></p> <p>“Yeah I felt scared. I didn’t know what to do, I didn’t know who to turn to, um, I just didn’t know what to do with myself either, and er I just felt more alone than ever.” (Claire: 60-61)</p> <p>“I hid myself away in my bedroom, and I didn’t come out, um, I would only come out briefly for my dinner or you know if I had to go to school or college or something. And I’d just like listen to my music all the time.” (Claire: 202-204)</p> <p>“I didn’t have a job, I dropped out of college, I broke up with my girlfriend. I was just a drug addict really. (...)I managed to ruin quite a lot of relationships over those couple of years. Friendships were alright. I became quite anti-social, I didn’t want to see my friends anymore. I just kind of locked myself away and used drugs all the time. Erm and yeah my relationship with my family deteriorated, I became quite aggressive and would smash things, argue and fight with people, yeah and just really anti-social really.” (Carl: 62-73)</p>
	<p>Theme 2.1: “It’s all like some giant story or something, I don’t know what to make of it” – Struggling to understand</p>

<p><u>Superordinate Theme 2.0</u> “I can’t say it in words”: More than words</p>	<p><u>Initial Explanations</u></p> <p>“I felt a bit disturbed by it because I was trying to figure out why I was wanting to hear screaming in the hell.” (Ellie: 116-117)</p> <p>“cos my mum’s mentally like ill, I just associated it with that cos she’s got like schizophrenia like “great I’m getting schizophrenia” that was immediately what came into my head.” (Rachael: 79-82)</p> <p>“Scary, cos at one point I thought he was like coming to hurt me and that because of me, like everything that was happening in the family with my Grandma and my Dad and that (...) You know I thought he was going to like come for me and haunt me or something. I know it’s like sounds a bit dramatic, but that’s what it was.” (Claire: 271-275)</p> <p>“I started thinking it was just me thinking really, but then I started thinking (...) that um one of the triads had wired me (...)” (Jake: 12-15)</p> <p>“It was at the time that I was using an awful lot of drugs as well, so it was a bit like, I don’t know, at first I assumed I ‘d taken too many drugs and then, well I guess that was exactly what happened, yeah it was quite a distressing part of my life” (Carl: 27-29)</p> <p>“I think I heard it cos of lack of sleep and erm I kept on telling myself stuff and my brain probably went overload so that’s probably why I couldn’t cope with it.” (Harry: 90-91)</p>
	<p><u>Fear of Losing Reality</u></p> <p>“It’s all like some giant story or something, I don’t know what to make of it (...) I don’t know if I’m making it up or if I’m really on a wire. I had a MRI scan and it didn’t detect anything (...) like a little speaker-microphone or some type of equipment in my ear or something.” (Jake: 92-98)</p> <p>“before that I could sort of tell the difference like when I was hearing voices and when someone was saying something cos that’s what like this year I’ve been a bit like scared about cos I didn’t like the fact that I sometimes I can’t like tell if it’s reality or not, it’s a bit like fuzzy sometimes.” (Rachael: 154-157)</p>

	<p>“when I’m actually ill when I hallucinate and stuff I don’t really, I don’t have that much of a grasp that I’m hallucinating it’s more just that I’m in that sort of moment and that’s going on. It’s not until a few days later that I’ll think, I’ll like look back and be like ‘that can’t have been real.’” (Carl: 362-365)</p>
	<p><u>Distancing from Psychosis</u></p> <p>“no-one in my year or anyone else when I went into school was horrible to me about it they just thought that that is perfectly normal.” (Harry: 149-150)</p> <p>“Er, yeah but never, well my parents just ignored it cos they knew that wasn’t me. Not the real me.” (Harry: 45-46)</p> <p>“I don’t really get how that’s psychosis. I thought that was just normal really.” (Jake: 229)</p>
	<p>Theme 2.2: “Because I’m taking the meds I think I’m obviously just going crazy like”</p>
	<p><u>Make it go away/Disappointment</u></p> <p>“I think it might be because of the medication that I take. And that’s because Dr X [<i>Doctor’s name</i>] said to me that it would get rid of the screams and I think he said that it would also get rid of the voices in my head (...) That did help the voices go away.” (Ellie: 258-262)</p> <p>“It [<i>medication</i>] hasn’t like got rid of them, but that’s what I’m hoping, I hope it will.” (Rachael: 182)</p> <p>“it doesn’t actually remove my symptoms though, like I feel like that’s what I want it to do. I want to just take and then be symptom free” (Carl: 422-423)</p>

Medication: Conflict Between ‘Sick’ Role and Wanting it to go Away

“That did help the voices go away.” (Ellie: 262)

“I feel like ill now and I don’t like that feeling (...) I’ve never had anything wrong with me before (...) I feel like I’m putting medication in (...) I do like the fact that it’s getting treated and I can talk to people and they can give me explanations as to why I’m experiencing this stuff” (Rachael: 278-283)

“since I’ve been taking the meds I just feel a lot calmer (...) I don’t know if the meds like actually take the voices away, but because I’m taking meds I think I’m obviously just going crazy like, it makes me think “oh I’m just going crazy, they’re just voices like, it’s just some big made up story like” which is why I keep taking my meds like. I’m obviously making it all up.” (Jake: 134-138)

