Peer support groups for unusual beliefs: a qualitative analysis of members' experiences

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Contents

Acknowledgments 6

Abstract 7

Chapter 1: Introduction 9

Chapter summary 9

Defining 'delusions'…. 9

A brief note on language 11

From a categorical towards a continuum-based understanding 11

'Delusions' as out of keeping with a person's culture 13

'Delusions' as unintelligible beliefs…. 14

'Delusions' as false beliefs… 15

'Delusions' as impervious to change 16

Theories of 'delusions' 17

Biological theories… 18

Psychological (cognitive) theories… 20

Trauma, adverse life experiences and unusual beliefs…. 23

Early adverse experiences…. 23

Racism and discrimination 25

Socioeconomic disadvantage and inequality 26

Spiritual explanations…. 27

'Delusions' in context…. 29

The service user/survivor movement 34

Defining peer support… 35

The Hearing Voices Movement…. 37

Paranoia and Unusual Beliefs Groups… 38

Theories of peer support… 39

Experiential knowledge 40

The helper-therapy principle…. 41

Social support…. 41

Yalom's therapeutic factors… 41
Research into peer support groups for psychosis……..42
Research on Hearing Voices Network peer support groups……44
Rationale for the present study 51
Chapter 2: Methodology 53
Chapter summary 53
Rationale for using a qualitative approach… 53
Epistemological and ontological positioning 54
Ontological assumptions… 54
Epistemological assumptions… 55
Epistemological and ontological assumptions of the current study 57
Reflexivity 59
Design… 61
Methods of data analysis 61
Interpetative Phenomenological Analysis (IPA) 61
Grounded Theory (GT) 62
Thematic Analysis 62
Participants and sampling 64
Sample size 64
Inclusion/Exclusion criteria 65
Procedure 65
Service user involvement… 65
Study development… 66
Recruitment procedure 67
Data collection… 67
Data analysis 68
Ethical considerations… 70
Obtaining ethical permission… 70
Informed consent… 70
Confidentiality and anonymity 70
Participant safety 71
Researcher's safety 72
Quality assurance 72
Dissemination… 73

Chapter 3: Results.....74
Chapter summary.....74
Study sample.....74
Recruitment site details….....75
Analysis.....75
Theme 1: In search of an 'oasis'….....76
'It's alright to think that you are God here'….....76
'It became quite an intimidating environment'….....81
Theme 2: Choice means something different here.....83
Group membership and attendance: a voluntary affair.....84
'And slowly slowly I opened up'.....85
Theme 3: This is peer support, not therapy.....87
'We are not focusing on fixing the person'.....88
'Who decides what's an unusual belief?': Problematising 'delusions'….....91
Theme 4: From the 'I' to the 'We'….....93
Chapter 4: Discussion.....99
Chapter summary.....99
In search of an 'oasis'….....99
Choice means something different here.....103
This is peer support not therapy.....105
From the 'I' to the 'We'.....108
Strengths and limitations.....109
Implications….....110
Future research….....111
References.....112
Appendices.....149

Appendix A: Recruitment Advert
Appendix B: Participant Information Sheet Appendix C: Interview Topic Guide
Appendix D: Examples of extracts of data collated for three codes
Appendix E: Ethical Approval
Appendix F: Resources in the event of distress
Appendix G: Receipt of Payment

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Abstract

Background: Typically referred to as delusions, unusual beliefs are commonly regarded as symptoms of a psychotic disorder, requiring treatment. Drawing on the Hearing Voices Network's approach to voice-hearing, peer support groups for unusual beliefs aim at providing mutually supportive environments where members can share their experiences and support each other. Despite the growth of an active network of unusual beliefs peer support groups, to date, there has been no research in this area.

Aims: The present study aimed at exploring participants' experiences of attending peer support groups for paranoid and unusual beliefs and the impact of group participation, as perceived by members.

Methods: The study adopted a qualitative research design. Individual semi-structured interviews were conducted with 11 participants and data were thematically analysed.

Results: Four themes were developed from the data: (1) 'In search of an 'oasis'', reflects the safety and acceptance that the group afforded, as well as situations during which some of the very components that rendered the group a safe and accepting haven, seemed to be jeopardised; (2) 'Choice means something different here', explores the ways in which the group enabled participants to reclaim a sense of agency and control which was often either denied or was unavailable in other contexts; (3) 'This is peer support, not therapy', captures the group's non-clinical character and the ways in which participants' accounts questioned dominant assumptions about the nature of unusual beliefs; and (4) 'From the 'I' to the 'We'', explores the sense of community that the group forged for participants.

Discussion: This is the first study to explore the Hearing Voices Network approach to unusual beliefs. The implications of the study for the user-led network as well as for clinicians supporting people with distressing or overwhelming beliefs are discussed and suggestions for future research are offered.

‘They’re trying to kill me,’ Yossarian told him calmly.

‘No one’s trying to kill you’, Clevinger cried.

‘Then why are they shooting at me?’ Yossarian asked.

‘They’re shooting at *everyone*,’ Clevinger answered.

‘They’re trying to kill everyone.’

‘And what difference does that make?’

—Joseph Heller, *Catch-22, 1961*

Chapter 1: Introduction

Chapter summary

This chapter will begin by briefly presenting current definitions of unusual beliefs before moving on to explore some of the difficulties associated with contemporary attempts at definition. It will then provide a summary of different explanatory frameworks concerning the nature and origin of these experiences. Next, the current mental health landscape will be mapped and the place of peer support therein will be examined. The chapter will go on to summarise existing research on peer support groups in the field of psychosis. The chapter concludes with the rationale and aims for the present study.

Defining 'delusions'

Often referred to in the clinical literature as 'delusions', unusual beliefs are commonly regarded as manifestations of mental illness. Reflecting Jaspers's (1913) work, the World Health Organisation (2018) defines 'delusions' as firmly held beliefs that are "demonstrably untrue or not shared by others, usually based on incorrect inference about external reality" (WHO, 2018, p. 20). The definition continues by indicating that such beliefs are held with conviction and are "not ordinarily accepted by other members of the person's culture or subculture" (WHO, 2018, p. 20). Similarly, the latest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM), defines 'delusion' as "a false belief . . . that is firmly held despite what almost everyone else believes" (APA, 2013, p. 819). Unlike previous versions of the manual, the DSM-5 suggests that the distinction between a strongly held belief and a 'delusion' is not always easy to make and partially depends "on the degree of conviction with which the belief is held despite clear or reasonable contradictory evidence regarding its veracity" (APA, 2013, p. 87). Conventional diagnostic systems further distinguish between bizarre and non-bizarre 'delusions', with the former being considered implausible and un-understandable to same-culture peers (APA, 2013) and the latter highly improbable (Sedler, 1995). However, whilst this distinction (which has been present since the DSM-III) previously had diagnostic implications, this is no longer the case in DSM-5. This change came about in response to evidence highlighting the poor inter-rater reliability in the assessment of bizarre 'delusions' (Tandon et al., 2013).

These experiences are frequently a source of distress and preoccupation and they often

interfere with a person's day-to-day life. Within psychiatric classification systems, they are included in the criteria for all psychotic disorders and are central to the conceptualisation and definition of schizophrenia and delusional disorders (APA, 2013; WHO, 2018). Nonetheless, 'delusional' beliefs could be considered 'transdiagnostic' phenomena (Bebbington & Freeman, 2017) as they may be associated with a range of categories including depression and certain personality disorders. Indeed, the lack of diagnostic specificity of 'delusions' has contributed to debates about the validity and usefulness of what some regard as broad and heterogeneous constructs (e.g., schizophrenia: e.g., Bentall, Jackson, & Pilgrim, 1988; Boyle, 2002; Read & Bentall, 2013), as well as to a growing body of research that investigates them in their own right (e.g., Bentall, Corcoran, Howards, Blackwood, & Kinderman, 2001; Freeman, Garety, Fowler, Kuipers & Bebbington, 2002).

Although 'delusions' vary widely in their content, it is commonly held that they tend to reflect a small range of themes, such as persecution, reference and grandiosity (Bentall, 2003). It is suggested that 'delusions' occur in approximately 70% of people with a schizophrenia spectrum diagnosis (e.g., Fenton, McGlashan, Victor, & Blyler, 1997; Kimhy, Goetz, Yale, Corcoran, & Malaspina, 2005). Although it is acknowledged that "schizophrenia has blurred borders . . . especially with bipolar disorder and with depression" (Schizophrenia Commission, 2012, p. 11), research on the frequency of 'delusions' in people with diagnoses other than psychosis has been limited. Maj, Pirozzi, Magliano, Fiorillo and Bartoli, (2007) report that approximately 20% of people with a diagnosis of major depression may experience 'delusions' and the *lifetime* prevalence of these experiences in those with a diagnosis of bipolar disorder has been found to be as high as 65% (Upthegrove et al., 2015). Persecutory (paranoid) 'delusions'—beliefs that others intend to cause one harm—are considered the most common type of unusual beliefs (e.g., Kalra, Bhugra, & Shah, 2012) and have received the most attention in the literature (Bentall et al., 2001). It is estimated that paranoid beliefs are experienced by up to 90% of individuals with first-episode psychosis (Elahi, Perez Algorta, Varese, McIntyre, & Bentall, 2017).

However, and despite their centrality in clinical theorising for more than a century, the very definition of 'delusion' remains under dispute (Bentall, 2018) and several commentators have noted the myriad semantic and epistemological difficulties associated with the clinical usage of the term (Bell, Halligan, & Hadyn, 2003). Arguably, this conceptual and definitional ambiguity is neither a peripheral nor merely a theoretical matter. On the contrary, more than

any other psychiatric diagnostic term, at the heart of the notion of 'delusion' are questions about sanity and madness (McKenna, 2017) and about experiences that are considered to sit outside the boundaries of rationality. As Georgaca (2014) notes, what is at stake in the case of 'delusions' "is the very reality of the person" (p. 56). Before reviewing different theories concerning the nature and origin of unusual beliefs, some difficulties associated with contemporary definitions will be briefly explored.

A brief note on language

This thesis acknowledges that the term 'delusion' is contested and that "the way in which language is used to describe something has many implications and can represent forms of power and control" (Hunter, 2018, p. 8). For example, Romme and Escher (2012) suggest that terms such as 'delusions' and 'auditory hallucinations' have the potential to alienate people from their experience, as they are often used to judge people instead of listening to them and taking their experiences seriously. Moreover, as a medical term, 'delusion' is associated with a specific theoretical framework that many consider and experience as pathologising. Commenting on the usage of the term in the scientific literature, Boyle (2002) notes that one is left with a misleading impression that being 'delusional' is a straightforward aspect of one's identity. Thus, the British Psychological Society's Guidelines on Language (BPS, 2015) encourage the usage of terminology that describes experience in non-medical terms such as 'beliefs others find unusual' or 'paranoid thoughts'. Alternative terms include unusual or unshared beliefs (Knight, 2009; May, 2012) and "having beliefs in conflict with consensus reality" (Hunter, 2018, p. 8). Acknowledging these issues as well as the lack of a universally accepted way of viewing these experiences, this thesis will either use the aforementioned alternative terms or put the term delusion in inverted comas.

From a categorical towards a continuum-based understanding

It has been suggested that despite their attempt to introduce a more dimensional approach to conceptualising mental health difficulties, current classification systems remain categorical at their core (e.g., Bredström, 2019; Kincaid, 2017). Thus, the dichotomous distinction between presence and absence of 'delusions' still holds as does the assumed qualitative difference between 'delusions' and 'normal' beliefs. However, as philosopher of psychiatry George Graham (2010) puts it "Avidly searching for a definitive or precise mark of a delusion is hunting for a hard-and-fast criterion where none exists" (p. 9).

Indeed, opinion polls consistently show that 'irrational' beliefs are more widely held than categorical schemes suggest. For instance, a US public opinion poll (Newport & Strausberg, 2001) found that 42% of the sample believed that people are sometimes possessed by the devil and 24% that extraterrestrials have visited earth in the past. A similar proportion (21%) believed that one can communicate with someone who has died. Similarly, an interview study of 4,096 adults in the UK, found that 12.4% of respondents claimed to have experienced mystical experiences, 11.5% telepathy and 10.4% after-death communication (Castro, Burrows, & Wooffitt, 2014). In a methodologically more robust study, Pechey and Halligan (2011) used the Cardiff Beliefs Questionnaire; a psychometrically valid measure addressing a wide range of beliefs including bizarre (e.g., "Do you believe that you are infested by parasites?") and non-bizarre (e.g., "Do you believe that certain people are out to harm or discredit you?") 'delusion-like' beliefs. The authors report that 38% of their general population sample (N=1,000) strongly endorsed at least one 'delusion-like' belief. Thus, 'irrational' beliefs that lack supporting evidence appear to be widespread and are not invariably considered symptomatic of mental illness (Corlett, 2018). This, then, seems to raise questions for attempts to justify the bizarreness of beliefs solely on statistical or conceptual grounds (Bell, Halligan, & Hadyn, 2003).

Moreover, data from large-scale epidemiological studies demonstrate that 'delusional' beliefs—as defined by diagnostic criteria—are experienced by a sizeable minority of the general population. For example, a study by van Os, Hanssen, Bijl and Ravelli (2000) found that 8.7% of their general population sample met criteria for 'delusional' beliefs which, nevertheless, were neither experienced as distressing nor required intervention. A further 3.3% were found to experience 'true', psychiatrist-rated 'delusions'. Notably, only 26 of 1,237 individuals (2.1%) in this study had received a psychosis-spectrum diagnosis, suggesting that the prevalence of these experiences is markedly higher in comparison to that of psychosis (e.g., Jablensky, 2000). A similar conclusion was reached in a review of epidemiological studies exploring both clinical and sub-clinical 'delusions' in the general population (Freeman, 2006) and these findings are further supported by a meta-analysis of 61 studies showing that such beliefs have a median population prevalence of 4.9% (Linscott & van Os, 2013).

Nevertheless, the frequency of these experiences in the general population varies among

studies depending on the assessment methods used (e.g., self-report or clinical interview) and the types of beliefs studied (Bell & Peters, 2014). Several studies have focused specifically on paranoid (persecutory) beliefs. Here, too, a growing body of evidence from both survey- based (e.g., Bebbington et al., 2013; Freeman et al., 2011) and experimental studies (e.g., Ellett, Allen-Crooks, Stevens, Wildschut, & Chadwick, 2013) demonstrates not only that these experiences occur frequently in the nonclinical population, but also that paranoid thinking is often associated with reductions in wellbeing and social functioning (e.g., Freeman et al., 2011).

Cumulatively, this body of literature highlights that beliefs considered 'delusional' are more common than often assumed (Bell & Peters, 2014). Moreover, it provides support for the notion that these experiences are not discrete all-or-none phenomena (Freeman, 2006), but instead exist on a continuum with ordinary beliefs (Bentall, 2003; BPS, 2017). Thus, if one takes paranoid thoughts as an example, this perspective would imply that transient, everyday experiences of suspicion and mistrust are found at one end of the continuum and persecutory 'delusions' at the other. Consequently, it has been suggested that whether or not people present to mental health services for help may depend not on the belief itself but, rather, on the associated levels of distress and preoccupation (Peters, Day, McKenna, & Orbach, 1999; Peters, Joseph, Day, & Garety, 2004), the meaning ascribed to the belief (e.g., Chadwick, Birchwood, & Turner 1996), as well as the reactions of those around the person (e.g., Heriot-Maitland, Knight, & Peters, 2012). This thesis focuses on people who are, or have been, in contact with mental health services in relation to their experiences.

'Delusions' as out of keeping with a person's culture

There seems to be a related, and less widely recognised, difficulty with contemporary definitions' emphasis on cultural sharing of beliefs. Whereas the aforementioned body of evidence appears to render problematic the idea that 'delusional' beliefs are "not shared by anyone else from the sufferer's culture" (Taylor et al., 1994, p. 163), it could be argued that the very concept of culture itself is used in an oversimplified way.

It is generally assumed that 'delusions' are the idiosyncratic products of individual minds (Gaines, 1995), which rests on the notion of thinking as a solipsistic, private activity (Barrett, 2004). Yet, exploring the category of 'delusions' from a cultural perspective, Gaines (1995) suggests that the mind makes extensive use of its culture's ideas, assumptions and

constructions of reality, without which it could not function at all. Gaines joins other anthropologists in emphasising the profound cultural shaping of experience. However, if one accepts that culture—conceived broadly as the "shared symbols and meanings that people create in the process of social interaction" (Jenkins & Barrett, 2004, p. 5)—informs every aspect of human experience, is it possible to also sustain the view that 'delusions' lie outside it? In other words, can one suggest that these experiences are external to culture?

Furthermore, it has been argued that conventional definitions often depict culture as a fixed and inert phenomenon (Bredström, 2019). Indeed, the assertion that 'delusions' are incompatible "with the socially shared beliefs of the individual's background and culture" (WHO, 1994, p. 27) appears incongruent with contemporary views of culture as a dynamic and ongoing *process* in a state of flux (e.g., Lopez & Guarnaccia, 2000). Portraying culture as static, runs the risk not only of ignoring intra-cultural variation (Guarnaccia, Kirmayer, & Sartorius, 2007), but also of disregarding the fact that people immerse themselves in myriad cultures and subcultures, which impact on their construing (Tindall, 2011). For example, Hornstein (2018) narrates the story of a service user who believed that her house was under surveillance due to her comrades suspecting her of being a police informer. These distressing experiences culminated in several psychiatric hospital admissions. At the time, the person was involved in political activism in Northern Ireland and these beliefs were indeed an accepted, albeit unsettling, part of the political culture within which she operated.

'Delusions' as unintelligible beliefs

Pilgrim (2007) notes that there is a continuing dispute about whether beliefs regarded as 'delusions' might be comprehensible within the context of an individual's personal background and life situation. Critics claim that these experiences are typically viewed as unintelligible and, thus, their content is frequently judged to be unimportant in clinical practice (e.g., Boyle, 2002; Read & Argyle, 1999). Whilst this matter remains largely unexplored, a few studies suggest that clinicians are often reluctant to attend to the content and personal meaning of one's unusual beliefs (e.g., McCabe, Heath, Burns, & Priebe, 2002; Steele, Chadwick, McCabe, 2018). Moreover, it appears that even when 'delusions' are addressed during consultations, the links between a person's beliefs and their life experiences are not routinely explored (Zangrilli et al., 2014).

Nevertheless, evidence from a number of qualitative studies suggests that unusual beliefs are

often meaningful and reflective of a person's life experiences and concerns (e.g., Campbell & Morrison, 2007; Drinnan & Lavender, 2006). Thus, viewing these experiences as understandable responses to, often extremely difficult, life circumstances has been described as a more accurate and helpful perspective (BPS, 2017). Returning to the example offered above, Hornstein (2018) highlights that, whilst complex and confusing, the person's paranoid beliefs were intelligible in the context of her life history; they were precipitated by a political identity crisis which had led the individual question key tenets of her ideology. In other words, the person's beliefs could be understood as an indirect expression of the conflict she experienced (Hornstein, 2018).

'Delusions' as false beliefs

A key definitional criterion for 'delusions' is their falsity and it is this aspect that has been described as most problematic from an epistemological perspective (e.g., Harper, 2004; Harper & Cromby, 2014). For example, critical scholars note that traditional theorisations of 'delusions' are premised on a naïvely realist perspective which postulates the existence of an objective reality and a sole, true way of perceiving it (Cromby & Harper, 2009; Georgaca, 2000; Harper, 2004). However, social constructionism questions the notion that one can have transparent access into veridical reality, suggesting instead that there are "competing ways of knowing and being that generate competing facts and truths" (Pettman, 2012, p. 145). These, essentially, philosophical matters will be further explored in the following chapter.