“my [friend’s name] was like “what tablets are these?” I said “they’re my like paranoia and stop me from hearing voices” and the whole room just went silent and everybody didn’t think I’d hear voices like that.” (Claire: 608-609)

Getting to Know the Voices: Triggers

“drug abuse, when you have no sleep and high stress. (...) like if I’m very paranoid about something, like often I think people are trying to kill me and stuff, if that’s particularly bad then that can trigger it, but that kind of, paranoia and stress just kind of triggers the whole lot so I’ll get the visual and the audio” (Carl: 253-258)

“I did have a phase when I drank a bit too much as I had just turned 18, but it just made the voices worse.” (Megan: 98-99)

“They turn it louder after I’ve had a spliff.” (Jake: 325)

“when you’re like, when you get scared about it, it tends to like build up more yeah. Like because when I get um scared about my voices then I get anxious then it becomes sort of like worse.” (Rachael: 311-313)

	<p><u>Please Understand and Help Me Make Sense</u></p> <p>“I felt so much better after telling the pastoral coordinator from college, as it felt like a weight had been lifted.” (Megan: 115-116)</p> <p>“I think the most helpful thing was having someone to off load all my worries and problems onto, and just having someone there to listen.” (Megan: 134-135)</p> <p>“I felt better knowing that people kind of knew and understood” (Debbie: 253)</p> <p>“I don’t really know, I was given like a possible one at first, but I don’t know whether it still applies and that was in August so...I haven’t see the Psychiatrist since so I don’t know whether he still thinks the same thing or not.” (Debbie: 211-213)</p>
	<p>Theme 2.3: “I don’t know how to explain what I mean”</p>
	<p><u>Difficulty Constructing Experience Through Language</u></p> <p>“ Um, you know when I mentioned that I hear voices in my head, you know I mentioned that I heard voices, you know when I explained why I hear voices in my head, you know the reason why I, um, I told you the reason why [pause]. Um, I’m trying to explain properly.” (Ellie: 448-451)</p> <p>“Yeah, because um, [sighs] I think it was mainly because I was scared, [sighs] oh I don’t know how to explain it now, because mainly I was scared, I heard my Grandad.” (Claire: 216-217)</p> <p>“well initially it was just kind of they’d come on in phases while I was in quite an er, I don’t know how to describe it, like [pause] being well I guess in a psychotic state.” (Carl: 45-46)</p>

Minimal Disclosure, Hiding Difference, Concealing Distress

“It’s just the STEP Team and my parents and you that know about the voices that I hear.” (Ellie: 160)

“I don’t really talk about it to other people.” (Rachael: 144)

“only really my family and one of my friends who kind of like forced it out of me [laughs]. (...) obviously the Psychiatrist [laughs] (...) Other than that I don’t think anyone else really knows.” (Debbie: 222-238)

“she [*Mum*] thinks I’m better than I am I think. I like it like that because she worries and gets stressed. As long as I’m not really, really bad she doesn’t know about it.” (Carl: 333-334)

“Erm, I think my Mum was quite surprised cos she hadn’t noticed anything, she thought everything was kind of getting better, and so yeah I think everyone was quite surprised.” (Debbie: 240-241)

A Shaming Experience: Things Remaining Unspoken

“Cos I don’t want them to judge me [laughs].” (Rachael: 255)

“I was very reluctant of telling people as I was worried about the whole stigma of having mental health problems. I didn’t want people to treat me any differently.” (Megan: 113-115)

“Cos I didn’t want them treating me differently and judging me because of the fact I’ve got stuff going on inside my head.” (Claire: 371-372)

“I don’t really talk about it to my friends at all really, I avoid it if possible like. It’s not something I feel comfortable talking about to them really (...) I don’t really want everyone to think of me as a crazy person.” (Jake: 256-260)

“I would expect people to think I was quite weird.” (Harry: 168)

“if I was to tell everyone what I experience they’d be like ‘well this guy’s nuts,’ do you know what I mean?” (Carl: 366-368)

“I don’t really tell people. Um, like only really my family and one of my friends who kind of like forced it out of me [laughs]. Um, it doesn’t really get talked about that much, every now and again they just kind of ask me” (Debbie: 222-224)

“Well I don’t really talk about it ever to anyone. I’ve never really had another opinion on it. (...) It’s, I find it somewhat embarrassing.” (Carl: 314-316)

Misunderstood: Others Unable to Relate to Experience

“That made me feel misunderstood because they probably thought there was something wrong with me.” (Ellie: 332)

“they don’t understand so they’re not likely to say much about it I don’t think. (...) I just wished it was, I dunno that I feel understood more. (...) I can talk to my friends about everything apart from this one thing (...) I don’t think they’d understand. They’d probably just think I was crazy or something [laughs]” (Rachael: 244-248)

“At first I could tell that they didn’t really understand, a few people just avoided me.” (Megan: 112)

“I’m worried that everyone will kind of find out cos I don’t think people will really understand it and they’ll just think I’m weird or something [laughs]. I would like to tell my friends cos I think sometimes they do kind of wonder what’s wrong cos I get a bit odd sometimes.” (Debbie: 258-261)