Even if one sets aside questions about the nature of reality, the criterion of falsity seems to ignore the fact that there are numerous beliefs, whose truth status is undeterminable (Read & Bentall, 2013; Harper & Cromby, 2014). Indeed, "some of humankind's most widespread and important belief systems are also some of the least testable and scientifically tenable" (Friesen, Campbell, & Kay, 2015, p. 515). In addition, this criterion appears inconsistent with what we know more generally about belief updating, as a robust body of evidence suggests that people make systematic judgement and prediction errors. For instance, according to confirmation bias theory, people tend to search for evidence that supports their prior beliefs and discount or deny disconfirming information that appears to conflict with them (Oswald & Grosjean, 2004). A related phenomenon (desirability bias), suggests that people revise their prior beliefs assigning more weight to new information that is desirable, than new but undesirable (Sharot & Garrett, 2016). Consequently, philosopher of mind Lisa Bortolotti (2014, p. 75) suggests that "all human agents are epistemically irrational" and,

thus, the difference in rationality between individuals whose beliefs are considered 'delusional' and the non-clinical population "is a difference in degree rather than in kind". This is congruent with the increasingly appreciated notion of 'delusions' lying on a continuum with 'normality' (Bortolotti, 2018), outlined above.

'Delusions' as impervious to change

Lastly, the claim that 'delusions' are invariably held with conviction and are not modifiable by experience or counterargument appears problematic on several grounds. Boyle (2002, p. 271) suggests that "there is no evidence that delusional beliefs. . .are held with any greater conviction than equally improbable beliefs which would not be called symptoms". Indeed, people often hold political or religious beliefs with firm certainty (Taylor et al., 1994). Moreover, although contemporary definitions suggest that 'delusions' are firmly held "despite clear or reasonable contradictory evidence" (APA, 2013, p. 87), it has been argued that what would qualify as compelling counterevidence is unclear (Garety & Hemsley, 1997).

In addition, data from longitudinal studies suggest that beliefs considered 'delusional' are not fixed and unchangeable (e.g., Arndt, Andreasen, Flaum, Miller, & Nopoulos, 1995). On the contrary, there seems to be considerable variation in the strength and persistence of these experiences, even over relatively brief periods of time (e.g., Appelbaum, Robbins, & Vesselinov, 2004; Myin-Germeys, Nicolson & Delespaul, 2001).

Perhaps the most significant challenge to notion of fixity, comes from psychotherapy research suggesting not only that the degree of belief conviction is modifiable through therapeutic intervention, but also that it is possible to ameliorate the intensity and distress associated with the person's beliefs. In keeping with a continuum view, CBT for psychosis (CBTp) is premised on the notion that unusual beliefs can be challenged and weakened by exploring alternative perspectives (Chadwick, Birchwood, & Trower, 1996). It is worth noting that, to date, most intervention studies of CBTp have adopted a disorder-based approach. These tend to use broad outcome measures (e.g., global measures of 'positive symptoms' or general well-being), thereby obscuring any potential effects of therapy on 'delusional' beliefs per se. Nevertheless, as mentioned before, recent years have seen a growing clinical and theoretical interest in discrete experiences (e.g., beliefs, voices) and it has been suggested that the field is moving away from generic, traditional CBTp and toward 'symptom-specific' approaches (Hazell, Hayward, Cavanagh, Jones, & Strauss, 2016).

Indeed, a small number of studies have sought to examine the impact of CBT specifically on unusual beliefs. For example, a recent systematic review of individualised CBT focusing on paranoid beliefs found significant reductions in the outcomes measured (Lincoln & Peters, 2019) and meta-analyses of CBTp trials point towards significant small to medium effects on conviction (e.g., Mehl, Werner, & Lincoln, 2015; van der Gaag, Valmaggia, & Smit 2014). Furthermore, emerging evidence suggests that newer, mindfulness-based CBT approaches, too, hold promise in reducing belief conviction (e.g., Ellett, 2013), through accepting and letting go of distressing beliefs without directly challenging their content.

However, the strength of this evidence base is debated (Upthegrove & S.A., 2018) which could serve as an argument in support of the claim that 'delusions' do tend to persist. Studies that, in addition to group means, report on the proportion of clients who benefit from CBTp indicate that a substantial proportion remain distressed by their experiences. For example, a meta-analysis of 12 trials of CBTp found that reliable change occurred in 42% of CBT conditions (Gaudiano, 2006).

On balance, this literature seems to challenge the notion that unusual beliefs are static and unchangeable phenomena and offers support for a more fluid and dynamic understanding of these experiences.

Theories of 'delusions'

Having considered some conceptual difficulties associated with contemporary attempts at definition, the following section will outline some of the different explanatory frameworks that have been proposed regarding the nature and origins of unusual beliefs. Before proceeding, three points are necessary. First, as mentioned above, a growing body of research has explored 'delusions' in their own right (e.g., Bentall et al., 2001; Freeman et al., 2002). Whilst this alternative research programme has been actively pursued over the past few decades, this has been predominately from a cognitive perspective (Garety & Freeman, 2013). Indeed, 'single-symptom' research remains a relatively neglected strategy and the vast majority of literature on these experiences focuses on broader constructs such as psychosis or on contested (e.g., Bentall, Jackson, & Pilgrim, 1988; Boyle, 2002) categories such as schizophrenia. For example, a search of articles published in the British Journal of Clinical Psychology between 2015 and 2018, reveals nine papers making reference to 'schizophrenia' and three to 'delusions' in their title alone. Of those, only one used the more

descriptive "people with a diagnosis of schizophrenia". Consequently, some of the theories discussed below are not specific to 'delusions' per se. Second, the primary intention is to illustrate that there are multiple (indeed infinite) and sometimes competing ways of understanding these experiences and not to comprehensively evaluate the evidence for these theories. That said, this thesis acknowledges that some discourses are more powerful and privileged than others, not necessarily based on their actual validity. Indeed, it could be argued that the notion of validity itself cannot be understood devoid of context, but rather "is always conditioned by specific institutions and practices of power situated in time-space" (Bang, 2015, p. 76). Thirdly, and relatedly, it should be emphasised that the different frameworks discussed below are not of purely theoretical interest. On the contrary, they have distinct and profound practical implications for people who hold beliefs others find unusual.

Biological theories

It is commonly assumed that there is a biological basis for all types of 'delusions', even if this basis has not yet been precisely identified (Bortolotti, 2018). Moreover, whilst current classification systems claim to be atheoretical regarding aetiology, it has been argued that they are firmly premised on a biomedical model of distress (e.g., Carr & McNulty, 2016; Tobert, 2017). According to this dominant perspective, biological abnormalities are the main cause of experiences such as 'delusions' and these are best understood as symptoms of illness. For example, the website of the American Psychiatric Association, the organisation that publishes the DSM, frames schizophrenia as a "chronic brain disorder" (APA, n.d.) and the National Institutes of Health (2010, p. 1) as a "chronic and disabling brain disorder". A wide range of biological theories, each identifying different biological factors as causes of unusual beliefs, have been posited. Indeed, it has been suggested that the number of potential biological factors that have been identified is so vast that it covers "every aspect of biological functioning" (BPS, 2017, p. 40).

An influential and longstanding biochemical explanation is the dopamine hypothesis. This posits that hyperactivity of dopamine transmission in certain brain regions is responsible for experiences such as 'delusions' and 'hallucinations' (Desbonnet, 2016). A related line of inquiry has examined the role of brain structure (as opposed to the brain's chemicals). For example, research utilising brain imaging techniques has found subtle changes in cerebral structure and function, such as reduction in cortical grey matter in people with a diagnosis of schizophrenia (e.g., Bora et al., 2011) and 'delusional' disorder (e.g., Howard, Almeida,

Levy, Graves, & Graves, 1994; Vicens et al., 2016). A third area of research has focused on the possible role of genetics in the aetiology of these experiences, often by conducting twin and adoption studies (BPS, 2017). For example, a meta-analysis of 12 twin studies suggested that the heritability of schizophrenia is high and that the genetic contribution has a point estimate of 81% (Sullivan, Kendler, & Neale, 2003). A more recent study, estimated heritability based on family and adoption data and reported a lower, but still substantial heritability at 64% (Lichtenstein et al., 2009). A logical consequence of conceiving unusual beliefs as symptoms of a biologically-based mental illness is an emphasis on biological treatments in order to target the presumed abnormalities (Deacon, 2013).

Biological theories remain a matter of, often vehement, controversy and the notion that experiences such as unusual beliefs *should* be understood, first and foremost, as symptoms of a biological illness has been widely critiqued. In addition to the methodological limitations of biological studies in this area, that render the evidence of strictly biological causation equivocal (e.g., Boyle, 2002; Brown & Eyler, 2006; Moncrieff, 2009), critical commentators note the immense power of the pharmaceutical industry and its impact on biomedical research (e.g., Moncrieff, 2003). Moreover, it has been argued that an emphasis on biological-genetic explanations downplays the social and psychological factors implicated in these experiences and perpetuates unhelpful 'us' and 'them' dichotomies (e.g., Read, Haslam, Sayce, & Davies, 2006); a point that will be further discussed in the sub-section 'Delusions in context'.

In addition to this critique, one wonders whether the complexity and nuance of these experiences can be reduced to brain events or genes (Gach, 2008). Indeed, it could be argued that the issue in question here is not whether our biology is or is not implicated in mental distress. Biology is inevitably involved in any mental state that human beings experience and interacts with social and psychological aspects of experience (BPS, 2017). What appears problematic is what Davis-Floyd and St John (1998, p. 17) refer to as "the principle of separation" upon which much of biomedicine rests: the notion that the body can be separated from the mind, the individual from its constituent parts, and the person from their relationships and culture. And, as Nikolas Rose (2019) points out, whilst no one would doubt that experiences of distress involve brains, it:

> is necessary to put the brain back into the organism and the organism—the human—

> back to the interpersonal, cultural and physical milieu for which it has evolved, in which it develops from the moment of conception . . . and without which it would be unable to perform the most basic of its functions. (p. 115).

Psychological (cognitive) theories

As early as 1952, Aaron Beck (1952) described the use of cognitive therapy with a World War II veteran who held distressing paranoid beliefs, with positive results. In the past three decades, several cognitive models, each implicating different psychological processes in the development and maintenance of unusual beliefs, have been proposed. Despite their different foci, they are all premised on a continuum view of unusual beliefs and, thus, attempt to elucidate them drawing on processes and mechanisms involved in the development of 'normal' beliefs. Five influential psychological models will be summarised below.

An early model emphasised the role of probabilistic reasoning biases in the emergence and maintenance of unusual beliefs (Garety, 1991). This model suggests that individuals who hold such beliefs may have a tendency to 'jump to conclusions', that is, a tendency to draw conclusions using insufficient evidence. It is proposed that as a result of this bias, the person may prematurely accept improbable ideas without a consideration of disconfirming evidence or alternative explanations (Gatety & Freeman, 2013). It is further postulated that whilst this is a universal reasoning style, that serves an adaptive function in response to actual dangers, in people with 'delusions' this is extended to non-threatening situations (Dudley & Over, 2003).

Focusing mainly on paranoid beliefs, Bentall, Kinderman and Kaney (1994) have argued that these arise as a consequence of (latent) negative beliefs about the self and a tendency to make external personal attributions for negative events, that is, a tendency to attribute the causes of negative events to others' deliberate actions. In its original form, this theory highlighted the defensive function of paranoid beliefs. More specifically, it was hypothesised that through attributing negative events to others' hostility and malevolence, the person wards off unacknowledged feelings of low self-esteem. In other words, deep-seated negative beliefs about the self, do not reach consciousness and the persecutory beliefs function as an "extreme method of maintaining self-esteem" (Bentall et al., 1994, p. 334). This theory has since been revised, to take into account the dynamic nature of both people's self-concept (e.g.,

fluctuations in self-esteem) and their attributional responses. Thus, the revised Attribution–Self-Representation Model (Bentall et al., 2001) suggests that attributions influence future self-representations and the latter, in turn, influence subsequent attributions in a cyclical manner. Whilst the developmental origins of external personal attributions are not accounted for in this framework, it has been suggested that this cognitive bias is likely to develop in the context of adverse life events, experiences of victimisation and attachment insecurity (Bentall et al., 2001; Read & Bentall, 2013). The role of these experiences in the emergence of unusual beliefs will be discussed in the section on trauma-based understandings.

Building on the notion of paranoia as a defence against low self-esteem (Bentall et al., 1994), Trower and Chadwick (1995) have suggested that there are two, fundamentally distinct, forms of paranoia which they term 'poor me' (or persecution) and 'bad me' (or punishment) paranoia. The central proposition is that in the former, the self is experienced as good and the person believes that they do not deserve the malevolence they face. In 'bad me' paranoia, on the other hand, the self is experienced as bad and deserving punishment (Trower & Chadwick, 1995). Consequently, it is argued that whereas 'poor me' paranoia is accompanied by feelings of anger, 'bad me' paranoia gives rise to feelings of fear and anxiety (Chadwick et al., 1996). It was initially hypothesised that these two distinct types of paranoia are stable and that the 'poor me' variant exemplifies the defensive function of paranoia proposed by Bentall et al. (1994). The model was later revised (Chadwick, Trower, Juusti-Butler, & Maguire, 2005) to suggest that these beliefs are fluid and changeable. Thus, the revised model proposes that failures of the defence mechanism (and, hence, fluctuations in self-esteem) do occur and a 'poor me' stance may be succeeded by 'bad me' beliefs (Chadwick et al., 2005).

A fourth, neuropsychological theory, suggests that individuals who hold paranoid or referential beliefs, have theory of mind (ToM) difficulties (Frith, 1992; 1994), that is, difficulties in their ability to understand, reflect upon and predict others' states of mind, intentions and behaviour. This model is premised on the idea that these deficits in cognitive 'meta-representation', the origins of which are biological (Frith, 1992), cause one to misinterpret others' intentions. This, in turn, is posited to predispose the person to form 'delusional' beliefs (e.g., Frith; 1994; Frith & Corcoran, 1996).

Lastly, an influential theory that incorporates elements of all the models outlined above has

been put forward by Freeman et al. (2002). Premised on the observation that paranoid beliefs are often accompanied by anxiety and depression (e.g., Hartley, Barrowclough, & Haddock, 2013), the role of emotion in their formation and maintenance acquires a central role in this model (Gatety & Freeman, 2013). Based on a stress-vulnerability perspective, the model postulates that persecutory beliefs are the result of an interaction between biopsychosocial predisposition and stress. The latter, may also be biological, psychological or social in nature (Freeman et al., 2002).

It is proposed that the process of 'delusion' formation is set in motion by a precipitant (e.g., a stressful life event) that gives rise to arousal and, in some cases, unusual experiences (e.g., voices, unusual perceptions). Subsequently, the individual searches for explanations for these internal and external events. This 'search for meaning', is influenced by the person's core beliefs (about the self, others, and the world), their emotional state, as well as their reasoning biases (e.g., jumping to conclusions, external personal attributions, ToM) and culminates in the persecutory belief (Freeman et al., 2002). Crucially, in this model, pre-existing anxiety—possibly related to experiences of trauma—has a central role as it provides the threat theme characteristic of paranoid beliefs (Garety & Freeman, 2013). It is assumed that once formed, the belief is maintained though a range of processes including attentional and confirmatory biases, worry and the use of avoidance and safety-seeking behaviours (Freeman et al., 2002).

Advances in understanding the cognitive processes implicated in the development and maintenance of unusual beliefs have led to psychotherapeutic innovations in an area where, historically, psychological therapy was discouraged (Upthegrove & S.A., 2018). Arguably, the attempt to elucidate the meaning and function of one's unusual beliefs is an important strength of the models outlined above and CBTp appears to be an acceptable intervention to service users (e.g., Lawlor et al., 2017; Wood, Burke, & Morrison, 2015). However, cognitive accounts of 'delusions' have been critiqued for overemphasising presumed intra-psychic deficits and underplaying the social, relational and embodied aspects of experience (e.g., Boyle, 2002; Cromby & Harper, 2009). Moreover, it could be argued that even when social context is attended to, this is limited to the more proximal levels of one's environment (Bronfenbrenner, 1979), whereas more distal levels of culture and society (i.e., mesosystem, exosystem, macrosystem) remain largely absent in these accounts. This rather narrow understanding of context is illustrated in the following passage: "Social factors are sometimes overlooked in cognitive interventions . . . However, relationships with others,

levels of expressed emotion, and *beliefs* [emphasis added] about talking with others, may also be valuable topics for discussion in therapy" (Freeman et al., 2002, p. 342).

Trauma, adverse life experiences and unusual beliefs

In the previous section, it was suggested that rather than being un-understandable and devoid of meaning, unusual beliefs are often intelligible in the context of one's life experiences. Indeed, there is a growing appreciation that these experiences could be understood as natural and meaningful responses to trauma and adversity (BPS, 2017; Johnstone & Boyle, 2018) and a robust body of evidence has highlighted the causal role of social and environmental factors in their development and maintenance (Stilo & Murray, 2010). As research in this area is vast, only key findings will be considered followed by some of the processes that have been proposed to account for the links between adverse life events and unusual beliefs. It is important to note that the separation of the different forms of adversity is somewhat artificial in that they often co-occur and mutually influence each other (Johnstone & Cromby, 2013).

Early adverse experiences

A growing body of research has examined the relationship between traumatic childhood experiences and psychosis and several large-scale studies have found that people who have experienced neglect or abuse (physical, sexual or emotional) as children, are more likely to develop psychosis during adulthood. For example, a meta-analysis of 41 population-based and clinical studies found that individuals exposed to any type of childhood adversity (including sexual, physical and emotional abuse, bullying, parental death or neglect) were 2.78 times more likely to report psychotic experiences (Varese et al., 2012). Another meta-analysis, looking specifically at individuals with a diagnosis of schizophrenia and experiences of sexual abuse, physical abuse and neglect found a higher odds ratio of 3.60 (Matheson, Shepherd, Pinchbeck, Laurens, & Carr, 2013). Notably, research in this field provides strong evidence for a dose-response relation between adverse events in childhood and outcome. In other words, the greater the severity of the adversity or the more types of adversity a person experiences, then the greater the chance of developing psychosis (Read & Bentall, 2013).

A smaller number of studies have investigated the relationship between specific kinds of adversity and specific experiences like unusual beliefs. For example, paranoid beliefs have been found to be associated with neglect (Sitko, Bentall, Shevlin, O'Sullivan, & Sellwood,

2014), growing up in institutional care (Bentall, Wickham, Shevlin, & Varese, 2012; Shevlin, McAnee, Bentall, & Murphy, 2015) and emotional abuse (Hardy et al., 2016). However, other studies have found only partial support for the notion of differential associations between specific forms of adversity and specific experiences (e.g., Longden, Sampson, & Read, 2016; van Nierop et al., 2015), suggesting instead that the former "could be seen as proxies for a range of more general (and cumulative) environmental risks and disadvantages" (Longden et al., 2016, p. 355). Moreover, as Johnstone and Cromby (2013) note, the impact of childhood adversity (and, indeed, of any type of adversity) is not only cumulative but also synergistic, as the effects of one adversity can amplify the effects of another.

A number of processes through which exposure to early trauma and adversity may lead to unusual beliefs have been proposed. Some of the cognitive models presented in the previous section (e.g., Bentall et al., 2001; Freeman et al., 2002) may help elucidate the links between adverse childhood experiences and unusual beliefs through effects on affect, reasoning and beliefs about the self, others and the world (Morrison, Read, & Turkington, 2005). Moreover, it has been suggested that positive beliefs about the unusual beliefs themselves in response to trauma (e.g., 'Paranoia is a helpful coping strategy') may also contribute to their development and maintenance (Morrison, 2001).

Given that early adverse experiences may disrupt the formation of secure attachments (e.g., Alexander, 1993), it has been argued that attachment theory can helpfully complement cognitive theorisations (Read & Bentall, 2013). Crittenden and Ainsworth (1989) suggest that children who have experienced abuse tend to be selectively vigilant to threat cues. And whilst this could be an adaptive strategy in the context of unpredictable and threatening environments, if it persists, it could lead to hostile attributions about others' intentions (Fisher & Craig, 2008). Indeed, in several studies insecure attachment has been associated with paranoid beliefs (e.g., Pickering, Simpson, & Bentall, 2008) and anxious and avoidant attachment styles have been found to mediate the relationship between neglect in childhood and paranoid beliefs in adulthood (Sitko et al., 2014).

Some commentators have suggested that the pervasiveness and impact of early trauma and adversity call for a genuinely biopsychosocial approach; one that integrates the insights of different perspectives (e.g., attachment theory, neuroscience and trauma studies) without privileging biological over psychosocial factors (Dillon, Johnstone, & Longden, 2012).

Recent attempts at integration include the traumagenic neurodevelopmental model (Read, Perry, Moskowitz, & Connolly, 2001) and the integrated biopsychosocial model of childhood maltreatment and psychosis (Barker, Gumley, Schwannauer, & Lawrie, 2015).

Racism and discrimination

Other investigations have pointed to the causal role of racism and discrimination in the development of psychosis. For example, in analysing data from the National Survey of Ethnic Minorities in the UK, Karlsen and Nazroo (2002) found that those who reported experiences of racially motivated assaults or property damage were 4.77 times more likely to have experiences of psychosis. Similarly, a large, general population study explored the association between perceived discrimination (on the grounds of skin colour or ethnicity, gender, age, appearance, disability and sexual preference) and 'delusional' ideation (Janssen et al., 2003). It was found that individuals who reported experiences of discrimination in more than one domain, were five times more likely to develop such ideation than those who did not. Whilst these studies focused on broad constructs such as psychosis or 'delusional' thinking, other studies have suggested that racial discrimination is specifically associated with paranoid beliefs (e.g., Combs et al., 2006; Shaikh et al., 2016).

The links between unusual beliefs and experiences of racism and discrimination could be accounted for in a number of ways. Experiences of racial victimisation can result in a range of negative emotional states including depression and anxiety as well as hypervigilance and low self-esteem (e.g., Fernando, 1984; Paradies et al., 2015) which, as previously discussed, have all been implicated in the development of paranoid beliefs. However, discrimination is not just a matter of an idiosyncratic incident—it is deeply embedded in the structure and institutions of society and operates both interpersonally and systemically. As Frantz Fanon noted, "In a racist society . . . all relations are permeated by racism" (as cited in Gibson & Beneduce, 2017, p. 19). Indeed, living in a hostile social environment often calls for personal and collective survival strategies (Lowe & Hopps, 2007). Thus, interpersonal wariness and suspicion, as well as beliefs about others' malevolence can be understandable reactions to extremely difficult life circumstances (Johnstone & Boyle, 2018). Nevertheless, over time these, once self-protective, strategies may lose their prior adaptive function (Crittenden, 2000) and lead to distress.

Socioeconomic disadvantage and inequality

Lastly, it has been suggested that out of all the adversities considered thus far, poverty is the social factor most powerfully associated with being given a diagnosis of schizophrenia (Read & Bentall, 2013) and numerous epidemiological studies have demonstrated that this diagnosis is markedly overrepresented among those at the lowest socioeconomic levels (e.g., Byrne, Agerbo, Eaton, & Mortensen, 2004; Werner, Malaspina, & Rabinowitz, 2007). Moreover, it has been found that income inequality in a society may be an even stronger predictor of a schizophrenia diagnosis than poverty (e.g., Burns & Esterhuizen, 2008).

Two prominent sociological theories that attempt to elucidate why schizophrenia is diagnosed more frequently among those in the lower social classes are the social drift and the social causation hypotheses (Rogers & Pilgrim, 2014). The former, asserts that people who have unusual and distressing experiences are often unable to stay in employment and, thus, move to poorer urban areas or become homeless as a result of their difficulties (Davey, 2011). In other words, it is assumed that people 'drift' down the social scale and their difficulties lead to poverty. Social causation theory, on the other hand, suggests that poverty precedes and contributes to the development of these experiences in the first place (Read, 2010). According to this perspective, experiences of socioeconomic deprivation in highly unequal societies are stress-inducing and can negatively affect people's well-being (Wickham, Taylor, Shevlin, & Bentall, 2014).

The studies discussed in this section have been valuable in demonstrating the links between adversity and experiences commonly thought of as psychosis. And research on childhood trauma and adversity, in particular, has been seminal in the development of trauma-informed approaches to mental healthcare (Sweeney & Taggart, 2018). Undoubtedly, the notion that mental distress has its roots in social adversity, inequality and various forms of injustice has important implications. Indeed, it has been argued that mental health is an inherently political matter and that distress cannot be thought about just as a problem *within* individuals (Recovery in the Bin, 2016).

However, the findings presented in this section have been interpreted in various ways. For example, some have argued that "There is abuse and there are the effects of abuse. There is no additional 'psychosis' that needs explaining" (Johnstone, 2009, p. 187). According to this perspective, experiences such as unusual beliefs are, invariably, natural human responses to

trauma and adversity. As with all the explanations presented in this chapter, this will not resonate with everyone's experiences and, arguably, the idea that "there is a single, fundamental level of explanation to which all other explanations reduce" (Tekin & Bluhm, 2019, p.8) carries dangers. Others, have suggested that the term psychosis is replaced with terms such as 'trauma and emotional distress' or 'trauma and dissociation' (Jordan, 2018). Yet, others still—either implicitly or explicitly—consider adverse life events as mere triggers of an underlying pathology. It has been suggested that this latter view remains the dominant way of theorising the links between adversity and 'delusions' (Longden & Read, 2016). For example, a recent review article notes that "Childhood adversities trigger specific biological alterations in psychosis" (Misiak et al., 2017, p. 393). Similarly, a study exploring the association between a schizophrenia diagnosis and socioeconomic status goes as far as to suggest that residing in a socioeconomically deprived neighbourhood is a "substantially heritable trait" (Sariaslan et al., 2016, p. 4).

Spiritual explanations

Whilst religious or spiritual understandings of unusual experiences are common in many parts of the world, these have largely been absent in the industrialised and increasingly secularised West (Fabrega, 1996). Nevertheless, frameworks that draw on indigenous and Eastern spiritual and mystical traditions (Friedman & Hartelius, 2014) have contributed to the growing interest in the idea that experiences of psychosis may have a spiritual element to them.

The notions of spiritual emergence and spiritual emergency are important in this context. The former, refers to the gradual process of spiritual growth which is seen as a natural aspect of human development (Randal & Argyle, 2005). It is postulated that when this process occurs suddenly or rapidly, it can give rise to a spiritual crisis or emergency (Grof & Grof 1989). The latter, takes the form of unusual or non-ordinary states that, if understood and appropriately supported, can be transformative experiences offering opportunities for growth and healing (Lucas, 2011).

Whilst some authors distinguish spiritual from 'psychotic' experience (e.g., Greyson, 1993; Lukoff, 2012), others see this distinction as problematic. Indeed, it has been suggested that "both psychotic and spiritual experience come from the same potential of human experiencing" (Clarke, 2016, para. 4) and that this way of experiencing the world is

accessible to everyone. From this perspective, the distinction between psychosis and spiritual emergency is neither clear-cut nor particularly useful (Clarke, 2011; House, 2010) and the very notion of spiritual emergency is seen as incongruent with biomedicine's framing of distress as illness (Grof, 2011; House, 2010). Instead, crises typically seen as 'psychotic' are viewed as "crises of the evolution of consciousness . . . comparable to the states described by the various mystical traditions of the world" (Grof & Grof 1989, p.3). Examples of such non- ordinary mind states include those that Shamans experience as part of shamanic initiatory crises, or the states that native cultures experience during rites of passage (Grof, 1992). These non-ordinary states of consciousness may involve physical sensations, sensory changes, visions and unusual thoughts (Krippner, 2003). According to Grof and Grof (1989), although such experiences are often unhelpfully dismissed or ignored as 'delusions' they can be replete with meaning and transformational possibilities such as a sense of deeper connection with others and the world.

It is acknowledged that going through a spiritual crisis, or, in Isabel Clarke's (2011) term, facing 'unshared reality' can be an extremely challenging and frightening experience. Thus, organisations like the Spiritual Crisis Network aim at supporting people safely navigate their experiences (Clarke, 2013). To facilitate this process, a range of strategies have been suggested including grounding, validation, contact with others, self-expression, exercise and mindfulness (Rush, 2013). In mainstream mental health services, too, there is a growing recognition of the importance of respecting and acknowledging the spiritual dimensions of service users' experience (e.g., Department of Health, 2009).

This section outlined different perspectives regarding the nature and causes of unusual beliefs. One notes the multiplicity of views held, not only between but also *within* different explanatory frameworks (e.g., different cognitive theories). As mentioned at the beginning of this section, this overview has not been exhaustive and there are infinite ways of understanding these experiences. For example, some people may adopt parapsychological, political, or philosophical explanations for their beliefs (Romme & Escher, 1989), to name a few. Arguably, then, attempting to "reduce all instances of psychosis to one single explanatory system" (Aronovich, 2017, p. 29) seems problematic on several levels.

‘Delusions’ in context

This section will attempt to map the current mental health landscape in the UK and describe some of the challenges faced by service users both within and outside the mental health system. Whilst some of the issues explored here will be specifically relevant to people who hold beliefs that others don’t share, others will be of a broader nature.

Few would disagree that biomedical approaches currently dominate in the mental health field and that ‘delusional’ beliefs are typically understood as symptoms of mental illness, requiring treatment. Critiques of biomedical and diagnostic approaches to mental distress abound. For example, a report by the United Nations notes that “the field of mental health continues to be over-medicalized and the reductionist biomedical model . . . dominates clinical practice, policy, research agendas, medical education and investment in mental health around the world” (United Nations, 2017, p. 5-6). It has been suggested that this hegemony is evident not only within psychiatry but also within allied health professions such as psychology, nursing and social work (LeFrançois, Beresford, & Russo, 2016).

The British Psychological Society (2013) suggests that the ‘illness model’, on the one hand minimises the role of psychosocial factors in people’s distress, and on the other leads to an overreliance on physical interventions whose efficacy and safety have been exaggerated (e.g., Read, Runciman, & Dillon, 2016). For example, as previously mentioned, feelings of paranoia may be linked to one’s marginalised social location; a link that is, arguably, obscured by viewing these experiences solely as symptomatic of a medical illness (Cromby & Harper, 2009). With regard to the second point, a recent retrospective analysis found a consistent increase in the number of atypical antipsychotics prescribed in the UK between 2007 and 2014 (Roberts, Neasham, Lambrinudi, & Khan, 2018). Based on the data provided by the authors, for some of the most commonly prescribed antipsychotics, the increase has been as high as 307%.

Notably, it has been shown that biomedical beliefs about the causes of psychosis increase, rather than reduce, negative attitudes towards people experiencing mental health difficulties (e.g., Read et al., 2006). Many service users experience this framework for understanding and responding to their distress as one that inherently pathologises and dehumanises them (Beresford, Nettle, & Perring, 2009), and that reinforces passive patient/active expert roles

(Dillon & Hornstein, 2013).

Moreover, whilst clinical guidelines (e.g., NICE, 2014) recommend that psychological therapies such as CBTp or Family Intervention should be offered to people with experiences of psychosis, the current reality of service provision appears very different with only a minority having access to these interventions. For example, the Second National Audit of Schizophrenia found that only 39% were offered CBT and 12% Family Intervention (Royal College of Psychiatrists, 2014). Indeed, access to talking therapies for people with diagnoses such as schizophrenia or bipolar disorder has been described as "notoriously poor" (Mind, 2013, p. 21) and it has been suggested that service users are rarely supported to make informed choices regarding the therapies they receive, even if they are deemed to have decision-making capacity (Morrison, 2019). The latter notion, as well as the related notion of 'insight'—typically taken to mean 'unawareness of the fact of being mentally ill' (Case, 2016, p. 364)—have been repeatedly critiqued (e.g., Beck-Sander, 1998; Høyer, 2000). For example, it has been suggested that lack of insight tends to mean that the person disagrees with medical/expert opinion regarding their experiences (Kirmayer, Corin, & Jarvis, 2004). As sociologist David Heise (1988) suggests, the diagnosis of 'delusion' involves a conflict between competing versions of reality, wherein the view of the person with more social power—the professional—is upheld (Heise, 1988). Thus, the person's account is often discounted and their testimony is seen as less credible which has been theorised as an assault on one's personhood (Fricker, 2007; Sanati & Kyratsous, 2015). Importantly, lack of 'insight' overrides the need to obtain consent for treatment (Rogers & Pilgrim, 2014) and coercion remains one of the most controversial aspects of mental health services (Johnstone & Boyle, 2018).

Over the past few years, involuntary psychiatric admission rates have increased by more than a third (Sashidharan & Saraceno, 2017). People with experiences of psychosis are more likely to be treated coercively in acute settings (Kalisova et al., 2014) and, in addition to being more likely to be diagnosed with schizophrenia (Schizophrenia Commission, 2012), people of African-Caribbean and African origin are also more likely to be subjected to compulsory treatment (e.g., Barnett et al., 2019; Bhui, Brown, Hardie, Watson, & Parrott, 1998). According to NHS digital figures, in 2017-2018 those in the 'Black or Black British' ethnic group were over four times more likely to be detained under the Mental Health Act than their white counterparts and over eight times more likely to be subjected to a

Community Treatment Order (NHS Digital, 2018). Thus, some have called attention to differential positions of power and status within mental health systems and the racism inherent therein (e.g., Fernando, 2017; Metzl, 2010). Moreover, given that experiences of trauma and adversity are common in those experiencing mental distress (as discussed in the previous section), coercive practices can be re-traumatising, perpetuating feelings of powerlessness (Johnstone & Boyle, 2018). Similarly, Knight (2002) suggests that the very practices employed by mental health services and the accompanying erosion of civil rights may, in themselves, induce and sustain paranoid thinking. These issues are reflected in many contemporary first-person accounts from users of services who often describe their encounters with mental health services as disempowering and demeaning (e.g., Cochrane, 2018; Gray, 2019).

Recent years have witnessed additional forms of oppression that, for many, have been even more debilitating than the hurtful experiences outlined above (Watts, 2018). It has been suggested that cuts to public mental health provision in the context of austerity have limited the support available to people in distress (Moth, Greener, & Stoll, 2015), marking a shift from coercion to neglect (Spandler, 2016). For example, Docherty and Thornicroft (2015) found that the decline in government investment in mental health services, from 2008 onwards, has resulted in a 48% decrease in the number of people who receive publicly funded mental health care. At the same time, current welfare reforms, which disproportionately affect people with mental difficulties, constitute an attack on claimants' livelihood and dignity (Cummins, 2018). It could be argued, then, that in such a social reality, "in a very real sense others *are* in control of your life and it may feel as if they are persecuting you" (Harper, 2011, p. 59).

Moreover, negative attitudes towards people with mental health difficulties remain highly prevalent (e.g., Schomerus et al., 2012). In comparison to other diagnoses, those in receipt of a diagnosis of schizophrenia are viewed more negatively by the public (Angermeyer & Matschinger, 2003; Wood, Birtel, Alsawy, Pyle, & Morrison, 2014) and are often perceived as incompetent, dangerous and unable to recover (Corrigan, Larson, & Rüsch, 2009). In a large survey (N=2,500) carried out in the UK, as many as 87% of respondents reported experiences of stigma and discrimination (Schizophrenia Commission, 2012). Negative attitudes, stereotypes and the acts of exclusion and discrimination that accompany them can have profoundly deleterious consequences for one's well-being, especially if stigmatisation

is internalised (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Indeed, a large body of research suggests that such experiences can lead to loss of social (e.g., employment, housing and education) opportunities, depression, hopelessness, diminished self-esteem, decreased life satisfaction and suicidality (e.g., Corrigan & Kleinlein, 2005; Livingston & Boyd, 2010; Yanos, Roe, Markus, & Lysaker, 2008). Furthermore, and contrary to popular cultural stereotypes, a robust body of evidence suggests that people with mental health difficulties are often the victims rather than the perpetrators of violence. For example, a meta-analysis found that 24.3% of those with mental health difficulties had been subjected to violence in the previous year alone (Hughes et al., 2012). In addition, both social isolation and loneliness are pervasive with over 80% of people with experiences of psychosis reporting feeling lonely in the past 12 months (Stain et al., 2012).

It has been suggested that the notion of 'stigma' may misleadingly individualise what are, essentially, collective discriminatory responses towards people with a psychiatric diagnosis. (e.g., Rogers & Pilgrim, 2014; Sayce, 2000). In other words, according to this perspective, and similarly to what was discussed above regarding racism, 'stigma' is not merely a matter of personal failing or a trait (e.g., a 'belief') but something that is embedded in our institutions and the social fabric of our society. Nevertheless, it could be said that practices of othering and discrimination take place at *both* interpersonal and institutional levels and both can be devastating (Bullock & Lott, 2014). Indeed, just as a sole focus on the micro-level of people's interactions may obscure structural aspects of discrimination, an analysis that is restricted to "social systems and *things*" (Scheper-Hughes & Lock, 1986, p. 137) could lead to a neglect of local (in a broad sense), contextual meanings and the subjective reality of othering and exclusion.

Whilst there is still need for radical changes in mental health services (BPS, 2017), it could be argued that experiences commonly thought of as psychosis, are beginning to be seen differently. For example, the British Psychological Society's (2017) 'Understanding Psychosis and Schizophrenia' report, highlights that there is not one right way of understanding phenomena such as unusual beliefs. This document advocates for a multifactorial understanding; one that contextualises emotional distress and recognises that each individual's experiences are unique. This is congruent with calls from within psychiatry, to move beyond the primacy of the biomedical model of distress and its attendant treatments (e.g., Bracken et al., 2012).

Moreover, the recovery approach is increasingly used as the overriding principle for service provision in the UK (DOH, 2011) and, for some, has led to positive changes within services for psychosis (BPS, 2014). According to the oft-quoted definition of recovery put forward by rehabilitation psychologist William Anthony (1993), recovery is "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles . . . a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness" (p.13). Thus, a key idea is that recovery does not equate with 'cure' or the elimination of an illness and this approach has been said to mark a shift in emphasis from symptoms, impairment and professional expertise to empowerment, participation and expertise by experience (Slade et al., 2014). A number of different models that attempt to describe the key components of recovery have been developed. For example, following a narrative synthesis of the personal recovery literature, Leamy, Bird, Le Boutillier, Williams and Slade (2011) identified five key processes underpinning recovery: feeling connected, hope and optimism for the future, finding meaning in life, feeling empowered and discovering one's identity (CHIME).

Nevertheless, and despite its ubiquity, the notion of recovery remains highly contested (Le Boutillier et al., 2015) and seems to mean different things to different people. As Rose (2019) notes, whilst the notion of recovery, as pioneered in the work of survivor activists, "was initially a radical alternative to conventional psychiatric norms and practices" (p. 161), over a surprisingly short period of time it became professionalised and was stripped of its progressive elements. Others have suggested that the notion has been "colonised by mental health services" (Recovery in the Bin, 2015, p. 21) in order to serve neoliberal agendas rather than uphold the rights and interests of service users (Beresford, 2015). Indeed, it has been argued that the recovery approach is often used to justify cuts in public health services, reinforce a responisbilising discourse and shift the focus away from the social determinants of distress (e.g., Beresford, 2015; Harper & Speed, 2012). However, it is worth highlighting, that whereas some critical commentators seem to reject the notion outrightly, others direct their critique to what the term has come to mean.

Many of the themes outlined in this section, such as the medicalisation of distress, oppression and silencing both within and outside the mental health system, stigmatisation, as well as lack of choice and poverty of service provision, have been prominent in the discourse and practices of the mental health service user/survivor movement. And at the heart of the latter

lies peer support (Faulkner, 2017).

The service user/survivor movement

Wallcraft and Bryant (2003) define the term service user/survivor movement as the "the work of individuals who advocate for their personal and collective rights within the context of discrimination faced as a result of having experienced mental health difficulties and/or being diagnosed as having a mental illness" (p.3). Whilst its origins have been traced by some as far back as the 17th century (e.g., Bracken et al., 2012; Wallcraft & Bryant, 2003), it was not until the 1970s and 1980s that formal organisations or informal groups led by people who have experienced the mental health system emerged (for a review, see Beresford & Campbell, 2004). For some, this movement is an example of the emergence of new social movements (Crossley, 2006) such as civil rights, feminist, LGBT and ecological movements, which are often seen as distinct from traditional (i.e., class-based) social movements.