“I don’t think people could even begin to understand what it’s like.” (Carl: 316)

	<p><u>Finding a Voice to ask for Help and Support</u></p> <p>“most people were really supportive and tried to understand which I didn’t really expect as I was very reluctant of telling people as I was worried about the whole stigma of having mental health problems.” (Megan: 112-115)</p> <p>“He was just like do you hear them anymore, are you ok (...) he doesn’t like treat me differently just cos I hear voices (...) It makes me feel good because he takes me for who I am and not what I’m, like what’s going on in my head.” (Claire: 351-360)</p> <p>“told my Dad about it but he just thought I was insane [laughs]. (...) I said to my Dad about getting him arrested but he said I was being daft.” (Harry: 43-48)</p> <p>“my mate actually helped me through it. He knew I wasn’t in a good stable frame and was very good at understanding how I felt and never took the mick out of me for it.” (Harry: 165-166)</p>
	<p>Theme 3.1: “I will make sense bout it in the minute” – The complexity of making sense</p> <p><u>Rejecting, Refining and Accepting Others’ Explanations</u></p> <p>“Dr X said it might be memories and I said to him that it’s definitely not memories.” (Ellie: 162)</p> <p>“I reckon that if it was the spirits what I was hearing then the spirits would have heard me talking to them because you know all about psychics. Psychics know that the spirits would talk to them back if you asked them questions in your head. Cos when I tried asking them questions, um, they didn’t reply. The friends that I heard in my head, the friends really did give it away because my friends that I heard in my head are still alive today, so that’s the other reason why I know it’s not spirits.” (Ellie: 501-506)</p> <p>“well my mum thinks sort of I might be psychic or something, but I don’t think it’s that [laughs].” (Rachael: 141-142)</p> <p>“I met this one lady when I first started having the hallucination and voices, she told me to tell them to cross over, she thought I was seeing dead people, didn’t really go down to well as I was terrified, but honestly thought it was a load of rubbish.” (Megan: 96-98)</p>

<p>Superordinate theme 3.0 “It just makes a lot of sense like, that I was a bit crazy like”: Trying to make sense of voices</p>	<p>“Maybe I’ve always been a bit crazy cos like I was saying earlier I’ve sort of been hearing a voice in my head for as long as I can remember really. Um, so I don’t know if that means I’ve been crazy for as long as I can remember. (...) Cos you quite often put thoughts into, think thoughts as words even if you don’t say them. (...) I don’t really get how that’s psychosis. I thought that was just normal really.” (Jake: 217-229)</p>
	<p><i>‘They’ are Me: I don’t have to Fear Myself</i></p> <p>“I am not scared of the voices anymore, they are a part of me and are what makes me who I am” (Megan: 61)</p> <p>“I’d see mine as just being me.” (Claire: 511)</p> <p>“Even though they are still quite negative and demanding, I do not feel threatened by them anymore, as I now know that I am the one that controls them and I do not need to be scared of myself. I think that my view on them has changed as I understand why I have them now, to be honest I can’t really imagine life without them.” (Megan: 67-70)</p>
	<p><i>Complexities of Growing Up</i></p> <p>“I had just taken my first lot of AS levels at 6th form, which I found very stressful, also for some reason I seemed to become more emotionally aware, I think it was just due to the age I was, I just seemed to be a bit more sensitive than normal. I believe it was mainly due to the fact that in the past I had never really accepted or shown any emotion, it was all bottled up from my childhood. And it just felt like everything had been slowly leaking into my conscious memory that had been blocked for many years.” (Megan: 39-45)</p> <p>“He died when I was little, but it’s just, it not long ago hit me, like, you know, cos when you’re little you don’t even notice anything, but when you’re older it hits you more.” (Claire: 221-222)</p> <p>“I wasn’t feeling myself and maybe I was going through changes as well in my body and myself, and maybe that’s also what it was cos I was sort of growing up and everything and you know what it’s like at this age, you have a lot of mood swings and changes.” (Claire: 446-448)</p> <p>“Err, no not rea...apart from adolescence, and that’s about it.” (Harry: 64)</p>
	<p><i>Revisiting the Past to Make Sense of Now</i></p>

	<p>“It felt like it meant something and now I’ve only just realised that it might be because people do talk about me a lot” (Ellie: 73)</p> <p>“the main thing that happened, which I got, oh erm basically [laughs] like got pregnant and had an abortion and I was really depressed about it, and that, I think that whole thing and then I didn’t really know what I was doing at uni and I was just really down about...and I do think that’s where it sort of stemmed from as well as moving away from home and just, yeah everything.” (Rachael: 120-124)</p> <p>“the first bit was briefly because everything was changing and I was getting bullied at the time as well, and we had like family problems, um and everything was all falling into place and um, I just felt alone and I just started hearing voices in my head. I just started doing things that I just really shouldn’t, I shouldn’t have done and I do regret it, anyway and it does hurt.” (Claire: 18-22)</p> <p><u>Relating to Ongoing Experiences</u></p> <p>“That’s why I need to stop being paranoid because I’ve realised if I’m going to be the way I am and be paranoid all the time then I’m going to push people away who I love the most (...) like my boyfriend.” (Claire: 599-603)</p> <p>“after we’d been together for a while I said ‘there’s probably something you should know about me.’” (Carl: 336)</p> <p>“now I think “oh shit am I having a psychotic episode a bit” and then I sometimes still think “oh shit I’m on a wire.” (Jake: 302)</p> <p>“I get quite like erm paranoid, it’s kind of they weren’t really related, and I think over time it’s like gradually been linked together in a way. (...) it like saying that it will kill my family erm other people and stuff and like they’ll hurt me if I don’t kill myself (...) cos I think people are like watching me and are going to like kidnap me and stuff so I like relate that to the voice.” (Debbie: 185-191)</p> <p>Theme 3.2: “Psychosis...That’s what everyone tells me” – The dominant explanation for voices</p>
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Psychological and Psychiatric Models