The term 'movement', in its singular form, may misleadingly give the impression that all service user/survivor groups and organisations have an agreed set of shared objectives. However, as Campbell (2013) notes, the service user/survivor movement is noteworthy for both the diversity of its actions as well as the views that underpin these actions. For example, whereas some user groups concentrate their efforts on campaigning against stigma and discrimination or on seeking improvement in existing services, others strive for service user-led forms of support as alternatives to, or in conjunction with, mainstream mental health services (e.g., user-run crisis houses). Some groups bring attention to rights abuses that occur *within* mental health institutions (e.g., Speak Out Against Psychiatry) and others still, focus on more than one of these areas. Relatedly, different groups hold different views about the origins and meaning of people's mental distress (Rogers & Pilgrim, 2014). Thus, whilst some user-led groups accept biomedical frameworks of distress, others challenge the illness paradigm and the primacy of professional models of expertise, promoting positive alternatives to traditional medical discourses and practices. Despite this diversity, however, what these different forms of collective action have in common is that they are premised "on the key principles of valuing people's own first-hand experience and experiential knowledge, and speaking and acting for themselves" (Beresford, 2012, p.70).

A number of policy initiatives over the past few decades have resulted in an expansion of

service user groups and organisations. Policies and government Acts such as the Community Care Act (1990) and the National Service Framework for Mental Health (DOH, 1999) have made the involvement of service users in service planning, delivery and evaluation a requirement. Whilst few would see this as an unwelcome development, it has been suggested that, as a result, more progressive forms of activism have "dissolved into 'user involvement'" (Faulkner, 2017, p. 14). Moreover, users' participation rights in mental health care (similarly to users' involvement in research which will be discussed in the following chapter) are often applied in a tokenistic fashion and this can be detrimental to their wellbeing. For example, Barnes and Bowl (2001) note that service users who participate in consultative processes often remain unheard and feel patronised despite a seeming organisational commitment to user involvement.

Defining peer support

Peer support has been defined as a process of "giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful" (Mead, Hilton, & Curtis, 2001, p. 135). Similarly, Adame and Leitner (2008, p. 148) define peer support as "a mutual, non-hierarchical mode of being with other people who have had struggles similar to one's own". The term is often used interchangeably with self-help and, despite important differences between these notions, they both have mutual aid and reciprocity at their core (Seebohm, Munn-Giddings, & Brewer, 2010). Yet, peer support has come to hold different meanings for different people and its proliferation over the past decades renders a definitional distinction between different types of peer support necessary. A distinction between three broad types of peer support has been suggested (e.g., Bradstreet, 2006; Davidson et al., 1999).

The first type of peer support refers to the naturally occurring, informal support that people with lived experience of distress offer to one another such as the mutual support that may occur among people on an inpatient ward (e.g., Galloway & Pistrang, 2019). Arguably, this informal type of peer support predates and forms the basis for the other two. As Faulkner and Basset (2012a) point out, the practice of people with shared experiences of distress coming together to support each other dates as back as the 19th century.

The second type refers to participation in user-run groups or programmes such as peer-led self-help/peer support groups. Having its origins in the service user/survivor movement of

the 70s and 80s, this form of peer support has been "intertwined with feelings of powerlessness within the mental health system and with activism promoting human and civil rights" (Penney, 2018, p. 2). These words echo those of Deegan (2006, para. 3) who describes peer support as a "response to the alienation and adversity associated with being given a psychiatric diagnosis". Peer support and self-help are, and historically have been, key activities of service user groups and organisations in the UK. For example, a survey of user/survivor groups found that self-help and social support was the most commonly reported activity (79%) followed by consultation with decision makers, training and education, creative activities, and campaigning and advocacy (Wallcraft, Read, & Sweeney, 2003). Some have highlighted that this type of peer support grew out of an opposition to the overmedicalisation of distress (Beales & Wilson, 2015) and is, therefore, incongruent with many of the fundamental principles of statutory services (Filson & Mead 2016).

Lastly, the third type of peer support reflects a more recent development wherein service users are employed as paid peer support providers. Notably, this formalised version of peer support (often referred to as Intentional Peer Support) has been defined as almost antithetical to the other two. For example, Davidson et al. state that "unlike mutual support and consumer-run programs", peer support involves "an asymmetrical—if not one-directional—relationship, with at least 1 designated service/support provider and 1 designated service/support recipient" (Davidson, Chinman, Sells, & Rowe, 2006, p. 444). This form of peer support is predominantly offered not on a group basis, but on an individual one. For Faulkner and Basset (2012b), this shift is interlinked with policy developments in healthcare and the move towards 'individualisation' and personalisation. For example, under the vision of personalised care, people are said to have 'choice and control' and manage *their own* mental health. However, as a result, opportunities for collective and group-based forms of support and action (the basis of user-led organisations as discussed above) are reduced.

Peer specialist training and certification programmes have been introduced in several countries, including the UK and peer support workers are now increasingly employed in statutory mental health services, complementing or carrying out clinical functions (Gillard, 2019). For example, people with lived experience of mental health difficulties may be employed as peer support workers in community mental health teams or on inpatient wards. Indeed, peer support workers are considered an essential component of recovery-oriented mental health services (NICE, 2014) and peer support is included in the government's mental

health strategy (DOH, 2011). Unsurprisingly, over the past decades research has overwhelmingly focused on this formalised type of peer support, often utilising methodologies and measures of outcome that many see as incongruent with the core values and ethos of peer support (e.g., Dillon & Hornstein, 2013). This point will be further developed later in this chapter.

However, the exponential increase of formal peer support worker roles, has been accompanied by an increasing lack of clarity about what peer support is (Beales & Wilson, 2015). For example, a recent systematic review of one-to-one peer support found that among the 13 qualitative studies reviewed "'‘peer support'' described advocacy, crisis support, training roles, roles in the statutory sector, volunteer roles and supervisor positions" (Watson, 2017, p. 10). Whilst the formalisation of peer support has been welcomed by many service users, others have been sceptical or even strongly opposed to it (Faulkner & Basset, 2010). Some have suggested that, similarly to the notion of recovery, peer support "has been re-invented and co-opted by mental health services" (Faulkner, 2017, p. 12), highlighting the way in which peer support has transmogrified into a service-led 'intervention'. A key question then, according to Erick Fabris (2013) is whether peer support will merely supplement stigmatising, biomedical approaches to distress, or if it will "advance self-help. . . mutual aid, and choice" (p. 131).

The Hearing Voices Movement

The Hearing Voices Movement is an international service user/survivor movement that aims at promoting the perspectives and needs of voice-hearers (Longden, Read, & Dillon, 2017). It originates in the work of Marius Romme and his colleague Sandra Escher (Romme & Escher, 1989), who worked alongside voice-hearers to develop an alternative approach to understanding experiences commonly referred to as 'auditory hallucinations'. The latter, alongside 'delusions', are typically seen as central symptoms of 'schizophrenia'.

This approach is premised on a number of key ideas and values. In contrast to biomedical framings, voice-hearing is seen as a normal human variation that is not, in itself, an indication of 'illness'. As such, it is argued that it is not open to 'cure' but only to coping with the distress that may be associated with it (Romme & Escher, 1993). Moreover, hearing voices is viewed as a meaningful experience that can be understood in many ways. That said, it is acknowledged that voice-hearing is often linked to past adverse experiences, particularly

abuse (Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014; Longden & Dillon, 2013). Lastly, the approach emphasises that the support offered to people who hear voices should be based on acceptance, respect, informed choice and an understanding of the subjective meaning that the voices have for the person (Intervoice, n.d.).

Since its founding in 1988, the movement has markedly grown. There are currently networks in 30 countries and the 'hearing voices community' comprises of both experts by experience as well as professional allies such as clinicians and academics (Corstens, et al., 2014). As previously mentioned, user/survivor groups and organisations often engage in a diverse range of activities (Wallcraft et al., 2003). The work of the Hearing Voices Network, too, is diverse and encompasses a number of activities including promoting advocacy for the rights of voice- hearers, offering workshops and training, critiquing traditional understandings of voice- hearing and supporting the development of user-led peer support/self-help groups for people who hear voices (e.g., Corstens, et al., 2014; Longden & Dillon, 2013). It is this last aspect of its work that has attracted the most attention and there are now over 180 such groups in the UK (Longden & Dillon, 2013) and over 1,000 groups globally (Kay, Kendall, & Dark, 2017).

Paranoia and Unusual Beliefs Groups

'*Unusual beliefs are meaningful and symbolic, they are not merely the bizarre misfirings of a faulty brain*' (May, 2012, p. 141).

Drawing on the Hearing Voices Network's approach to voice-hearing (Longden & Dillon, 2013; Romme, & Escher, 1993), peer support groups for paranoid and unusual beliefs have begun to be established over the last decade. These groups arose from an acknowledgment that people who hold beliefs others find unusual, but don't necessarily identify as voice-hearers, could benefit from a similar kind of support to that offered by hearing voices groups. The first groups in the UK were set up in Sheffield (James, 2003), Exeter (Knight, 2009) and Bradford (May, 2007) by experience-based experts. Often affiliated with the National Paranoia Network (Dillon & Longden, 2012), these groups have steadily grown over the past few years. For example, the database of the London Paranoia & Beliefs (P&B) Network—which is part of the broader London Hearing Voices Network—currently lists 15 active groups in this region alone.

Paranoia and beliefs groups aim at providing mutually supportive environments where members can feel less isolated and share their experiences and coping skills (Knight, 2009; May, 2007). They are based on the premise that individuals may have different explanations about the nature and causes of their beliefs and a range of frameworks are accepted as valid (May, 2007; 2012). As Tamasin Knight (2005)—a mental health survivor whose ideas have been influential in the development of these groups—notes, it is important to accept individuals' own realities and "help them to cope with and live with that reality" (p. 38). Groups are organised on the basis of members' shared experience and, as such, are inclusive regardless of diagnosis or psychiatric status. Indeed, the re-framing of 'delusions' as unusual beliefs attests to the fact that different ways of seeing reality are not pathologised (Jacobson & Zavos, 2007; Knight, 2005, 2009; May, 2007, 2012) and group membership is open to individuals who have never been in contact with mental health services. Describing the formation of the first group of its kind in the UK, Peter Bullimore (2010) highlights the important support that participants with no psychiatric histories are able to offer to members for whom paranoia is much more debilitating.

The vast majority of unusual beliefs peer support groups operate in non-statutory, community settings. Groups are peer-led, do not follow a predetermined structure and are open-ended. Moreover, these groups have an open membership, which means that new members are able to join an already established group and existing members can leave at any time. Cumulatively, the origins and key features of these peer support/self-help groups render them more closely aligned with the second type of peer support described earlier.

Theories of peer support

Having described the main types of peer support and introduced the Hearing Voices Network approach to unusual beliefs, this section will outline different theories that can elucidate the processes in operation in peer support groups. These explanations are not mutually exclusive, but to a great extent complementary.

Before proceeding, three points are noteworthy. First, the notion of peer support as a collective, mutually supportive activity in the face of distress, alienation and injustice, explored in the previous sections, could be seen as a framework through which one can examine peer support groups. Arguably, this more explicitly social-political framing is particularly relevant for understanding groups such as those affiliated to the Hearing Voices

Network. As Corstens et al. (2014, p. S289) highlight, hearing voices groups emerged from the Hearing Voices Movement "as a *social movement* and were developed and implemented primarily by mental health service-users and community workers rather than clinician researchers". Second, some of the theories presented below derive from studying self-help groups (e.g., Schizophrenics Anonymous, GROW). Whilst there are important similarities between self-help and peer support, the two practices are arguably not identical. As Seebohm, Munn-Giddings and Brewer (2010) note, in a broad sense, peer support tends to focus on mutual aid, is outward-looking and seeks (social) change whereas self-help is driven by a 'help yourself' motivation and is often inward-looking and apolitical. However, these distinctions are not black and white. Indeed, peer support and self-help often share important characteristics such as group ownership by its members, the coming together of people with similar experiences, the exchange of information and strategies and, indeed, the giving of help to others, which the term 'self-help', paradoxically, obscures (Seebohm, Munn-Giddings & Brewer, 2010). Third, the frameworks outlined below are mainly professional frameworks. In other words, they represent the attempts of scholars and clinicians to understand the phenomenon of peer support. However, one might question the wisdom of applying professional understandings in order to elucidate practices that sometimes question or challenge the dominance of professional expertise.

Experiential knowledge

Borkman (1976; 1990) has suggested that members of peer support groups possess experiential knowledge which she defines as the "truth learned from personal experience with a phenomenon" (Borkman, 1976, p. 446). For Borkman, this form of knowledge is qualitatively different from professional knowledge; it is the defining characteristic of peer support groups and what distinguishes them from clinician-led therapy groups (Borkman, 1976). Through the sharing of stories among peers (including attempts at coping with a shared difficulty), mutual support groups are said to function as "experiential learning communities that create, apply and disseminate experiential knowledge" (Borkman, 1990, p. 23). The kind of knowing that Borkman refers to—the experiential knowledge that stems from living with distress and using mental health services—has historically been marginalised in favour of expert understandings.

The helper-therapy principle

Peer support is characterised by *mutual* support and reciprocity, as people have the opportunity not only to receive but also to offer help to others. According to the helper-therapy principle (Riessman, 1965, p. 28), "the act of helping another helps the helper more than the person helped". It has been suggested that the benefits for helpers could arise as a result of enhanced feelings of self-efficacy, increased agency, as well as a sense of equality between helper and helpee (Riessman, 1990). Moreover, this theory postulates that this beneficial impact extends to the peer support group as a whole, as "not only are individual members aided through helping other members…but the group as a whole may be strengthened in manifold ways as it continually offers assistance to individual group members" (Riessman, 1965, p. 32). This links the helper-therapy principle to the notions of 'cohesiveness' and 'altruism' described below.

Social Support

Several scholars have attempted to theorise the benefits derived from peer support drawing on the broad, and often poorly defined, construct of 'social support'. Social support is thought to have three components: emotional, informational and instrumental support. Helgeson and Gottlieb (2000) note that at the heart of peer support is the sharing of experiences and feelings with people facing similar difficulties to one's own. This sharing is expected to lead to emotional support; that is, expressions of caring, encouragement, attentive listening, and reassurance, as members can easily empathise with each other (Pistrang, Barker, & Humphreys, 2010). Such exchanges, serve to normalise one's struggles and foster the experience of feeling accepted, cared for and valued despite one's difficulties (Dennis, 2003; Helgeson & Gottlieb, 2000). Such supportive interactions are believed to reduce distress by enhancing one's self-esteem, decreasing one's sense of isolation and stigma and encouraging the expression of emotions (Helgeson & Gottlieb, 2000; Loat, 2011). Informational support refers to the sharing of guidance, suggestions and advice. The provision of informational support within peer support groups is thought to increase one's coping skills and sense of mastery and control (Loat, 2011).

Yalom's Therapeutic Factors

Drawing on a large body of theoretical and research literature, Yalom and Leszcz (2005) suggest that 11 therapeutic processes influence change in group psychotherapy. The authors of this highly influential text suggest that most of these healing factors are present in mutual

support groups too (Yalom & Leszcz, 2005) and this framework has recently been applied to elucidate the experiences of Hearing Voices Network group attendees (Payne, Allen, & Lavender, 2017). Important processes are said to include, among others, 'universality' (a sense that one is not alone in their struggles), 'cohesiveness' (the degree of 'we-ness' of a group which is seen as the group equivalent of the therapeutic relationship in individual therapy), 'altruism' (the benefits of offering help to others), 'catharsis' (the sense of relief that accompanies the expression of emotions) and imparting information (the exchange of information, advice and guidance).

Research into peer support groups for psychosis

A number of recent systematic reviews have examined the effectiveness of peer support among people with a diagnosis of psychosis (e.g., Chien, Clifton, Zhao, & Lui, 2019; Chinman et al., 2014; Lloyd-Evans et al., 2014). Out of the 20 studies included in the review by Chinman et al. (2014), 6 involved peer-delivered structured curricula in a group format such as the Health and Recovery Peer programme. The authors found that in comparison with professional staff, peer workers delivering such programmes were more effective in reducing inpatient use and demonstrating improvements in a range of recovery outcomes. In contrast to these findings, the meta-analysis by Lloyd-Evans et al., (2014) found that mutual support groups (n=4) had a small effect on empowerment and quality of life but not recovery. However, recovery was only studied in one of these 4 studies and all studies were deemed of low quality. The authors conclude by suggesting that "current evidence does not support recommendations or mandatory requirements from policy makers for mental health services to provide peer support programmes" (Lloyd-Evans et al., 2014, para. 41). A similar conclusion was reached by the most recent Cochrane review that examined trials comparing manualised peer support interventions in addition to routine care with routine care alone. A recent meta-review of the outcome literature characterises the evidence for peer support equivocal, suggesting that more robust evidence exists "for the more structured peer-delivered self-management programs" (Bellamy, Schmutte, & Davidson, 2017, p. 166).

Yet, more fundamental questions seem to emerge from this body of literature. Bellamy et al. (2017) join others in highlighting the lack of clarity about what constitutes peer support and the ways in which the work of peer support workers is different to that of clinicians. As mentioned in the previous section, the term has come to encompass almost any type of

support provided by a person with lived experience of distress. For example, among the 21 different services provided by peer support workers as outlined by King and Bender Simmons (2018), one finds CBT, psychoeducation and case management. Indeed, one wonders, as Fabris (2013, p. 131) puts it, whether peer support has come to represent "another brand of mental health product".

Several other commentators have critiqued the currently dominant research paradigm in the field (e.g., Gillard, 2019). The interventions included in the aforementioned reviews are predominately time-limited, structured and organised around scientifically contested diagnostic categories such as schizophrenia. Notably, the language used in this body of literature is no different to that employed in traditional therapy outcome research with no consideration of its appropriateness in the context of peer support. Relatedly, the outcomes examined reflect clinician-defined notions of recovery and are, primarily, outcomes at which clinical interventions would aim (e.g., symptomatology, number of hospitalisations, service use). Interestingly, in an era of recovery-oriented services, only 3 out of 13 studies in Chien, et al.'s (2019) review used a measure of recovery. Thus, it could be said that the interventions included in these reviews are incongruent with the values and grassroots origins of peer/mutual support described in the previous sections. Dillon and Hornstein (2013) question the idea that randomised designs constitute the only bases for making evaluations about 'what works' in peer support groups. Instead, they highlight the value of first-person experience as evidence for their 'effectiveness'. Similarly, Corstens et al. (2014) point out that qualitative research, investigating members' experiences is required in order to explore the effects of such groups.

Whilst research in the field has mainly been quantitative, a smaller number of qualitative studies have been conducted. These studies, too, have focused on paid peer staff (offering mainly one-to-one support). Moreover, qualitative studies have predominantly explored the perspectives of peer support workers rather than those of 'recipients', as evidenced in recent systematic reviews of the qualitative literature (e.g., Walker & Bryant, 2013; Watson, 2017). Indeed, it has been argued that research into peer support has tended to exclude the experiences of people receiving peer support (Bailie, Tickle, & Rennoldson, 2016).

In sum, following the introduction of peer worker roles, research into peer support has primarily focused on this more formalised type of support, typically, within statutory services

(Faulkner, 2013). Consequently, less is known about peer-led, grassroots approaches (Gillard, Foster, & Turner, 2016) and research on this more independent form of peer support is relatively scarce (Gillard, 2019). To date, only one study has systematically reviewed Hearing Voices Network groups (Ruddle, Mason, & Wykes, 2011). However, this review (which is now nearly a decade old) was not peer support specific and none of the identified studies examined groups specifically for people with unusual beliefs.

Research on Hearing Voices Network peer support groups

Despite the substantial theoretical literature on the Hearing Voices Network, until recently, investigations into this form of peer support were limited to a handful of unpublished or non-peer-reviewed evaluations (e.g., Meddings, Walley, Collins, Tullett, & McEwan, 2006; Slater, 2010). However, over the past 5 years, a small but growing number of studies have begun to examine the experiences of those attending Hearing Voices Network groups, as well as the effects of group participation.

Two studies (Beavan, de Jager, & Dos Santos, 2017; Longden, Read, & Dillon, 2018) have employed a survey design. An Australian study by Beavan et al. (2017) sought to investigate the outcomes and effectiveness of Hearing Voices Network groups from members' perspectives, as well as the potential processes underpinning these effects. Twenty-nine group members completed a purpose-built questionnaire consisting of 10 questions regarding recovery-related outcomes (e.g., self-perceived ability to cope) and 11 questions addressing clinical outcomes (e.g., frequency and power of voices). Participants were asked to indicate their level of endorsement of these items and an open-ended question, inviting respondents to note the most useful aspects of the group, was also included.

The majority of participants reported improvements in a number of recovery-related outcomes. Seventy-five percent reported feeling more understood, whereas 68% feeling less isolated and better about themselves. The vast majority (75%) reported feeling better at being with others and the same proportion more able to talk about their voices. A notably smaller proportion of participants (43%) believed that the group was helping them cope better with their voices, whilst 32% felt that there was no change in their ability to cope. Self-reported clinical outcomes were more varied. For example, nearly half (46%) felt that it was 'not true' that they needed less medication, whereas 61% reported having fewer hospital admissions

following group attendance. With regard to changes specifically around voice-hearing, 64% reported little or no decrease in voice frequency and more than half (54%) responded that it was 'not true' or 'a little bit true' that the power of their voices had reduced since attending the group. Notably, however, the majority (57%) reported feeling less afraid of their voices, suggesting a change in the way participants related to their distressing experiences, despite their continued presence. Participants' responses regarding the most useful aspects of the group were thematically organised. The themes outlined by the authors included: 'Sharing and feedback', 'Support and understanding of relatedness' (the alleviation of feelings of isolation and the sense of belonging that the group provided), 'Changes in relating to voices' and 'Normalising of experiences'.

Key strengths of this study include its wide geographic representation (respondents were drawn from multiple peer support groups, spread across a large urban and rural geographical area), the diversity of its sample in terms of age, gender, length of group involvement and length of voice hearing, as well as the inclusion of an open-ended question, enabling participants to reply in their own terms. Despite these strengths, there are several important limitations worth noting. The study's design precludes a causal inference between group attendance and perceived outcomes. This study is also limited by its purely descriptive nature (i.e., merely reporting percentages) and its relatively small, self-selected sample. No information on the reliability or validity of the survey instrument utilised is provided and it is unclear whether the questionnaire was piloted and refined prior to the study. Moreover, whilst non-response is an important potential source of bias in survey-based studies (Barclay, Todd, Finlay, Grande, & Wyatt, 2002), the authors neither report response rates nor acknowledge the influence of non-responders. Lastly, the study's small qualitative component (i.e., participants' responses to the open-ended question) lacks methodological rigor, thus limiting the conclusions that can be drawn from these results. For example, whilst the authors note that responses were organised into "themes", there is no mention of whether and how data were analysed and no description of how "themes" were developed.

A more recent survey study with a similar research aim, albeit in a UK context, addressed some of these methodological shortcomings. Longden et al. (2018) investigated the perceived impact and effectiveness of community-based Hearing Voices Network groups. One hundred and one members were surveyed using a questionnaire developed for the purposes of the study—the Hearing Voices Groups Survey. The latter, consisted of 28 items,

organised in 3 subscales exploring, respectively, participants' experiences within the group; the group's impact on life outside the group (which included items relating to social, occupational and clinical outcomes); and the group's impact on emotional wellbeing. Items were rated on a five-point Likert scale and were analysed by comparing ratings for individual items to the neutral midpoint.

The study found a range of benefits across all domains. The emotional wellbeing subscale had the highest mean of all, with a mean score of 21.07 (*SD* = 3.18, range: 7-25, maximum possible score = 25). This was followed by 'Experiences within the group' (*M* = 44.43, *SD* = 7.28, range = 8-55, maximum possible score = 55), and 'Life outside the group' (*M* = 31.53, *SD* = 9.07, range = 8-56, maximum possible score = 60). A composite score was also calculated, representing respondents' overall satisfaction with the group. The latter was found to be high, with a mean total satisfaction score of 99.65 (*SD* = 15.78, range = 33-129) out of a maximum possible score of 140. An interesting finding was that total satisfaction scores were not found to differ based on length of group membership, suggesting that both established as well as newer members benefited from attending these groups. Among the most strongly endorsed questionnaire items were those indicating that the group was a safe and confidential space to discuss difficult experiences, that the group provided support that was unavailable in other contexts and that it was useful to meet others with similar experiences. In addition, the authors note the overall agreement among respondents that the group was helping them cope with their voices. Further analyses found that positive experiences within the group were positively correlated with a number of emotional wellbeing and social/occupational outcomes, including feeling more hopeful about the future and making more friends. Similarly to the findings of Beavan et al. (2017), statements that focused on voice-hearing were not among the most strongly endorsed items and group attendance did not seem to affect respondents' medication use. Notably, and despite the wide-ranging benefits of group participation, 34.6% of respondents reported finding the group distressing at times.

The study has a number of strengths. Participants were recruited from various groups across the UK (62 groups were contacted) which may, arguably, have increased the diversity of the sample (e.g., a broad range of group experiences) and the generalisability of the findings. Importantly, the survey instrument was piloted prior to data collection and was refined following feedback from members of the Hearing Voices Network. During the piloting

stage, the questionnaire was assessed for its face and content validity, as well as for its clarity and readability. That said, scale reliability data are not reported by the authors (for a review of reporting practices in user satisfaction research, see Sitzia, 1999). Additional strengths include the fact that several questions were worded in a manner that allowed respondents to express their concerns with the group, as well as the robustness and depth of analysis which, unlike the study of Beavan et al. (2017), moved beyond descriptive results. Limitations of this study include its cross-sectional design which does not permit cause-effect conclusions, the likelihood of a self-selection bias, as well as the failure to report response rates. It should be acknowledged, however, that establishing response rates is complicated by some of the key features of hearing voices groups (e.g., these groups don't necessarily have a stable membership). Moreover, and although the study included a respectable number of participants, the sample was ethnically homogeneous, with the vast majority of respondents (82.2%) identifying as White-British. Consequently, the findings may not apply to different populations. It is notable that whilst the study aimed to focus on peer support groups, groups facilitated solely by mental health professionals also took part in the survey. This is despite the same authors' acknowledgment elsewhere that "mental health workers…cannot, by definition, supply or be responsible for peer support" (Longden & Dillon, 2013, p. 155). Thus, it could be argued that the sample was too heterogeneous to serve as a unified group and this could be seen both as a conceptual and as a methodological limitation. Lastly, by computing a composite score of overall satisfaction, one assumes that all outcomes have similar importance which may not be the case (McPherson & Richardson, 2003).

In addition to this quantitative work, 3 studies have, to date, qualitatively investigated the experiences and perspectives of peer support group members. Two studies (Dos Santos & Beavan, 2015; Payne, Allen, & Lavender, 2017) employed Interpretative Phenomenological Analysis (IPA) and one study (Oakland & Berry, 2015) used thematic analysis as the analytical approach.

Dos Santos and Beavan (2015) sought to explore the experiences of those attending hearing voices peer support groups in an Australian context through conducting individual semi-structured interviews with 4 members from 3 different groups. The analysis yielded 3 superordinate themes (each with a number of subthemes), capturing participants' journey through different stages of group membership. The first theme, 'First experiences, first discoveries', focused on participants' feelings of uncertainty and anxiety upon joining the

group, as well as their accompanying initial reluctance to talk about their voices in the context of the group. The following theme captured key experiences and processes that occurred 'within the groups'. Confirming and extending the findings of the above-mentioned research (Beavan et al., 2017; Longden et al., 2018), these included the opportunity to network and socialise in an informal environment and the value of openly sharing experiences with other members. The importance of others' feedback and support, such as the exchange of suggestions and coping techniques, as well as facilitators' gentle guidance (e.g., reiterating ground rules) were also felt to be valuable. Lastly, the impact that the peer support group had on participants' broader lives was described in the theme 'Beyond the group'. Participants reported that the group helped them speak more openly about their voices with others outside the group, feel more confident, gain a sense of agency in their recovery and develop a different, more helpful, relationship with their voices.

The authors demonstrated reflexivity by reflecting upon their own roles, backgrounds and preconceptions and by making explicit the position from which they are speaking. For example, one of the authors conveyed her role as a committee member of the Hearing Voices Network and her "vested interest" (Dos Santos & Beavan, 2015, p. 29) in the work of these groups. This is an important strength of the study in that it enables the reader to evaluate the researchers' interpretation of the data (Elliott, Fischer, & Rennie, 1999). Moreover, the authors situated the study in the broader literatures on 'auditory hallucinations' and peer support, as well as in the current policy context, thus usefully connecting this research to a wider body of knowledge. In addition to providing a detailed description of the analytic method used, there was some evidence of verification procedures such as cross-checking the themes with an independent researcher. That said, additional credibility techniques such as negative case analysis, triangulation, or member checking (Larkin & Thompson, 2012) were not utilised, which could be seen as a limitation of this study. Furthermore, as the study was based on a self-selected sample, the extent to which participants' experiences are representative of other hearing voices peer support group members is unclear. For instance, only members who have had a positive experience of the group may have agreed to take part in the study. Lastly, whilst the authors state that participating groups operated in both urban and rural areas, key contextual information about the participants and the research sites is lacking which makes it difficult to determine how widely the findings can be applied. For example, participants' ethnicity is not reported, it is unclear whether the groups were peer-led (or co-facilitated by mental health professionals), and whether the groups operated in

statutory or non-statutory settings.

A more recent UK-based study (Payne et al., 2017) also used IPA to analyse semi-structured interviews with 8 members from 2 peer support groups. This study sought to identify members' most salient group experiences with the aim of elucidating likely mechanisms of change within Hearing Voices Network groups. Four superordinate themes and accompanying subthemes were developed from the data. The theme 'Healing: connecting with humanity', described the importance of a caring and compassionate environment, highlighting how this enabled participants to 'connect' with others who were in a similar situation to themselves. At the same time, the authors suggested that fears of rejection and interpersonal struggles within the group constituted barriers to 'connecting' and could lead to frustration and distress, which was illustrated in the subtheme 'Challenges to connecting'. Drawing on Bion's (1962) notion of 'containment' and Bowlby's (2005) concept of a 'secure base', the second theme ('Group as an emotional container') captured the feelings of safety that participants derived from the group's containing capacity and continuity. This finding is consistent with that of Longden et al. (2018) concerning the centrality of safety within Hearing Voices Network groups. The valued opportunity to freely explore and find meaning in one's experiences was articulated in the theme 'Making sense of the voices and me', echoing the findings of previously described studies (Beavan et al., 2017; Dos Santos & Beavan, 2015). The final theme of 'Freedom to be myself and grow' conveyed that participants valued the ownership of the group by its members. This strong sense of ownership, in turn, meant that the group opened up space for enjoyment and creativity, ultimately allowing participants to express their individuality.

The authors provided a very good level of contextual detail (for the groups, the research settings and the participants), thereby allowing the reader to assess the applicability and relevance of the findings to other settings (Elliott et al., 1999). For example, the authors usefully explain that whilst peer-led, the groups were co-facilitated by NHS staff. Moreover, and in addition to a thorough description of data collection and analysis procedures, credibility was addressed by obtaining respondent validation (2 participants endorsed the themes developed by the authors) and by cross-checking the themes with the first author's supervisors. Notably, although there was no formal user involvement in the design of the study, the interview schedule was refined following feedback from a service user, which was an additional strength of this study. The study was limited by the absence of any information

around the role of the researchers, their relationship to the topic, or their potential biases. As mentioned above, such information would have allowed a fuller evaluation of their interpretations. Whilst the sample size of the study was consistent with IPA guidelines (e.g., Smith, Flowers, & Larkin, 2009), sample size considerations were not discussed and no justification for the chosen sample size was provided. Lastly, although a good balance of men and women was achieved, the majority of participants (75%) identified as White-British. Thus, the findings may not reflect the experiences of members from different ethnic backgrounds.

Using thematic analysis, Oakland and Berry (2015) sought to explore the experiences of 11 participants from 3 different Hearing Voices Groups in the UK. Analysis of semi-structured interviews revealed 5 themes. Echoing the finding of Dos Santos and Beavan (2015), the theme 'Discovery' described participants' anxiety upon first joining the hearing voices group, while 'Group structure' highlighted aspects of the group's set up that were considered important. In keeping with the findings of Payne et al. (2017), these included the ownership of the group by members, the horizontal, non-hierarchical relationships within the group, as well as the absence of restrictions as to how long one could attend. As described in the theme 'Acceptance', the group was seen as a 'normalising' space and provided opportunities for social interactions in a context wherein participants felt accepted as people "rather than being viewed purely by their experiences or as a patient" (Oakland & Berry, 2015, p. 124). 'Hope' illustrated the inspiration that participants derived from witnessing fellow members' recovery, while 'Group benefits' referred to the perceived benefits of participation. Similarly to the aforementioned studies in the Hearing Voices Network literature, learning new coping strategies, having a space to explore distressing experiences in depth, as well as increased confidence from being able to offer help to others, were all seen as beneficial aspects of the group.

A key strength of this study was its consultation with members of the Hearing Voices Network in the research design. More specifically, the study's interview schedule was collaboratively developed with 2 Trustees of the user-led organisation, in order to ensure that it adhered to the ethos of these groups and was relevant to participants. Moreover, the authors demonstrated reflexivity not only by providing a thorough reflection on their own values and roles, but also through considering the influence that these might have had on their analysis. For example, they note that given their preconceptions and their relationship to the topic they

might have been more inclined to direct their attention towards perceived benefits. Data analysis procedures were clearly described and verification procedures were used to ensure the credibility of the findings. For example, the analysis was discussed with the study's supervisor and 2 members of the Hearing Voices Network. That said, the results of the study were not shared with the participants for their feedback and formal member checking was not used. Furthermore, and unlike the other qualitative studies reviewed here, the authors justified their chosen sample size in terms of data and thematic saturation. Despite these strengths, the study suffers from the typical limitations associated with self-selection bias described above. Moreover, the study recruited 5 participants who identified as group facilitators (and had received facilitator training) which could have led to confounding the experience of being a facilitator with that of being a group member. Lastly, although a good level of contextual detail is provided by the authors, somewhat surprisingly, participants' ethnicity was not reported.

Rationale for the present study

The studies discussed in this section have been valuable in illuminating a form of peer support that, up until recently, remained largely unexplored. Whilst formal investigations have begun to appear in recent years, to date, only 5 studies have focused on those attending Hearing Voices Network groups, which underscores the need for further research in this field. Importantly, none of the studies reviewed above examined peer support groups specifically addressed to people holding unusual beliefs. This gap in research exists despite the growth of an active network of such groups over the past decade. As mentioned in the Introduction, not everyone who holds beliefs that others consider unusual necessarily identifies as a voice-hearer and these groups were borne out of this recognition. Relatedly, it is unclear whether the needs of this population are best met in groups that focus primarily on voice-hearing. For example, a recent survey (Jones, Marino, & Hansen, 2016) of hearing voices group facilitators (N=32) found that respondents were somewhat divided as to how narrow or broad the focus of these groups should be. When asked what would constitute an 'ideal' membership, 18.8% of respondents expressed a preference for including solely people who hear voices or see visions. Only a small majority (53%) felt that hearing voices groups should, ideally, include individuals with all types of experiences typically viewed as 'psychosis' such as "unusual beliefs, paranoia, "delusions"" (Jones et al., 2016, p. 110).

Furthermore, the British Psychological Society (2017) makes reference to support groups for

individuals holding paranoid or unusual beliefs and recommends that professionals inform service users about groups affiliated to the London Paranoia & Beliefs Project. Leading mental health charities, too, (e.g., Mind, 2016) advocate the use of such peer support groups. This further highlights the need for research specifically into these groups, the literature on which remains theoretical (e.g., Knight, 2009; May, 2012; Hornstein, 2018). Taking the above into account, the current study aims to add to the small, but growing, body of research on the Hearing Voices Network by exploring the experiences of individuals who attend paranoia and beliefs peer support groups.

Thus, the present study will address the following questions:

•What are participants' experiences of attending a paranoia and unusual beliefs group?

•In what ways, if any, does the group impact on participants' lives?

Chapter 2: Methodology

Chapter summary

This chapter outlines the theoretical and epistemological underpinnings of the study. In addition, it details the choice of data analysis method and explains the procedures that took place with regard to participant recruitment, data collection and analysis. Lastly, this section discusses ethical considerations as well as issues regarding the assessment of the study's quality.

Rationale for using a qualitative approach

Qualitative and quantitative research approaches do not need to be conceptualised in opposition to one another as they seek to address very different questions (Rohleder & Lyons, 2015). Indeed, it could be argued that there are no right or wrong methods but, rather, methods that are more or less appropriate for addressing specific research questions (Harper, 2017). And, as Willig (2013) suggests, research questions should always precede one's choice of methodology.

The primary aim of this study was to explore participants' experiences of attending peer support groups for unusual and distressing beliefs and the perceived impact of group participation on members. As mentioned in the Introduction chapter, to date, the existing literature in the field remains theoretical (e.g., Jacobson & Zavos, 2007; Knight, 2009; May, 2012) and there are currently no published studies examining these peer-led, open-ended groups.

Qualitative research aims at producing rich and nuanced accounts that privilege the experience and perspectives of participants (McLeod, 2011) and is particularly well-suited to areas that have not been previously researched (Barker et al., 2015). Moreover, qualitative enquiry emphasises contextualised understandings (Willig, 2013). It acknowledges that the meaning of constitutive elements of lived experience cannot be understood in isolation and without context. On the contrary, meaning resides *in* context and cannot be removed from it (Willis, Jost, & Nilakanta, 2007). Thus, a qualitative approach was considered the most congruent with the study's aims. This is consistent with calls for a greater emphasis on qualitative approaches in investigating peer support groups that prioritise lived experience as an important source of evidence (e.g., Corstens et al.,

2014; Dillon & Hornstein, 2013).

Epistemological and ontological positioning

A common misconception is that qualitative research comprises a homogenous inquiry paradigm and that there are no philosophical differences between different qualitative methods (Harper, 2012). It would be more accurate to refer to qualitative *methodologies*, thus acknowledging that qualitative research is characterised by a diverse range of ontological and epistemological positions which form the philosophical basis of a research project (Hesse- Biber, 2017). Indeed, these positions determine what constitutes meaningful knowledge and underpin a study's methodology (Braun & Clarke, 2013). Thus, it is important for researchers to be transparent about their epistemological and ontological assumptive positionings.

The following section briefly outlines the differing stances that researchers may assume, followed by the considerations made when deciding upon the current study's philosophical foundations. However, it should be noted that there is considerable variation and overlap among the positions outlined below (Barker et al., 2015; Rohleder & Lyons, 2015).

Ontological assumptions

Ontology refers to "The study of being and existence. The attempt to discover the fundamental categories of what exists". (Burr, 2006, p. 128). The question driving ontology is 'What is out there to know?' (Hesse-Biber, 2017). As Willig (2013) notes, ontological concerns are fundamental and it is impossible not to make assumptions about the nature of the world and the phenomena in it.

A *realist* ontology (also referred to as naïve or direct realist) postulates that objective reality is an entity 'out there' and that the world is made up of relatively stable structures and objects that are subject to causal laws (Willig, 2013). Thus, realism holds that "the external world exists independently of being thought of or perceived" (Burr, 2006, p. 128). As mentioned in the Introduction, it has been argued that traditional conceptualisations of delusions are premised on a naïvely realist perspective which asserts the existence of a singular, objective reality (e.g., Cromby & Harper, 2009; Georgaca, 2000).

In contrast to realism, *relativism* challenges any notion of a singular, mind-independent reality, suggesting instead that there are multiple, socially constructed realities (Brooks & King, 2017; Burr, 2006). Relativism holds that the latter are produced by, and cannot exist independently of, our thought processes and language (Burr, 2006). It has been suggested that relativism rejects notions such as 'truth' or 'knowledge' (Willig, 2013) and emphasises all perspectives and accounts as equally valid.

Between the ontological positions of realism and relativism, lies *critical realism*, which, unlike relativism, does not reject reality itself "as an epiphenomenon of human activity" (Rogers & Pilgrim, 2014, p.12). On the contrary, critical realism assumes a relatively autonomous existence of a social reality, outside of human constructions of it (Brooks & King, 2017), albeit one that can only be partially known under historically transient descriptions (Rohleder & Lyons, 2015). In other words, critical realism postulates that it is not reality that is (socially) constructed but our theories about reality as well as the methods we employ in order to investigate it (Pilgrim & Bentall, 1999). Thus, from a critical realist perspective, it is accepted that some people do hold beliefs that others may consider unusual and these experiences are understood as real (Johnstone & Boyle, 2018). What is considered socially constructed is the knowledge that we use in order to describe these experiences (e.g., as symptoms of a 'mental disorder' or 'schizophrenia').