“yeah well psychosis basically. That’s what everyone tells me as an explanation for it. I just accept that and think well they’re obviously right. I just keep taking my meds and hopefully it’ll get better like....” (Jake: 208-210)

“The Psychiatrist at the hospital was more just like “What are you experiencing” and I’d tell him and he’d be like ‘right I’ll give you Lorazepine’ (...) I don’t think it really helped my understanding very much.” (Carl: 411-417)

“I feel I was misdiagnosed because although I may have had a psychotic episode that was induced by drugs, they were all telling me ‘you’ll take Loranzepine for a year and a half to two years and you’ll get better or we’ll take the dose down or we’ll take you off Loranzepine.’ (...) I don’t feel I’m getting better.” (Carl: 464-474)

“I don’t feel as scared about it cos I did have this massive thing like that I just assumed I had schizophrenia (...) I feel a lot calmer about it and stuff um and my medication I just feel like a lot better about stuff.” (Rachael: 171-175)

Confidence to Cope with Future Episodes and Fear of Relapse

“I never want it to happen again.” (Harry: 209)

“I can now control them, by just simply rationalising and understanding what I am anxious about, which I could definitely not have done 3 years ago.” (Megan: 62-64)

“the longer I live with it the better I get with coping with it.” (Carl: 241)

	<p><u>Learning to Cope</u></p> <p>“Just keep thinking that I’m just having a psychotic episode” (Jake: 334)</p> <p>“I sometimes like write poems and like, you know draw and stuff, and I’d sometimes like get a notebook out or something and just do little scribbles and distract myself. (...) Just how I’m feeling and just like quotes and stuff (...) If you can’t write lyrics or something quotes are pretty good to express your feelings down.” (Claire: 96-108)</p> <p>“I almost like try and meditate sort of thing to try and clear my own thoughts and see if that helps.” (Jake: 184-185)</p> <p>“Kind of sometimes I’d feel like painting to kind of like let everything out and like distract myself, so to just kind of get a paintbrush and just paint whatever, which I found really helped.” (Debbie: 70-72)</p> <p>“I write stuff down now if I need to remember, I don’t tell it over in my head.” (Harry: 113-114)</p>
<p>Theme 3.3: “Everyone thinking I’m crazy” – Finding my voice, telling stories of stigma, injustice and resilience</p>	
	<p><u>Longing to be Normal</u></p> <p>“I didn’t want them looking at me and thinking what’s going on inside her head and, I just wanted them to look at me like they’d look at anybody. You know, I didn’t want them treating me differently.” (Claire: 374-376)</p> <p>“I just wanted to be a normal teenager and just go to school without hearing any voices, self-harming myself, getting bullied, having family problems. I just wanted to wake up in the morning and think “ah today’s going to be a good day; not oh today’s going to be a horrible day” or always making out that I’m ill and not going in cos I always said that I was ill, but I wasn’t. I just wanted to stay in bed and just like shut myself away.” (Claire: 557-561)</p> <p>“I just wanted to be someone different and fit in if you know what I mean.” (Harry: 83)</p>