Arguably, there is a potential source of confusion here. Several commentators refer to critical realism as an ontology, whilst the above definition encompasses both ontological as well as epistemological considerations (i.e., our theories about reality). Indeed, from a critical realist perspective, ontology must be distinguished from epistemology and, at the same time, ontology determines epistemology. As Shipway puts it, according to critical realism "our efforts to interrogate the world are restricted in both their content and method by the ontological nature of the thing under investigation" (Shipway, 2011, p. 120).

Epistemological assumptions

Ontological and epistemological assumptions are intertwined. Epistemology is the "the study of the nature of knowledge and the methods of obtaining it" (Burr, 2006, p. 28). Whereas ontology asks what the world/experience 'really' is, epistemology concerns how the world/experience is known and represented (Cosgrove, Wheeler, & Kosterina, 2015).

One can see how the answer to the former, is inextricably linked to the latter. These somewhat subtle but important distinctions are not always explicated. For example, realism is inaccurately contrasted with social constructionism (e.g., Barker et al., 2015).

Positivism assumes that it is possible to acquire access to reality through rigorous and valid scientific methods. The latter, through eliminating various sources of bias, render possible an objective investigation of the social world (Hesse-Biber, 2017). For example, one could argue that the use of scales such as the Brown Assessment of Beliefs Scale (Eisen et al., 1998) could objectively measure one's 'insight' and 'delusionality'. With regard to qualitative research, a positivist/objectivist stance would imply that people's accounts provide direct access to their reality (Terry, Hayfield, Clarke, & Braun, 2017). At the heart of positivism lies essentialism; the view that objects have an inherent, discoverable nature (Burr, 2006).

Whilst positivism is often aligned with (direct) realism, some variants of *social constructionism* are often linked to the relativist ontological position outlined above. Social constructionism challenges the idea of any absolute foundations for knowledge (Madill, Jordan, & Shirley, 2000). Instead, knowledge is considered culturally, historically and socially specific—it is rooted in particular historical periods and is subject to changes in sociocultural norms (Johnstone & Boyle, 2018). Social constructionism not only considers language as central in the way people view the world, but also emphasises its constitutive function (Harper & Spellman, 2014). Thus, the study of language practice, in other words, of *how* language is used is often a focus of social constructionist research (Harper, 2012). In a methodological review of qualitative research on the lived experience of psychosis, Georgaca (2013a) suggests that studies premised on a social constructionist epistemology, typically undermine participants' agency. Indeed, it is argued that whilst this framework is valuable for elucidating the socially constructed character of knowledges and practices around distress, it not well-suited for studies aiming at foregrounding participants' voices and perspectives (Georgaca, 2013a) or, indeed, at exploring alternative practices and understandings (Georgaca, 2013b).

Between the epistemological positions of positivism and constructionism, lies *contextualism or contextual constructionism* (Braun & Clarke, 2013; Madill et al., 2000).

Contextualism holds that our historical, social and cultural context "is integral to how we live, understand and experience our lives" (King & Horrocks, 2010, pp. 19-20) and conceives knowledge as local, context-specific and provisional (Madill et al., 2000). With regard to qualitative research, a contextualist epistemology suggests that participants' accounts provide (inevitably partial) access to their version of reality. The latter, is always imbued with subjectivity and mediated by sociocultural meanings and values (Madill et al., 2000; Terry et al., 2017).

Relatedly, contextualism views the subjectivity of the researcher as integral to the research process and the notion of value-free knowledge is not considered attainable (Brooks & King, 2017). Several scholars note that the acknowledgement of the importance and potentiality of context renders contextualism compatible with a (critical) realist ontological position (e.g., King & Horrocks, 2010; Madill et al., 2000).

Epistemological and ontological assumptions of the current study

Willig (2013) has proposed a useful framework for elucidating a study's philosophical foundations which I used as a guide whilst reflecting upon and negotiating my ontological and epistemological positioning. During this evolving process, I realised that in positioning oneself in qualitative research the options available are far more nuanced than simple either/or choices (Brooks & King, 2017). Moreover, I came to realise that one's ontological and epistemological choices are not merely a matter of theoretical proclivity; they are more crucially dependent upon the research questions one seeks to address.

I was interested in understanding how participants made sense of their experiences of attending a peer support group for unusual beliefs and in what ways, if any, they perceived the group impacted on their lives. Thus, participants' accounts were theorised as, to some degree, representative of their current and prior lived experience. Still, I did not assume that these narratives provided access to the 'fundamental structures' or 'essence' of participants' experience (Cresswell & Cresswell, 2018) and, equally, I did not view these first-person accounts as mere discourses (Parker, 2005) or means of managing stake or interest (e.g., Potter, 2004).

I endeavoured to reflect the ethos and principles of the user-led network which privileges

members' voices and prioritises their right to define their own experiences (e.g., Longden, Corstens, & Dillon, 2013; May, 2012). Indeed, experiential knowledge is at the core of peer support and a key function of Hearing Voices Movement is the development and dissemination of an experiential knowledge-base (e.g., Blencowe, Brigstocke, & Noorani, 2018). More broadly, it was hoped that a focus on participants' lived realities would mirror something of the challenge posed by the survivor movement; a challenge that is fundamentally premised on personal experience (e.g., Beresford & Boxall, 2013; Campbell, 2013). As mental health system survivor Peter Campbell puts it "what service user activists bring to the table is their *personal experience* of living with mental distress and using mental health services. It is this personal experience and their reflections on it that they are demanding be valued" (Campbell, 2013, p. 143).

Nevertheless, I did not assume a direct access to participants' worlds. Instead, I acknowledged that the knowledge produced through the research was partial and, inevitably, contingent on both participants' as well as my own interpretations (Terry et al., 2017). As Reissman (1993) suggests, researchers can only obtain participants' representations of experiences which, in turn, are "imbued with meanings, interpretations, deletions, and additions" (Carter & Rivera, 2011, p. 119).

I acknowledged that this meaning-making "does not develop in a social vacuum but is rigorously situated within a socio-historical and cultural milieu of meanings and relationships" (Jaeger & Rosnow, 1988, p.66). Indeed, anthropology has long demonstrated that there are different ways of interpreting experience premised on differing cultural models of reality. For example, the Siona people believe that ayahuasca provides access to an alternate reality (Luna, 2011) and there is a long tradition of ethnographic studies documenting the socioculturally-embedded qualities of spirit possession phenomena (e.g., Bourguignon 1976; de Sousa, 1999). Nonetheless, this is not to suggest that people, even within the same society all share the same commitments, meanings and understandings. On the contrary, I acknowledged that even within the same sociocultural and historical context, "there are myriad cultures and settings in which we immerse ourselves, which impact on our construing" (Tindall, 2011, p. 102).

In her discussion of possible epistemological frameworks for survivor research, Diana Rose (2017) highlights the importance of foregrounding the voice of a marginalised group

"whose very speech has been deemed meaningless" (Rose, 2017, p. 781). However, Rose also draws attention to the dangers of relying on 'lived experience' as an incontestable authority and the sole ground of genuine knowledge. Instead, she argues that 'experience' should be historicised and understood with reference to the power relations and the social, institutional and linguistic practices that shape it (Rose, 2017). Other critical scholars and survivor activists, too, emphasise the need to understand service users' narratives in a historical and socio-political context (e.g., Boyle, 2002; Dillon, 2011; Harper & Speed, 2012). Thus, whilst the current study focused on personal sense-making, it was underpinned by a socially contextualised account of experience and participants' subjective experience was viewed as interwoven with social life (e.g., McNay, 2004). Indeed, the very nature of the user-led groups examined, whose origins are rooted in the psychiatric survivor movement, encouraged such a reading. Hence, throughout the research process, I endeavoured to remain attuned to the societal and historical context within which participants' meanings were negotiated as well as the interface between the personal and the collective. To this end, insights from discourse analysis proved useful and facilitated sensitivity to participants' perspectives and the socio-cultural context, albeit without undertaking a discourse analysis (Yardley, 2008).

The above framework is congruent with a contextualist epistemological approach. And whilst the study did not seek to obtain an objective or absolute sense of 'truth', it was nevertheless concerned with what participants experienced as true, in their particular contexts (Brooks & King, 2017). It has been argued that insofar as one formulates research questions about people's experiences and understandings, by definition, an ontological status is attributed to these phenomena (Willig, 2016). As Collier states "Experience is always an encounter with what existed before the experience" and it cannot be examined independently of "the reality that is given though it" (Collier, 1998, p. 48). By taking this ontological position, I sought to remain consistent with the principles of the network which questions the notion of a single, definitive truth (e.g., May, 2012) without advocating, as Thomas and Longden put it, "a descent in the morass of relativism" (Thomas & Longden, 2013, p. 124).

Reflexivity

Qualitative approaches acknowledge that researchers' interpretative frameworks, beliefs and experiences impact on the research process (Barker et al., 2015). Within a contextualist

framework, in particular, the researcher's subjectivity is viewed as an analytic resource rather than a source of 'bias' to be overcome and there is a strong rationale for articulating the positions from which the researcher writes (Madill et al., 2000). It could be argued that this mirrors a key principle of the Hearing Voices Network: namely the need to speak from the "I" position.

I am a 33-year-old, white male, training to become a clinical psychologist. Growing up as a Greek citizen of Armenian origin in an ethnically homogeneous context, encouraged me to think about issues of sameness and difference early on in my own development. I became curious about the effects of being positioned as Other which left me with a sense of commitment to social justice. I was able to develop these interests during the final years of my undergraduate degree, through elective modules on 'Deinstitutionalisation', 'Critical Psychology' and 'Self-Help Movements'. I began to have contact with the service user movement through participating in meetings organised by the Hellenic Observatory for Rights in the Field of Mental Health, an organisational member of the European Network of Users and Survivors of Psychiatry. In this context, in 2009, I was introduced to the work of the Hearing Voices Movement. These early encounters with service users, carers and professional allies were helpful in questioning 'us' and 'them' dichotomies and undoubtedly influenced my subsequent approach to clinical work. I value people's understandings of their distress and I consider it an ethical imperative to respect people's own explanatory frameworks.

My interest in peer-led forms of support stems from my belief that service users hold expertise by virtue of their experience. I was attracted to the ethos of the Hearing Voices and Paranoia Networks of aiming to give voice to, understand and empower a marginalised group whose experiences have traditionally been deemed as devoid of meaning. Nevertheless, I do not view peer support as a panacea and I acknowledge that, just like professionally-led care, it does not provide the sole answer for all individuals. This has led me to appreciate the importance of offering people choice around the type of support they receive. Although I have no personal experience of psychosis, I have worked with people who have experienced psychosis in inpatient and community settings prior and during my clinical training. I have been involved in facilitating therapeutic and support groups and, prior to clinical training, I attended group facilitation training through the London P&B Network. As discussed below, I attended further, more extensive, facilitation training

through the network prior to data collection.

Cumulatively, these experiences and beliefs have influenced the way I interacted with participants during interviews. It is also likely that these prior experiences and beliefs influenced the ways in which I made sense of the data during the analysis stage—for example through drawing my attention to helpful aspects of the group experience. Thus, I used research supervision and kept a reflective log in order to explore and reflect upon my pre- held views and experiences and support a reflexive engagement with the data.

Design

The study employed a qualitative design using individual semi-structured interviews to enable an in-depth exploration of participants' experiences and perceptions. Semi-structured interviews were used to ensure that the study's key areas of interest were covered whilst allowing the exploration of unexpected topics relating to participants' views and experiences. Members of the service user network, including group facilitators, were consulted during the planning and design phases of the research and further details regarding user involvement are provided in the following sections.

Methods of data analysis

There are various methods of analysing qualitative data and key considerations in choosing an analytical method are its appropriateness for the research question(s) one seeks to address, as well as its compatibility with a study's philosophical underpinnings. The following section will provide an overview of the different methods of data analysis considered for the current study before discussing the rationale for selecting thematic analysis.

Interpetative Phenomenological Analysis (IPA) was considered as a potentially suitable methodology, given the study's focus on participants' lived experience and perceptions. IPA is a phenomenological approach whose main aim is to explore participants' meaning-making in detail (Smith et al., 2009). Moreover, due to its focus on the person in context, IPA is viewed as a broadly contextualist approach (Larkin, Watts, & Clifton, 2006). According to Larkin et al. (2006) IPA has two core aspects: a phenomenological and an interpretative. The former is concerned with giving voice to participants' concerns and the

latter with making sense of these concerns from a *psychological* perspective. Indeed, in studies employing IPA, interpretation is premised on exploring the data "through a psychological lens and interpreting it with the application of psychological concepts and theories" (Pietkiewicz & Smith, 2014, p. 11). This defining feature of IPA was considered problematic for the current study, which was underpinned by a more socially contextualised account of experience. As Boyle (2002) suggests "an emphasis on personal meaning without reference to the social structures . . . which shape what we have come to think as 'personal meaning', could provide a route back to the . . . 'individual knowers' of contemporary psychology" (Boyle, 2002, p. 301). Moreover, IPA studies utilise relatively small and homogeneous samples and focus not only on patterns across cases but also on individual cases (Braun & Clarke, 2013) which was incongruent with the present study's aims and sampling strategy. Due to the lack of studies exploring this type of peer support groups, it was considered more appropriate to gain a larger sample than what is typical of IPA studies and focus, primarily, on patterns across cases.

Grounded Theory (GT) was also an alternative approach considered for the current study. Similarly to IPA, some varieties of GT (e.g., Henwood & Pidgeon, 2003) could be broadly considered contextualist. The overall aim of a GT analysis is not only to provide rich descriptions but also to generate theory (Barker et al., 2015). As Tweed and Charmaz (2012) state "Primarily, the goal of grounded theory is to develop an inductively driven theory of studying basic social or psychological processes" (Tweed & Charmaz, 2012, p. 134). The current study did not seek to explicate the influencing factors and processes that underpin a phenomenon (Braun & Clarke, 2013) and, thus, GT's focus on theory generation was considered incongruent with the study's aims. Thus, in the absence of research literature on the topic, it was considered more appropriate to capture aspects of participants' experiences rather than elucidating a "fundamental process occurring among the research participants" (Tweed & Charmaz, p. 134).

Thematic Analysis. The method of analysis chosen for the present study was thematic analysis (TA). TA is a widely used method for identifying and analysing key patterns of meaning (themes) in qualitative data (Braun and Clarke, 2006; 2013; Joffe, 2012). In TA, themes, patterns, or constellations of meaning refer to broad, overarching ideas that run through the data, relative to a study's research questions. Whilst the analysis of themes is also characteristic of IPA and GT, unlike these approaches, TA can be applied within a

range of theoretical frameworks (Braun & Clarke, 2006; Terry et al., 2017) and, as Braun and Clarke (2006) note, there are several precedents for using TA within a contextual constructionist epistemology.

TA was considered appropriate for the aims of the current study, as it is well-suited for elucidating "the specific nature of a given group's conceptualisation of the phenomenon under study" (Joffe, 2012, p. 212). Moreover, the systematic version of TA developed by Braun and Clarke (2006; 2013; 2014) provided a robust and transparent framework for exploring group attendees' experiences and perceptions. Lastly, TA has been highlighted as a particularly useful approach for applied research, as its findings can be accessible to a non- academic community, without losing in depth and sophistication (Braun & Clarke, 2014). Indeed, there are several examples of both collaborative as well as user-controlled research employing TA (e.g., Gilburt, Rose, & Slade, 2008; Bonnington & Rose, 2014). This was considered particularly important, as the study aimed to produce knowledge that would be of direct relevance to the groups, the work of the network, as well as professionals supporting people with distressing or overwhelming beliefs.

As a result of TA's theoretical flexibility, researchers need to make a number of choices regarding their approach to coding and data analysis and determine their particular version of TA (Braun, Clarke, & Terry, 2015). Two key analytic decisions are whether data are approached inductively or deductively and whether coding focuses on semantic or latent content.

The exploratory nature of this study as well as its epistemological position, suggested that an inductive rather than a deductive approach would be more appropriate. Inductive TA has been described as a 'bottom up' approach, according to which the researcher does not try to fit the data in a pre-existing theoretical framework or coding frame (Braun & Clarke, 2006; Braun et al., 2015). As discussed in the Introduction, unusual beliefs peer support groups embrace a plurality of explanations (e.g., Hornstein, 2018; Knight, 2009; May, 2012) and it could be argued that there is a danger of premising analyses on preconceived, theory-derived categories or particular psychological models (Harper, 2017). However, a purely inductive approach is neither possible nor desirable. Indeed, I acknowledged that my own position, as well as my ontological, epistemological and theoretical lenses inevitably shaped my engagement with and interpretation of the data (Braun et al., 2015;

Joffe, 2012; Terry et al., 2017). Nevertheless, by not employing particular theoretical concepts (e.g., psychological theories about group processes) during the analysis stage, I aimed to ground my analytic observations in participants' accounts.

Moreover, the analysis focused on both semantic and latent content in the data. More specifically, in the initial stages, coding aimed at capturing explicit meaning in participants' accounts. This choice, reflected the study's aim to stay close to how participants made sense of their experiences (Braun & Clarke, 2013). As the analysis progressed, it also explored more latent aspects of the data. It is suggested that latent coding goes beyond what participants explicitly state and explores underlying assumptions, ideas and conceptualisations "that are theorised as shaping or informing the semantic content of the data" (Braun & Clarke, 2006, p. 84). A common misconception is that semantic coding in TA, inevitably, results in superficial or unsophisticated readings of data (Terry et al., 2017). Nevertheless, it could be argued that methods don't come with an inherent guarantee of sophistication and just as in most qualitative approaches, the aim of TA is the explication and interpretation of *meaning* (Watts, 2014). Indeed, both semantic as well as latent coding require interpretative analysis (Braun & Clarke, 2014). Thus, whereas methods such as content analysis use a descriptive approach in both coding and interpretation, TA aims at producing a rich and nuanced account of data (Vaismoradi, Turunen, & Bondas, 2013), which was congruent with the overarching aim of this study.

Participants and sampling

The study aimed to recruit participants from different community-based peer support groups. A purposeful, maximum variation sampling strategy (Patton, 2002) was used in order to explore the topic from diverse perspectives and angles (Gavin, 2008) and identify salient "shared patterns that cut across cases" (Patton, 2002, p. 235).

Sample size

Qualitative research generally utilises smaller samples in comparison to quantitative research. Whereas tools for determining sample sizes in qualitative inquiry have been proposed (e.g., Fugard & Potts, 2015), it has been argued that such approaches are problematic as they are premised on a quantitative logic which is incongruent with the qualitative and exploratory ethos of TA (Braun & Clarke, 2016). Consistent with recommendations found in the TA literature (e.g., Braun & Clarke, 2013; Terry et al.,

2017), the current study aimed to recruit between 10 to 15 participants to enable the identification of patterns in the data. In order to enhance transferability and the ability of the reader to determine the relevance of the study's findings to other contexts, an effort has been made to describe the study's participants and service settings in detail (Lincoln & Guba, 1985).

Inclusion/Exclusion criteria

In line with the National Paranoia Network's and the London P&B Network's ethos (e.g., Bullimore, 2010; May, 2007; 2012), participants were not included or excluded on the basis of their diagnosis. In addition, participants did not have to self-identify as individuals holding paranoid or unusual beliefs (see also Oakland & Berry, 2015; Payne et al., 2017). Individuals were considered eligible if they were aged 18 years or above and had attended a paranoia and unusual beliefs group at least twice over the last 6 months. The latter criterion ensured that participants would be able to reflect on a range of experiences in the groups. Eligible participants were required to be willing to discuss their experiences during the interview, have this interview audio-recorded and be able to give written informed consent to participate in the study. Due to time and resource constraints, only English-speaking participants were eligible for this study.

In order to avoid confounding the experience of being a group member with that of being a group facilitator noted in previous studies (e.g., Oakland & Berry, 2015), this study aimed to sample exclusively group members who did not hold a facilitator role. In addition, individuals were not eligible to participate if they were experiencing high levels of distress that would prevent them from participating in the interview or were likely to experience high levels of distress from taking part in the interview. Individuals were also considered ineligible to participate if they were unable to give informed consent, as ascertained through discussion with group facilitators.

Procedure

Service user involvement

Service users' priorities often do not correspond to those of academics or research funding bodies (Rose, 2003) and service users have, traditionally, been the 'subjects' of research conducted by professionals rather than active participants in the research process (Faulkner,

2012). Having its origins in the user/survivor movement, user involvement in research refers to the process of actively engaging and involving users of services in research not as 'subjects' but as partners. Over the past three decades, service users "have taken part in planning, designing, and carrying out research along with professionals, or as researchers in their own right" (Wallcraft & Nettle, 2009, p. 1-2).

Faulkner (2012) has proposed a useful framework for distinguishing between different levels of service user involvement in research, which could be seen on a continuum ranging from consultation, through collaboration to user-controlled research. Whereas some scholars argue that user-controlled research is the sole legitimate aim (e.g., Turner & Beresford, 2005), others see a place for all three types of participation and involvement suggesting that different approaches are suitable for different research projects (e.g., Hanley, 2004). The current study is located more towards the consultation end of the continuum.

Study development

During the design and planning phase of the research, I consulted the London P&B Network in order to ascertain whether the research idea was considered relevant to its priorities and concerns. During this preliminary phase, approximately a year prior to participant recruitment, I consulted with the network's project assistant, its project manager (who is also a Trustee of the English Hearing Voices Network), as well as different group facilitators. The proposed study was introduced and members' perspectives were invited. I was interested in the topics they felt that should be covered and whether there was anything that would render the study particularly useful for the work of the P&B Network. I spoke about my background and my familiarity with the Hearing Voices Network's ethos, as described in the 'Reflexivity' section above, and explained that the proposed project would be completed as part of a doctoral degree.

It was suggested that feedback from group attendees in any form would be important and meaningful. Moreover, it was felt that it would be important to explore whether the groups were experienced as 'both safe and relevant', members' views about not only receiving but also offering support and whether groups were seen as non-judgmental spaces. In addition, some facilitators felt that the origins of one's beliefs should not be explored as this could be upsetting for participants in the context of a research interview. Overall, the study was

deemed interesting and of value to the work of the network.

In order to increase my familiarity with the philosophy and the ethos of peer-led unusual beliefs groups, I attended relevant events, including a 3-day 'Understanding & Supporting People with Paranoia & Beliefs' group facilitation training and a training session on user/survivor-led research in mental health. Moreover, in keeping with the collaborative stance of this study, I participated in the network's quarterly meetings where I held informal conversations with members and facilitators.

Recruitment procedure

Participants were recruited from a range of community-based peer support groups, the majority of which operate at the premises of third-sector organisations. An electronic version of the recruitment advert was included in the London Hearing Voices Network's newsletter (Appendix A). Moreover, I consulted the website of the London P&B Network and identified all the groups operating in the region. Copies of Participant Information Sheets and study posters (Appendix B) were distributed to facilitators who were asked to share information about the study with group members. Lastly, following discussions with facilitators, I was invited to four peer support groups in different boroughs in order to introduce the study to group members and answer any questions.

The Participant Information Sheet offered potential participants the chance to contact me either via email or telephone if they wished to find out more about the study and/or opt-in. Alternatively, individuals interested in taking part could approach their group facilitators and have their details passed on. In either case, individuals were given a minimum of 48 hours to review the information sheet prior to being contacted to confirm their interest and have the interviews arranged.

Recruitment lasted between November 2017 and May 2018. All interviews were carried out face-to-face in a private room at the same community venue where the group ran.

Data collection

Data were collected through in-depth semi-structured interviews based on a topic guide. The interview topic guide (Appendix C) was informed by the researcher's conversations

with members of the London P&B Network, including group facilitators, as outlined in the section on the study's development above.

The topic guide provided a framework for conducting the interviews. However, there was no fixed set of questions, to ensure that the interviews were responsive to unanticipated issues raised by participants (Mason, 2017). Thus, follow-up questions and prompts were tailored to the participant's developing narrative (Braun & Clarke, 2013). The key broad areas on the topic guide were the following: reasons for attending; helpful and not so helpful aspects of the group; relationships with other members; the effects of group participation; and the history of the group. In addition, general information regarding age, gender, ethnicity and length of attendance was also collected. Interviews were audio-recorded and transcribed verbatim.

During the course of the research, I recorded my observations and personal reflections in a field diary. These additional data enabled me to contextualise and better understand data generated through one-to-one interviews and capture the context within which group members interacted (Hennick, Hutter, & Bailey, 2010).

Data analysis

Following transcription, interviews were analysed following the six phases of TA (Braun & Clarke, 2006; 2013; Braun et al., 2015) in a recursive, non-linear manner. Data were analysed manually using MS Office. This software was also used to document reflections and coding decisions in an audit trail.

Phase one: Familiarisation with the data. Analytical engagement with the data began during the familiarisation phase. The transcripts were read and re-read several times in order to develop an understanding of the breadth and depth of content as well as the dataset's relevance in relation to the research questions. During this phase, prior to systematic coding, initial analytic observations and preliminary ideas were noted down. Moreover, in order to enhance familiarisation with the data, the audio-recorded interviews were listened and re- listened.

Phase two: Generating initial codes. The entire data set was coded systematically and thoroughly using a combination of semantic and latent codes. As mentioned above, in the

early stages of coding, the analysis captured primarily semantic meaning. As the analysis progressed and with greater depth of engagement, codes also captured more latent aspects of the data. In keeping with the study's chosen analytic approach, coding was an organic and recursive process wherein codes evolved, changed and were refined as the coding process proceeded. Given the study's broad research questions, coding was carried out widely and comprehensively (Braun & Clarke, 2013) and any parts that were potentially relevant to answering the research questions were coded (Braun et al., 2015). This phase ended by compiling the codes generated and collating the extracts relevant to each code. An example is provided in Appendix D.

Phase three: Generating themes. During this phase, the analytic focus shifted from codes to themes (Braun et al., 2015). Thus, the list of codes compiled during the previous phase was reviewed in order to identify potential broader and recurrent patterns of meaning across the whole dataset. This *active* process of constructing (provisional) themes and subthemes, involved clustering, combining and collapsing codes together into meaningful patterns that were relevant to addressing the research questions. Care was taken to avoid constructing what Braun and Clarke (2013) refer to as 'domain summaries' (i.e., 'themes' that bring together everything participants said in relation to an issue, without an underlying concept or idea that ties these data together). Equally, the analysis aimed to construct themes that went beyond, and did not simply mirror, the study's topic guide. Thematic maps were used to visually represent and better understand "the relationship between codes, between themes, and between different levels of themes" (Braun & Clarke, 2006, p. 89). This phase ended by collating all the extracts relevant to each provisional theme.

Phase four: Reviewing themes. The aim of this refinement phase was twofold. First, the provisional themes were reviewed in order to ensure that they adequately represented the collated data extracts. Thus, all the extracts associated with each provisional theme were re- read to ensure that they formed a coherent pattern. Second, themes were reviewed in relation to the entire dataset, to ensure that the themes conveyed a meaningful and convincing story that addressed the research questions (Terry et al., 2017). A key consideration was that themes were both distinct from each other and at the same time they related to each other. The refinement of the thematic map facilitated this process and, where necessary, themes were revised, collapsed or split.

Phase five: Defining and naming themes. Themes were given a clear definition and informative names were generated for each theme. Moreover, data extracts which would be included in the final analysis were chosen. The extracts were chosen both on the basis of their ability to reveal something interesting and distinct about a theme as well as their potential impact and contribution relative to the literature (Watts, 2014).

Phase six: Producing the report. Lastly, the writing-up phase consisted of intertwining the analytic narrative with data extracts in order to convey a coherent story about the data (Braun & Clarke, 2013).

Ethical Considerations

Obtaining Ethical Permission

Ethical approval was sought and gained from the University of Essex Ethics Committee (Ref. 17002) prior to recruitment and participant interviewing (Appendix E).

Informed Consent

The study adhered to the British Psychological Society's Code of Human Ethics (BPS, 2010) and written consent was obtained from participants prior to conducting the interviews. The Participant Information Sheet, stated that participation in the study was entirely voluntary and that participants could opt-out at any point without giving a reason and with no repercussions. The information sheet also stated that participants who changed their mind following completion of the interview, could withdraw their data at any point and have their recordings destroyed. This was reiterated during the interview. Participants were given multiple opportunities to ask any questions before agreeing to take part in the study (Thompson & Chambers, 2012), both during group meetings, privately and prior to the interview.

Confidentiality and anonymity

Research data were handled in accordance with the Data Protection Act (Great Britain Parliament, 1998). Interview recordings were stored electronically in a password-protected folder on an encrypted computer until the end of the project, after which they were deleted. Service user identifiable information was removed during transcription and anonymised transcriptions were stored on a password-protected folder on an encrypted computer.

Moreover, field diary entries did not include any identifying information such as names and locations. These were also stored in a password-protected file on an encrypted computer.

Participants were informed that only myself and the study's supervisors would have access to the interview transcripts. In addition, they were made aware that extracts may be used in the write-up. I was mindful of the fact that participants for this study were recruited from a relatively small target population which could potentially limit their anonymity (Harper, 2017) and this was taken into account in the presentation of participant demographics (e.g., using broad characteristics and age ranges rather than exact ages).

Participant Safety

The study was shaped through consultation with members of the London P&B Network, in order to ensure that it was safe and sensitive to participants' experiences. Nevertheless, it was acknowledged that participants could become distressed during the course of the interview. A range of procedures were followed in order to minimise any potential risk to participants. As part of the study's exclusion criteria, group members who were likely to experience distress as a result of taking part in the interview (ascertained through discussion with group facilitators), were not eligible to participate.

Interviews were carried out at the same venue where the group normally ran. These venues were staffed and interviews were arranged before or after the group to enable the provision of support from on-site members of staff, in case this was required.

Participants were made aware that they could take a break at any point during the interview and that they did not have to continue with the interview or share any experiences that they found difficult to talk about. Throughout the interviewing process, I carefully monitored participants' comfort and all participants were debriefed following the interview, via a post-interview discussion. Participants were provided with a list of contact details for additional sources of support, including emergency support services (Appendix F). Lastly, participants were informed about limits to confidentiality in relation to risk. No participant safety concerns arose during the process of data collection.

Participants were offered £20 as a token of thanks for their time and participation in the study and as compensation for any inconvenience (Appendix G). This amount is consistent

with relevant guidelines (Faulkner, 2004) and was considered substantial enough to incline individuals to participate in the study, without being large enough to be considered undue inducement.

Researcher Safety

All interviews were conducted during working hours, before or after the group, in order to ensure that members of staff were available on-site. No researcher safety issues were encountered during the research process.

Quality Assurance

Criteria utilised in evaluating quantitative research such as objectivity, reliability and generalisability are not easily translatable to qualitative approaches. Several scholars have proposed specific criteria for evaluating qualitative studies. The current research used Yardley's (2000) framework for ensuring quality in qualitative research.

'Sensitivity to context' refers to the awareness of "participants' perspectives and setting, the sociocultural and linguistic context of the research, and how these may influence both what participants say and how this is interpreted by the researcher" (Yardley, 2017, p. 295). Contextual sensitivity was demonstrated through engagement with the relevant theoretical and empirical literature in the field and through formulating a research question that had not been yet addressed. In order to foreground participants' perspectives, open-ended questions were used during data collection. This ensured that participants were encouraged to talk about what was important to them rather than being constrained by the preoccupations of the researcher (Wilkinson, Joffe, & Yardley, 2004). Moreover, sensitivity to context was aimed at by the study's epistemological orientation, which views socio-cultural context as integral to understanding people's accounts (King & Horrocks, 2010). Lastly, sensitivity was maximised through collaboration with the London P&B Network at the design stage and the researcher's sustained engagement with the activities of the network.

'Transparency' was ensured through a clear description of the data analysis and by keeping an audit trail of the analysis in order to illustrate how themes were developed. Moreover, examples of participants' verbatim quotes were provided to ensure that the themes were firmly grounded within the data and "allow readers to conceptualise possible alternative

meanings and understandings" (Elliott et al., 1999, p. 222).

'Commitment and rigour' was demonstrated through the researcher's in-depth engagement with the topic and through using an established and rigorous approach to TA. All the interview recordings were transcribed by the researcher in order to facilitate immersion in the data. The study's research supervisors regularly reviewed sections of analysed interview transcripts and provided feedback on codes and themes, ensuring expertise and skills in the analytic methods employed (Yardley, 2017). Whilst the study aimed at exploring patterned responses in the data, disconfirming instances and data that appeared to contradict emerging patterns were also accounted for. Moreover, in consultation with group facilitators, the findings of the study will be presented to participants and their feedback will be sought. However, formal member checking was not employed as this was considered incongruent with the study's ontological position. As Braun and Clarke (2013) note, member checking is often underpinned by a direct realist ontology that assumes the existence of a single truth that is discoverable through the research process.

Yardley suggests that a study's 'impact and importance' 'can only be assessed in relation to the objectives of the analysis, the application it was intended for, and the community for whom the results were deemed relevant' (Yardley, 2000, p. 223). From the outset, the study hoped to produce knowledge that would be of direct relevance to individual peer support groups, the work of the service user network as well as professionals supporting people with distressing or overwhelming beliefs.

Dissemination

The study's results will be shared with the London P&B Network and fed back to the groups that took part in the study with the aim of fostering reflection and action. In addition, at the end of the study, a summary report will be sent to participants who requested one. The preliminary results of the study were presented at the 21st International ISPS Conference (International Society for Psychological and Social Approaches to Psychosis). At least one paper will be submitted for publication in an appropriate academic journal and the current study appears to match the aims and scope of the journal *Psychosis*.

Chapter 3: Results

Chapter summary

This chapter presents the study's findings. Participant demographics will be summarised followed by a brief description of the contexts within which the groups operate. The themes and subthemes that were developed through the analysis will then be explored in detail along with illustrative quotes from participants' accounts.

Study Sample

A total of 13 members expressed interest in participating in the study. One member did not meet the study's inclusion criteria and one later changed their mind about taking part. Thus, a total of 11 participants were interviewed. Participants' demographics are illustrated in Table 2. The sample comprised of 7 women and 4 men whose ages are presented as a range to preserve their anonymity. Seven participants self-identified as White-British. Of those participants, one explained that they were not born in the UK but had lived in this country long enough to consider themselves British. The interview with this participant was conducted in both English and in another language (both the participant's and researcher's native language). Two participants self-identified as British-Asian and two as White-Other. All but one of the participants had been attending their respective groups for a year or more. The majority had found out about the group either through other members or on their own. Only one participant (who could not recall with certainty how she discovered the group) reported that she may have found out about the group through a mental health or social care professional. Interviews lasted between 32 and 75 minutes with an average of 52 minutes.

Table 2. Participant demographics

Group details	Pseudonym	Age range	Gender	Ethnicity (self-defined)	Attendance duration
Group 1	Louise	55-59	Female	White-British	3 years
	Tina	28-32	Female	White-Other	6 months
Group 2	Maria	56-60	Female	White-British	2 years
	Pickle	52-56	Female	White-British	4 years
	Brian	35-39	Male	White-British	3 years
	Anabelle	47-51	Female	White-British	2-3 years
	Anne	61-65	Female	British-Asian	1 year
	Claire	58-62	Female	White-British	1 year
Group 3	Mike	35-39	Male	British-Asian	2-3 years
Group 4	Andrew	61-65	Male	White-Other	4 years
	Stanley	59-63	Male	White-British	4 years

Recruitment site details

Participants from four different community-based peer support groups were involved in the study. Group 1 operates on the premises of a Recovery College but is distinct from the educational courses and workshops offered by the College. Running continuously since 2014, it is an open-ended group, sessions do not follow a structured format and members continue to meet during periods of the peer facilitator's absence. Group 2 is based at a voluntary sector organisation, whose history is somewhat unique compared to the service contexts within which other groups operate. It was founded as a grassroots, user-run centre when service users took over a Social Services day centre which, due to budget cuts, was threatened with closure. The organisation is now a co-produced mental health charity and the unusual beliefs group has been running therein since 2014. Groups 3 and 4 are both based at voluntary sector day centres; the former having commenced in 2010 and the latter in 2012. Members of group 4 continued to hold meetings during the facilitator's several months' absence.

Analysis

Four themes and associated subthemes were developed using thematic analysis (Braun & Clarke, 2006) and are presented in Table 3. It should be noted that whilst each theme is presented and explored separately, to a considerable extent, these themes are interconnected.

Table 3. Themes and subthemes developed from the data

Themes	Subthemes
In search of an 'oasis'	'It's alright to think that you are God here'
	'It became quite an intimidating environment'
Choice means something different here	Group membership and attendance: a voluntary affair
	'And slowly slowly I opened up'
This is peer support, not therapy	'We are not focusing on fixing the person'
	'Who decides what's an unusual belief?': Problematising 'delusions'
From the 'I' to the 'We'	

In search of an 'oasis'

Participants described the group as a safe and accepting space and this was an aspect of the group that was perceived as vital. The first subtheme ('It's alright to think that you are God here') explores the meaning and significance of this atmosphere of safety and acceptance as well as the factors that contributed to its emergence and sustenance. Based on participants' accounts, these notions are not merely conceived as individual or private states of being, but as profoundly social and relational phenomena; that is, as constituted by social relationships and (inter)actions—both within the group and beyond. Whilst infrequent, conflict and, at times, hostility, arose within the group as illustrated in the second subtheme ('It became quite an intimidating environment'). During those times, some of the very components that rendered the group a safe and accepting haven, such as trust, openness and inclusivity seemed to be jeopardised.

'It's alright to think that you are God here'

Most participants described the group as a safe forum, with some explicitly referring to the

group as a ‘safe place’, a ‘safe space’, or a ‘little oasis’. In participants’ narratives, safety was almost invariably linked to the group’s non-judgmental approach with Pickle echoing the sentiments of many.

> Pickle: Because it, it’s ok for me to talk about my paranoia and my distressing beliefs and when I talk about them…I’m in a safe place, I feel safe. No one is gonna laugh at me, no one is gonna tell me I’m mad, no one is gonna think anything. They’re gonna help me and explain, maybe they’ve been in a similar sort of position.

This accepting approach was largely attributed to the shared experience of mental distress among members and there was a sense among many that talking to others who ‘know how it feels like’ (Mike) almost naturally implied non-judgmental acceptance.

At the same time, however, some participants reflected that accepting others without judgment, especially when their realities were very different from one’s own, was neither a simple nor an effortless act. As a relatively new member remarked: ‘when you see that someone else’s reality is just so different from your own, it makes you question your own reality, doesn’t it? And that can evoke fear and anger’ (Tina). In contrast to conventional mental health programmes, the group did not aim to orientate members to an ‘objective’ reality, but rather to cultivate an openness to others’ subjective realities. This sometimes seemed to be an arduous endeavour. For example, Stanley explained how he is *trying to* be ‘non-judgmental of other people, sharing whatever they’re sharing’ in the context of the group.

> Stanley: I have been very judgmental and I have that disposition, predisposition and it’s better for me if I can drop it, just get away from it…but when people talking about difficulty with they don’t want to go out cause they’re frightened they might fall down the stairs, it’s hard for me to relate to. Cause I mean I’ve got no problems with anything physical at all…so sometimes it can be hard for me to relate to. And people who are hoarders you know. It’s a terrible thing but I don’t really understand it.

This acceptance of different perspectives was often coupled with a realisation of the futility of trying to impose one’s truth on another. And as some participants explained, this did not occur overnight but developed over time. For instance, Tina articulated her initial ‘urge’ to challenge other members’ beliefs and instead put forward what she saw as a more accurate view of the world. She described how the group was allowing her to move beyond the realms of certainty and towards greater acceptance of unshared realities, thus honing her ‘compassion’ for others.

> Tina:…there's one individual which has, has unusual beliefs and erm I erm, we all listen to him, and. I remember in the beginning I just, I found it hard to…deal with the urge to be like, to just say, say 'You're just being really paranoid' or 'This is just erm not true, what you talking about?', or just sort of challenging, in an aggressive way. Not in a shouting way but in a in a confrontational way. Because yeah, it was difficult to deal with that urge. **[How did you deal with it?]** Mm, I just listened.