	<p><u>Not Being Believed – how can I know what is real?</u></p> <p>“My parents believe me and I’m not sure if the STEP team believe me.” (Ellie: 321)</p> <p>“I know that I can like talk to my Mum about stuff but it’s hard actually like getting it out, and then because I never talk to her she, when I do she’s kind of like “Well this is a bit out of the blue, I had no idea anything was going on” so that makes me not want to tell her cos I feel like she won’t believe me.” (Debbie: 248-251)</p> <p><u>Putting Myself Back Together: Strengthening Sense of Self and Agency</u></p> <p>“It does help as I can now understand why I have experiences like this, I think that if I couldn’t understand why it was happening it would make it harder.” (Megan: 102-104)</p> <p>“I’ve realised that, now, cos of all of it as well, I’ve sort of like not cared what people think, and they can judge me all they like, they don’t know me. I only know myself.” (Claire: 755-757)</p> <p>“Just, that sort of I know who I am now. I’ve realised the things that I’ve been through have made me stronger in myself, and it’s gave me a lot more confidence then what I did have. And I know I could cope with more things and if there is stuff going on I can just get over it and just be myself kind of thing.” (Claire: 738-741)</p> <p><u>Support from Services</u></p> <p>“I didn’t learn how to manage them [<i>the voices</i>] until I met the STEP team, eventually I found that distraction techniques along with CBT helped, to lower my anxiety which made the voices eventually stop.” (Megan: 34-36)</p> <p>“I felt a bit guarded at first, I tried to be as like open and answer all of his questions as honestly as possible, but it wasn’t always easy like, sometimes you feel like they’re prying a bit.” (Jake: 403-405)</p> <p>“ Sectioning me really, I mean it could have been helpful in a way, but I don’t like being locked in a hospital very much and I wish they would have let me out a bit when I was there, but then I probably wouldn’t have come back to be honest.” (Jake: 438-440)</p> <p>“Sometimes I just needed to tell people my problems and maybe get advice of them to cope with everyday life.”</p>
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	<p>(Harry: 194)</p> <p>“They wouldn’t stop asking me lots of questions (...) And it was a bit strange because they asked me the same questions (...) it’s like as if they don’t believe me, that’s probably why they keep asking me the same question.” (Ellie: 360-395)</p> <p>“my Psychologist explained to me like some people (...) your tolerance to stress sort of like goes up and down according to your life experiences, your, maybe like your genes and stuff (...) I think that helped a lot cos it made me understand it a lot more.” (Rachael: 219-231)</p> <p>“I really liked the way that they seemed genuinely interested in each individual situation which didn’t always involve the voices or hallucination.” (Megan: 142-143)</p>
	<p><u>Stigma and Fear: Don’t lose sight of the person, ‘I’m still here’</u></p> <p>“Everyone thinking I’m crazy. I’d prefer to keep it to myself rather than speaking to the general public about it.” (Jake: 464-467)</p> <p>“I don’t really like telling people because I think everyone kind of has a whole misconception about like mental illness and stuff, but like, I don’t know how to say what I mean, like I’m not a complete and utter weirdo just cos that happens, I’m still me, like it doesn’t make me any different.” (Debbie: 333-336)</p>
	<p><u>Isolating Experience but don’t be silenced</u></p> <p>“Even though at first you feel quite alone, there is always someone out there that is willing to listen. And you are not the only one, so many people hear voices but suffer in silence, the sooner you talk about it the better.” (Megan: 153-155)</p> <p>“I’d say to someone that also thought they were on a wire (...) it’s quite an obvious conclusion to come to if you’re hearing voices (...) speak to the STEP team or something (...) get some help really.” (Jake: 454-461)</p> <p>“Just don’t let it bother you. Don’t let it get to you.” (Carl: 485)</p> <p>“there are people out there to help you, and to support you kind of thing, so and also you shouldn’t let anybody</p>

	<p>judge you or make you feel different (...) Just be yourself and if you believe in yourself stand up for yourself.” (Claire: 763-769)</p> <p>“you’re not alone.” (Harry: 220)</p>
	<p><u>More Sophisticated Ways of Making Sense</u></p> <p>“I was really upset and I had loads of changes going on, and like I said with the family (...) it just got too much for me and I also had like my Grandad’s voice (...) when you’re little it doesn’t, it doesn’t hit you much when your Grandad passes away.” (Claire: 264-268)</p> <p>“a little bit might be genetic, like earlier in my life I have experimented with drugs, I think it might be that as well, and I’ve had a lot of um like other experiences in, like when I was younger, which I don’t really want to talk about, and I think it’s to do with that. And I reckon it’s just to do with genetics and environmental stuff um and yeah everything really.”</p> <p>“Just kind of knowing this, just because I’m anxious kind of doesn’t seem so bad.” (Debbie: 219)</p> <p>“I believe that everything I hallucinate, everything I hear has, like I’ve picked up from somewhere (...) I’ve taken it in sub-consciously or learnt it somewhere, seen it somewhere as maybe as a sort of child and forgotten about it and can’t access it, but then if you add drugs into the equation or stress or whatever then it sort of comes back if you see what I mean.” (Carl: 291-296)</p>

3.2 Table showing the Development of Meaning about Voices over Time

Participant	Initial Ideas about Voices	Developing Ideas about Voices	Current Ideas about Voices
Ellie	Voices as a protective force: “it was trying to tell me that, um, I’m being bullied...it’s er something special letting me know that” (77-81)	Voices as meaningful: “The voices in your head are there for a reason.” (430) “helpful for me to someday figure out why.” (314)	Beginning to link voices to social world/bullying: “It felt like it meant something and now I’ve only just realised that it might be because people do talk about me a lot” (Ellie: 73-74)
Rachael	Voices as a hereditary brain disease: “my mum’s...got like schizophrenia...Immediately I just thought... ‘great I’m getting schizophrenia’” (79-82)	Biochemical explanation for voices: “I don’t think it’s anything like you know else apart from a chemical reaction in my brain” (199-200)	Integrated explanation for voices encompassing adverse childhood events, drug use and genetics: “a little bit might be genetic...I have experimented with drugs, I think it might be that as well...other experiences...when I was younger...and I think it’s to do with that.” (128-130)
Megan	Voices as madness: “the voice to me matched the person I was seeing, which appeared to be an old, middle-aged man...To me it was real, there was actually a man in my room” (13-17) “I had no idea what was happening, but knew it wasn’t right so convinced myself I was going crazy.” (21-22)	Linking voices to adverse childhood events and unhelpful ways of coping: “in the past I had never really accepted or shown any emotion, it was all bottled up from my childhood. And it just felt like everything had been slowly leaking into my conscious memory that had been blocked for many years.” (41-45)	Acceptance of voices as part of self and increased agency: “anything that I get anxious about causes the voices...I am not scared of the voices anymore, they are a part of me and are what makes me who I am, I can now control them, by just simply rationalising and understanding what I am anxious about” (61-64)
Claire	Supernatural explanation for voices: “I thought he was like coming to hurt me and that because of me, like everything that was happening in the family with my Grandma and my Dad and that...I thought he was going to like come for me and haunt me or something. I know it’s like sounds a bit dramatic” (271-275)	Beginning to link voices to adverse life events and emotional distress: “cos I was getting bullied, I dunno yeah probably because I felt depressed as well” (444)	Acceptance of voices as part of self resulting from unresolved bereavement and distressing and disruptive life events: “I was really upset and I had loads of changes going on...got too much for me and I also had like my Grandad’s voice...when you’re little...it doesn’t hit you much when your Grandad passes away.” (264-268) “I’d see mine as just being me.” (511)
Jake	Persecutory beliefs about voices: “I used to think...one of the triads had wired me...then the FBI wired me and they sort of, sort of helped to deal with the people who were after me” (23-31) “like someone had just put like a little speaker-microphone...in my ear and was communicating with me,	Finding evidence to elaborate on and support initial understanding of voices: “I had some argument with someone...he’s a triad...he’s sort of been...beating me up...following me home...putting me on a wire...I did think they were like speaking to me in my sleep more and like using sleep-	Oscillating between initial persecutory explanation and ‘psychosis’: “psychosis basically. That’s what everyone tells me as an explanation for it. I just accept that and think well they’re obviously right. I just keep taking my meds and hopefully it’ll get better like” (208-210) “at first...I was thinking ‘oh shit, oh shit,’...Except now I

	<i>broadcasting to me.” (51-53)</i>	<i>hypnosis and brainwash me” (68-73)</i>	<i>think ‘oh shit am I having a psychotic episode a bit’ and then I sometimes still think ‘oh shit I’m on a wire.’” (299-302)</i>
Debbie	Unable to make sense of voice-hearing experiences: <i>“I don’t think so, I just kind of accepted it really” (35)</i>	Explanation offered by professional only way of making sense of voices, yet some doubt remains: <i>“the Psychiatrist he said...I wasn’t like letting kind of my anxiety out by doing stuff with my OCD it was kind of like building up and he said it might have been what caused it, but I don’t know” (111-114)</i>	Ongoing uncertainty about voices, sense-making continues: <i>“I don’t really know, I was given like a possible one at first, but I don’t know whether it still applies...I haven’t seen the Psychiatrist since so I don’t know whether he still thinks the same thing or not.” (211-213)</i>
Carl	Voices a result of excessive drug use: <i>“at first I assumed I ‘d taken too many drugs and then, well I guess that was exactly what happened” (28-29)</i> <i>“I’d be seeing stuff that wasn’t there and hearing a crowd and I just kind of thought ‘Oh I’m losing my mind.’” (49-50)</i>	More sophisticated biochemical explanation for voices: <i>“too much methedrone, which flooded my brain with dopamine and now like that imbalance has just made all these psychotic symptoms come out” (231-232)</i>	Incorporating life experiences into biomedical explanation: <i>“everything I hallucinate, everything I hear...I’ve taken it in sub-consciously or learnt it somewhere...and forgotten about it and can’t access it, but then if you add drugs into the equation or stress or whatever then it sort of comes back” (291-295)</i>
Harry	Persecutory beliefs about voices: <i>“people like going up against me...like thinking people were pumping drugs into the water.” (15-16)</i>	Excessive stress and sleep deprivation caused onset of voices: <i>“I think cos I just got worked up and expected too much from myself” (81)</i> <i>“I’ve pretty much always thought it was cos I was tired.” (120)</i>	Biochemical explanation incorporating stressful life events: <i>“I think I heard it cos of lack of sleep and erm I kept on telling myself stuff and my brain probably went overload so that’s probably why I couldn’t cope with it.” (90-91)</i>

Appendix 4. Forms, Letters and Information

4.1 Care Co-ordinator’s Suitability and Screening Tool for Potential Participants



Care Co-ordinator Form for Suitability of Potential Participants

Name of Care Co-ordinator:

Name of Client:	Male / Female
Contact Number for Client:	Age of Client:

Why do you think this person may be a suitable potential participant for this research project?

.....

.....

.....

.....

.....

Inclusion/Exclusion Criteria	Yes	No
Was their first voice-hearing experience in the last three years?		
Are they willing to speak about their voice-hearing experience?		
Are they currently using illicit drugs or drinking a substantial amount of alcohol to an extent that would impact on their ability to take part in this study?		

Risk	Yes	No
Is there any information in relation to risk that the researcher should be made aware of?		

If yes, please provide details:		
Are there any issues relating to lone-visiting the client at home the researcher should be made aware of? If yes, please provide details:		

Capacity	Yes	No
Do you have any concerns about the person's capacity to consent to take part in this research?		

4.2 Confirmation of Research Sponsorship and Insurance Cover



RESEARCH & KNOWLEDGE TRANSFER

The Innovation Centre
 Rennes Drive
 University of Exeter
 Exeter EX4 4RN

Telephone +44 (0)1392 262000
 Fax +44 (0)1392 262000
 Email res@ex.ac.uk
 Web www.exeter.ac.uk

14th February 2010

Project Title Exploring Explanatory Frameworks Young People Use when Hearing Voices for the First Time
Chief Investigator Miss Samantha Bampton, Trainee Clinical Psychologist, Taunton & Somerset NHS Trust

Dear Sir/Madam,

The University of Exeter will act as sponsor for the proposed academic study titled 'Exploring Explanatory Frameworks Young People Use when Hearing Voices for the First Time.' Dr Avril Mewse is the academic supervisor. The University will undertake its responsibilities in this role as outlined in the Department of Health's Research Governance Framework for Health and Social Care (second Edition, 2005). In addition the University will ensure that the necessary ethical approval and cover for indemnity and insurance are in place before the study commences.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Michael Wykes'.

Dr Michael Wykes
 REF & Impact Manager
 Research & Knowledge Transfer
 University of Exeter
 01392 722351
m.c.wykes@exeter.ac.uk

4.3 Confirmation of Ethical Approval from the University of Exeter



Psychology Research
Ethics Committee

Psychology, College of
Life & Environmental
Sciences

Washington Singer
Laboratories
Perry Road
Exeter
EX4 4QG

Telephone
Fax
Email

To: Sam Bampton
From: Cris Burgess
CC: Avril Mewse
Re: Application 2010/233 Ethics Committee
Date: May 3, 2012

The School of Psychology Ethics Committee has now discussed your application, **2010/233** – *Exploring explanatory frameworks young people use when hearing voices for the first time*. The project has been approved in principle for the duration of your study.

The agreement of the Committee is subject to your compliance with the British Psychological Society Code of Conduct and the University of Exeter procedures for data protection (<http://www.ex.ac.uk/admin/academic/datapro/>). In any correspondence with the Ethics Committee about this application, please quote the reference number above.

I wish you every success with your research.

A handwritten signature in black ink, appearing to read "Cris Burgess".

Cris Burgess
Chair of Psychology Research Ethics Committee

4.4 Confirmation of Ethical Approval from the NHS

NRES Committee South West - Cornwall & Plymouth
 South West REC Centre
 Level 3
 Block B
 Whitefriars
 Lewins Mead
 Bristol
 BS1 2NT

Telephone: 0117 342 1330
 Facsimile: 0117 342 0445
 Email: Ubh-tr.SouthWest1@nhs.net
 10 May 2011

Miss Samantha C Bampton
 Trainee Clinical Psychologist
 Taunton & Somerset NHS Trust
 Musgrove Park Hospital
 Taunton
 Somerset
 TA1 5DA

Dear Miss Bampton

Full title of study: Exploring Explanatory Frameworks Young People Use when
 Hearing Voices for the First Time
 REC reference number: 11/SW/0037

Thank you for your letter of 16th April 2011 and the subsequent email of 10/05/2011. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 15 March 2011. Please note these documents are for information only and have not been reviewed by the committee.

Documents received
 The documents received were as follows:

Document	Version	Date
Lone Worker Policy	1	16 April 2011
Participant Information Sheet	2	16 April 2011
Participant Consent Form	2	10 May 2011

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

11/SW/0037	Please quote this number on all correspondence
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Yours sincerely

Charlotte Allen
Committee Co-ordinator

Copy to:

Dr Avril Mewse

4.5 Participant Information Sheet



PARTICIPANT INFORMATION SHEET

Exploring Explanatory Frameworks Young People Use when Hearing Voices for the First Time

You are being invited to take part in a research study. The research will investigate how young people come to understand their first experience of hearing voices. Taking part in this study is completely voluntary. Before you decide whether or not you would like to take part, please read this information sheet carefully. You may also like to discuss taking part in this research with other people, such as your family, friends, GP or Care Co-ordinator, before you make a decision. If you have any questions after reading this, please feel free to contact me (contact details are given at the end).

What is this research about?

This research is being conducted as part of the requirements of the principle investigator's Doctorate in Clinical Psychology, which is being undertaken at the University of Exeter. The research aims to explore the ways that young people come to understand their first experience of hearing voices. Research has indicated that between 10 and 40% of people report having heard voices. The experience of hearing voices commonly occurs for the first time during late adolescence or early adulthood. Most research has focused on adults' experiences of hearing voices, despite literature suggesting young people's difficulties may be more distressing. Early Intervention Services for young people experiencing first-episode psychosis have to base their interventions on research carried out with adults because young people have tended to be excluded. This raises questions about whether it is possible to generalise results to young people who hear voices. This research is interested in looking at whether young people's explanations for the voices they hear are similar to the explanations older adults may use to make sense of their experiences.

The research is being sponsored by the University of Exeter.

Why have I been chosen?

You have been chosen because you have experienced hearing voices for the first time within the last three years and one of the people working with you within the Early Intervention in Psychosis service (EIPS) thought that you might be suitable for the study.

Do I have to take part?

No, you do not have to take part. Your contribution to this research is entirely voluntary. If you do decide to take part in the study you will be given this information sheet to keep and will be asked to sign a consent form. You can contact me if you have any further questions. If you decide not to take part in the research the care you receive from the EIPS team will not be affected. If you decide to take part you are still free to withdraw at any time without having to give a reason and this will not affect the care you receive from the EIPS team.

What will I have to do if I decide to take part?

Taking part in this study involves taking part in a one-to-one interview about your experiences of hearing voices and will last approximately 45 minutes to 1 hour to complete. Interviews will be audio-recorded for the purposes of later transcription. You can bring a family member, friend or carer with you if you would like to. You will be given a £5 retail voucher for taking part in the research to thank you for your contribution. The cost of your travel expenses and any other expenses will be reimbursed to you. You can bring a family member, friend or carer with you if you like.

Will I have to travel far to take part?

The interview can take place at your home, or in a room at the EIPS service; whichever you prefer.

What are the possible disadvantages and risks of taking part?

Your health and wellbeing is the first priority and everything will be done to minimise any disadvantages or risks. However, there is a small risk that some people may become upset when they talk about their voice-hearing experiences and their explanations for their experiences. You don't have to discuss anything you don't want to and the interviewer will be sensitive to your feelings and concerns. The information gathered from the interview will be kept anonymous and confidential. The only exception would be if the interview revealed a significant risk of harm to yourself or others, in which case information may be fed back to your care co-ordinator but normally only after discussion with you. You can withdraw from the study at any time and if you would like to talk things through either during or after the study, we would be happy to arrange this.

What are the potential benefits of taking part?

We hope that the information gained in this research may provide an understanding of how young people come to understand their voice-hearing experiences and that this may be used in the future to inform the treatment of young people who hear voices, and particularly for improving wellbeing.

What will happen to the results of the research study?

It is hoped that the research will be published in an academic journal. Your identity will never be revealed in any report or publication. Some verbatim extracts from interviews will be used in the final report. You will have an option to co-analyse the data with the principle investigator and to collaboratively amend/expand interpretations of the data. The results may be presented back to the EIPS service to inform their way of working with young people who hear voices.

Who has reviewed the research?

The research project has been reviewed and approved by the University of Exeter, School of Psychology Ethics Committee. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and approved by the South West Research Committee (ref number 11/SW/0037).

I will be leading the research under the supervision of Dr Avril Mewse at the University of Exeter and Dr Phil Self at the North Devon Specialist Team In Early Psychosis (STEP) service.

What happens next?

An appointment will be made for the researcher to come and meet with you and you will have an opportunity to ask any questions you may have. If you are still happy to take part in the research you will be asked to sign a form to say so and will then be interviewed and given the chance to talk about your experiences.

What if I have any questions or concerns either now or in the future?

If you have any questions or concerns please feel free to contact me:

Samantha Bampton
Trainee Clinical Psychologist
School of Psychology
University of Exeter
Exeter
EX4 4QG
scb207@exeter.ac.uk

Thank you for taking the time to read this information.

4.6 Consent Form



Centre Number:
 Study Number:
 Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Exploring Explanatory Frameworks Young People Use when Hearing Voices for the First Time

Name of Researcher: Samantha Bampton

Please initial box

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

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

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

 Name of Patient

 Date

 Signature

 Name of Person taking consent

 Date

 Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix 5. Extensions to the Discussion

5.1 Future Directions for Further Research

Further research could take a discursive route and explore how some have described that many people with psychosis experience being deprived of a coherent 'I' (Carminero-Santangelo, 1998; Stone, 2006) and experience difficulties in understanding and using the first-person singular (Sass, 1998). Thus, this would be a way of further investigating the impact of psychosis on selfhood.

Appendix 6. Dissemination

6.1 Dissemination Plan

- A shortened written version of the report will be made available to each of the participants and workers who expressed an interest;
- A meeting with each of the participants will be offered to feedback the findings to honour their contribution and to show transparency;
- The results will be presented to the EIS teams that were involved in recruitment;
- Opportunities to present findings at relevant local or national conferences will be explored;
- This paper will be submitted for publication in the journal *Psychology and Psychotherapy: Theory, Research and Practice*³⁷. Following this, possibilities for wider dissemination of the findings in other peer reviewed journals will be considered.

6.2 Publication Guidelines for Psychology and Psychotherapy: Theory, Research and Practice

Author Guidelines

Psychology and Psychotherapy: Theory Research and Practice (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. The Journal aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies where mental health is concerned.

Circulation

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

Length

All articles submitted to PAPT must adhere to the stated word limit for the particular article type. The word limit does not include the abstract, reference list, figures and tables. Appendices however are included in the word limit. Qualitative papers: 6000 words

³⁷ See Appendix 6.2: Publication Guidelines

Submission and reviewing

All manuscripts must be submitted via <http://www.editorialmanager.com/paptrap/>. The Journal operates a policy of anonymous peer review.

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.
- 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.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- All Articles must include Practitioner Points – these are 2-4 bullet points, in addition to the abstract, with the heading ‘Practitioner Points’. These should briefly and clearly outline the relevance of your research to professional practice.

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