Group facilitators were seen as key to this process with many highlighting their open, embracing attitude and their role in ensuring that the group was a safe and accepting context to share.

> Louise:…she's (facilitator's name) just got such a great attitude of non-judgement and acceptance and (pause) respect. I think respect is very important, you know, she just got an inherent respect for the people who come.

This accepting atmosphere, in turn, not only enabled participants to share distressing or shameful aspects of experience more openly (i.e., retrospectively recount their experiences), but also to be in the group *during* times that were particularly difficult for them without the fear of negative repercussions. This seemed to extend beyond members' unusual beliefs. Behaviour that in other contexts would most likely be constructed as 'acting out', 'disruptive' or otherwise anti-therapeutic appeared to be accepted.

> Andrew: (facilitator's name) was the one that used to put up with the brunt of it. I used to shout at her and I felt really embarrassed after. I was so angry. In a way I was frightened of exploding...It was just a rage that I couldn't control and the slightest thing would upset me. Like, several times I just had to walk out. But I always managed to come back again.

Connected to this, there was a shared sense among participants that, within the group, they could just be themselves instead of trying to conform to sociocultural expectations: 'it's 'a place beyond egos. Beyond façade' (Stanley); 'So it's a place where you're comfortable to just be…I can just be who I am' (Pickle). For some, this meant that there was space for talking about beliefs and experiences that would be deemed unacceptable or pathological when judged by dominant standards of rationality.

The group's ground rules and other structural aspects of the group were felt to be important in engendering this atmosphere. Many spoke about trust and the paramount importance of the ground rule of confidentiality. This was also evident during the interviews when several participants explained that they wouldn't talk about other members in a way that would compromise their anonymity. Often constructed as mistrustful by dominant discourses

around paranoia, these participants highlighted that trust was indeed an important aspect of their experience in the group.

> Claire:…they listen and they don't talk to no one. What I was saying. It's only (facilitator's name) group...(facilitator's name) said it's only for us in the group, no one else.

Relatedly, participants explained that the open-ended nature of the group allowed relationships of trust to gradually build; an idea that is further explored in the theme 'From the 'I' to the 'We''. Notably, most participants were longstanding members of their respective groups with all but one having been attending for a year or more. Thus, whilst ground rules seemed to be important in ensuring an 'infrastructure' upon which trust was built, the latter was constructed as a relational process that evolved over time. And as Louise pointed out, this was not a given, but members had an active role in this process.

> Louise:…it's changed over time because we work together so much. If you call it work. It kind of is (pause). Yeah, I really love this group, you know, I'd be lost without it, you know, and that's why I am glad that we can still meet when (facilitator's name) can't come.

Thus, it was not only the longevity of interactions among members but also the quality and depth of engagement with each others' worlds, that seemed central in co-creating trust. Pickle offered a powerful description of this inherently mutual process, whereby being trusted by another allowed her not only to cherish their experiences but also cherish something of herself.

> Pickle: Especially when it's kind of the same group of people, so I think I know how dear I hold other people's thoughts that they've felt able to talk about something that might be really difficult for them. They've trusted me with that. And I hold that quite dear and that makes me feel that I can give myself.

This atmosphere of safety and acceptance seemed to stand in contrast to participants' experiences in their wider social worlds. Nearly all participants articulated a general sense of unsafety and lack of acceptance and the transcripts were replete with references to experiences of stigma, discrimination and exclusion. Participants spoke both about hurtful interpersonal interactions as well as oppressive cultural practices, with several openly expressing their indignation at what they saw as unjust treatment.

Like other participants, Anne described feeling dismissed and relegated as 'less of a person'

by those who could not bear to hear her story at a time when she needed it most. Anne repudiated such notions ('I am a human being, I've got these problems but that doesn't make me any less of a person') and contrasted her experience of talking to her family about her distress with what she found in the group.

> Anne: Well, I went through some family crisis and several time I talked about similar thing…I found that it was easy for me to talk in the group, they didn't judge me. With my family…when I talked a couple of time in detail with my family they said 'Oh you going through same same pain and same loss and same…so they like...they try to hush it, hush it down.

References to experiences of invalidation, however, were not limited to participants' personal or familial contexts. Brian spoke about the ill-treatment he had suffered at the hands of his former employer ('he's like talking to me to make me feel like <u>that</u> little'), whilst Pickle reported feeling 'judged and analysed' by professionals whom she sometimes perceived as dismissive of her beliefs. Patronising attitudes were also noted by some, with Anabelle indicating that she had been treated in a condescending way ('they talk to you like if you're a child') by her 'psychologist doctor'. These experiences were, invariably, juxtaposed with the group's approach.

> Pickle: Like, I can tell my CPN when I see him. I think because he's a professional and he's coming at it from a professional angle this is almost like he's telling me 'I <u>shouldn't</u> think like that' or 'That's <u>ridiculous</u> for you to think like that'. Whereas in that setting (unusual beliefs group), it's not like that…It's kind of how it's done, yeah it's not clinical.

And whereas some participants, like Anabelle, spoke about overt discrimination, others recounted more subtle, yet nevertheless painful, experiences of invalidation. For example, Mike explained how, in other contexts, his ability to offer a trustworthy perspective had repeatedly been questioned, leaving him feeling minimised and discounted: 'they question what I'm saying, is it actually true what I am saying? How can it be?'

> Anabelle: …they'd say, that's the word, some of them they'd go 'Oh God you need locking away or something', they'd say. And I don't like that, you know. But if I come to the group, the group wouldn't speak like that.

Others still spoke, more broadly, about oppressive cultural systems and institutions. In the extract below, Andrew makes reference to denigrating, stereotypical media portrayals of welfare claimants as 'scroungers'. Evoking images of fear and danger, Andrew frames such practices as direct threats to the safety of members that had to be defended against. Whilst

talking about such experiences, like other participants, Andrew expressed his anger towards a system that he perceived as oppressive and unjust.

> Andrew: We actually banned the Sun newspaper from here and the Daily Mail. Because they were the two worst papers, you know, and people I've seen actually crying…and frightened. I had this paranoia that, you know, erm that they bug my phone, they're watching me, or following me, you know, because all these things was on the papers...that's what they do with that propaganda. Is keeping you down and keeping you on your toes and frightening you.

What was notable was that participants didn't frame these experiences as exceptional or infrequent but as paradigmatic of their day-to-day dealings with the world. In the backdrop of these experiences, then, the group—with the safety and acceptance it afforded—appeared to serve as a refuge from an often hostile, 'punishing' (Mike) world.

'It became quite an intimidating environment'

Although the group was largely perceived as a safe and accepting space, more than half of the participants (including all male participants) readily spoke about conflictual experiences in the group. During these times, the atmosphere of respect and openness described in the previous subtheme seemed to be compromised.

Whilst all participants described the group as very cohesive, a few explained that it was not always a safe place to openly share. For a few participants, this reluctance centred on mistrust towards certain group members. This self-censorship, in turn, meant that some participants were not always able to contribute in group discussions in a way that would be helpful for them, as illustrated by Annabelle. This and other comments suggest that trust, a key component of safety as illustrated in the previous subtheme, was not a static condition, achieved once and for all, but rather a dynamic process.

> Annabelle: … I'm finding it a bit challenging to say what I really want to say, to get off my chest but I get paranoid that he (group member) will go back and, you know, tell his mum and dad and his sister about my business, what I say in the group...Because, although he'll sit there all like…smiley but I don't trust him…I can't say what I really want to say when he's there. But when he's not there, then I do say what's on my mind.

In addition to mistrust, a number of participants spoke about instances of behaviour that was experienced as authoritarian or domineering. These often seemed to originate from

misunderstandings or disagreements between members and were described as a source of distress. The participants' choice of words was telling of the powerful impact that these experiences had had both on members and the overall group atmosphere.

> Andrew...If he doesn't agree with you that's it...Well, they had a discussion about him but I don't want to see him in the group anymore because it's too. It's not on. A few people got frightened of him.
>
> Stanley: It was upsetting for me. Cause there was literally no space for anyone to talk. You know, that is completely selfish and violent and aggressive. That's violent.

Notably, many of the conflictual experiences described by participants involved new rather than established group members: 'there was one person there who I've not ever seen before… he was just like dominating the group.' (Stanley). It appeared that the inclusive character of the group and the absence of a clear process of joining meant that new members were not always familiar with an already existing group's ethos. This, in turn, seemed to provide a fertile ground for conflict as illustrated by Mike and Louise.

> Mike: There's not really a process when people join the group, I don't think it works through that process. He just turned up and it was quite, it was quite an intimidating environment.
>
> Louise: And there was another guy who came more recently. He got on my nerves, erm he kept talking about sort of his anti-psychiatry beliefs you know erm. Not that I am pro psychiatry but I just didn't think (pause). You know he wouldn't just talk about his week or how he was feeling, you know, and it is more of a group to talk about how things are going with you…what can I say it wasn't just what he was saying it was just. It's kind of insensitive.

Regardless of the precise nature of these occurrences, however, what was notable in the data was that conflict was both present and somewhat elusive in participants' accounts; almost as if it was simultaneously acknowledged and denied. Brian, like several other participants, explained that 'everyone gets on here' but shortly afterwards recalled a vehement exchange with a fellow group member. This is reproduced here in full as it illustrates some of the more unsettling dynamics that, whilst present, appeared to be largely unacknowledged and unaddressed.

> Brian: Well, I did have one person say. One person phoned me up and said to me more or less that theirs' is different to mine sort of thing. That their, their mental health is different to mine type of thing. More or less that…theirs' is

> true and mine is not type of thing... In other words, they're saying mine is more or less like bullshit...And theirs' like the best sort of thing if you know what I mean. **[The best in what way?]** I don't know (pause). That theirs' more genuine, mine's just like you can sort of just (pause) you can sort of snap out of it. **[And how did that make you feel?]** I don't know. I was probably, might 've been probably kind of bit angry about it**…[What was that person trying to…]**Achieve? I don't know. **[Have you spoken about it in the group at all?]** No, never. I just ignored it.

Brian's words point to an implicit hierarchy of distress, wherein some people's experiences are seen as genuinely severe or intense—thus drawing on normative ideas about mental health difficulties—and others' are denigrated as insignificant or as 'really stupid issues' (Stanley). Yet, despite their apparent impact on members, tensions appeared to remain unexplored, with Brian remarking that he 'just ignored' the strife between him and a fellow member. For others, it seemed that the only way to respond to strife was for either part involved to leave the group altogether rather than work out the difficulty collectively.

> Louise: I think I felt like not coming to the group. I think it was <u>that</u> bad, erm but in the end she stopped coming er she didn't come for all than long.
>
> Mike: we were talking about something and that gentleman found it really offensive what she said to him and they got into a little argument which led to the lady quitting the group altogether and subsequent attempts were made by the staff to get her back, she said she didn't she didn't want to come because of that one incident.

Moreover, it seemed that unpleasant experiences in the group could somewhat mirror prior and ongoing experiences of hurt, such as those illustrated in the previous subtheme.

> Stanley: And I got up and basically shouted some angry stuff about, made it quite clear why I was upset and left. But I mean yeah that happens all over the place, everywhere you go on the planet. It's the same thing.

Choice means something different here

This theme explores the ways in which the group enabled participants to reclaim a sense of control and agency which was often either denied or was unavailable in other contexts. The notion of choice appeared in relation to several themes but was particularly salient in relation to the group's voluntary membership, as well as the way in which participants' stories were shared in the peer support group.

Group membership and attendance: a voluntary affair

Several participants spoke about the voluntary nature of the group, noting that they could decide for themselves whether it matched their needs or not.

> Anabelle: You know you can pick up a leaflet to say what suits your best interest. So I was getting these like thoughts, paranoia thoughts erm, there were becoming overwhelming and I thought I'm gonna see about it. Because you can only see if it suits your needs. And basically, yeah, it did suit my needs, it's good for me, erm I understand it.

Anabelle drew on discourses of rights and needs whilst she described her decision to continue attending the group and portrayed it as consistent with her 'best interest(s)'. Indeed, in talking about exercising control in relation to group attendance, participants didn't seem to be drawing on a responsibilising discourse of 'patient choice'; a notion that for some appeared to be a floating signifier, given their apparent lack of choice within mainstream services.

> Maria: It wasn't very helpful but I felt like I couldn't say that I didn't want it…I kept going for six weeks but I was eagerly anticipating my groups (unusual beliefs and hearing voices groups)…And she [psychologist] asked me 'Have you learned anything?'…And I could have lied to her. But, instead, I said 'I will be honest with you. Thank you. You're doing your job which is your bread and butter. But I prefer my groups'. And she replied 'Well, I've seen you for six weeks, I will see you for two more weeks and you can then go'.
>
> Brian: When I got this call last year they were saying I don't need the CMHT, I need like therapy groups and to go to (location) hospital and things like that. That's what they said to me but nothing…**[Have you been there?]** I haven't been there no. I never heard no more.

Despite Maria openly expressing her views about the care and treatment she was offered, ultimately, the decision to continue or discontinue therapy was not hers and her expressed preferences seemed to be over-ridden. Similarly, Brian reported that he had no say around the support he received, as decisions were made on his behalf. Here, as in other interviews, participants' comments offered insights into how the group was experienced within the context of their wider experiences of mental health services. Interactions with professionals were often described as characterised by limited choice and un-shared decision making, perpetuating relations of domination/subordination. Yet, even when 'choice' was offered,

this was portrayed as a tick box exercise.

> Louise:… I saw one (care co-ordinator) today, I noticed I would say something and she would be trying to fit something that they could offer with something that I was saying.

By contrast, the group seemed to enable participants retain some control: 'But if they don't listen I won't come, but I do come and they do listen…' (Claire); 'For me, honestly, if it wasn't helpful…I wouldn't be coming' (Maria).

As explored in the subtheme 'It's alright to think that you are God here', the longevity of the group was highlighted as important. And whilst several participants explained that new members were always welcome, there was also a clear sense that it was not a drop-in group:'there is a core four of us including (facilitator's name) who always come or nearly always' (Louise).

However, the voluntary nature of the group and the absence of restrictions around attendance seemed to allow participants to take part as they deemed appropriate to their situation and needs and not as an obligation they had to fulfil. For example, Stanley explained that he had taken some time out of the group in order to 'develop (himself) musically' which he described as important for his 'growth process'. For Pickle, this flexibility allowed her to take a 'step back' and reconsider her role in the group.

> Pickle: It's important to me this group that I come every week. Having said that, recently I took about three weeks out, I needed to have a little step back. But then I come back and hopefully I can be useful to other members in the group as well that might be suffering similar things.

'**And slowly slowly I opened up**'

Group attendance was not dependant on an obligation to speak and this was viewed as important by many. Claire, like other participants, described her apprehension when she first attended the group. 'It was hard in here when I come the first time, it was hard to talk…to people'. Similarly, Andrew explained that he harboured intense feelings of anger when he initially joined which made it difficult for him to open up. 'I was very closed in the beginning, you know, sometimes I wouldn't talk at all when I started the group'. Knowing that one could share as much or as little as they felt comfortable appeared to be a source of comfort and reassurance and group facilitators were seen as key to this.

> Claire: Sometimes I say, I say (facilitator's name) I don't wanna talk and he ask me why, but I don't say. I like (facilitator's name)…And (facilitator's name) says that's alright, yeah.

Moreover, there was a sense among some participants that the initial sharing of personal experiences within a new interpersonal environment had the potential to make them vulnerable by exposing aspects of their life that were not known to other members. For Pickle, it was important that she was in charge of this process.

> Pickle: When I came and listened to other people's stories. Cause I was quite guarded and. Obviously till I got comfortable with the group I was quite not secretive but I didn't maybe tell the whole story. Only told them what I wanted them to hear and I kind, could kind of manipulate it. Not manipulate but maybe yeah. Manipulate what I wa. Do you know?

This sense of control seemed important especially when it came to sharing particularly painful aspects of their experience. For example, Anne, spoke about gradually feeling comfortable to share her 'sorrows' and the 'pain' '(she) was going through'. 'But coming here, I really appreciated that people did hear me out when I said things in bits and they shared their experiences'. For Anne, this permission to share 'things in bits' and open up 'slowly slowly' was a valued experience and was contrasted to encounters with professionals which she described as invasive and almost interrogative.

> Anne: I was referred by my GP to counselling…and erm I was there for an hour or 2- hour session…All the time he (the counsellor) was throwing questions on me and I was telling. I was so distorted by and I cried most of the session. Because he brought up so many of memories to surface he didn't do nothing about it. He was only only listening and at the end he did not even give me appointment…I became quite depressed after that, you know. Cause he brought so many memories to surface...He just wanted to know everything instead of being concerned.

Thus, the group seemed to allow a more fluid sharing of personal material wherein neither the completeness nor the linearity of one's story was a requirement. The group didn't require 'everything' to be told at once and aspects, fragments or 'bits' of one's story could be told and re-told which appeared to enable participants to talk about difficult experiences at their own pace. Moreover, the open-ended nature of the group seemed to facilitate this gradual sharing of experiences, often over the course of several months or years.

This ability to exercise control over the decision to talk was not limited to the early stages of one's group membership and there was a shared sense among some participants that

there was no expectation or pressure to contribute in every group meeting. A few commented on the importance of knowing that they could still attend even if they didn't: 'Sometimes I can come and there's nothing going on…but I'd like to think that I can be there' (Pickle) and many valued the opportunity 'just to hear somebody else's experience of psychosis' (Mike). The factors that seemed to influence participants' decision-making process around sharing varied, as illustrated by Brian.

> Brian:…Sometimes you might not wanna say things in front of certain people. It can be various different things. Sometimes you might not want to talk cause you don't feel like talking. Or just, you might just have a little bit to say.

At the same time, there was an assumption that some level of participation was important in ensuring the 'groupness' of the group. For example, there was an acknowledgment that even if one didn't have a lot to say, or didn't wish to share, they were still expected to check-in and briefly let other members know how things were for them. Similarly, as Pickle noted, persistently silent members had the potential to increase feelings of mistrust.

> Pickle:…but couple of people…don't speak in group, don't participate, don't. Just sort of come 'No, really got anything, I got nothing to say'. 'Why are you here?'. Cause you come for six weeks, you never say anything and then you don't come for three months. <u>They</u> are the people I don't trust.

This suggests that the exercise of choice neither occurred in vacuum nor was a strictly individual affair but was underpinned and shaped by the group context and the social relations within it. Indeed, in discussing their decision to share their experiences within the group, some participants like Brian in the extract above and Pickle alluded to inherently interpersonal phenomena such as (mis)trust.

This is peer support, not therapy

This theme draws attention to the non-clinical character of the group. In talking about their experiences of attending the group, participants articulated, either directly or indirectly, a broader critique of dominant practices in the field of mental health and of the discourses upon which these are based. The subtheme 'We are not focusing on fixing the person' explores the group's distinctiveness as a form of support that was not premised on notions of cure, clinical recovery or change. The second subtheme captures the ways in which participants' accounts questioned dominant assumptions about the nature of unusual beliefs.

‘We are not focusing on fixing the person’

All participants have had contact with mental health services, some for several years and some for much less, yet none framed peer and professional support in a simplistic either/or fashion. For example, Pickle described her experience of psychotherapy as ‘one of the best things I’ve ever done in my life’. Yet, there was also a sense that there was something distinctive about the peer-based, non-clinical ethos of the group. Whilst the group was described as ‘therapy’ by a few, it was clear from participants’ accounts that the type of healing it offered differed from that experienced in traditional helper-helpee relationships. As Stanley remarked: ‘it’s the group doing therapy together. So I’d like to think of it as a collective, like we’re all like hanging out together and support each other’.

There was an assumption underlying participants’ accounts that contemporary systems of care are often narrowly focused on notions of wellness, recovery or change in ways that don’t reflect their understandings, preferences and experiences. For many, the group seemed to offer a more congruent and personally resonant approach.

Andrew challenged the idea that distress is best ameliorated through solutions that ignore the social and relational dimensions of people’s lives. He explained how ‘just really listening to stories’ and talking about his difficulties in the space of the group put him ‘on the pathway to recovery’. In the extract below, he juxtaposes this healing through sharing with culturally dominant ways of responding to pain.

> Andrew: Like you know how people keep things in and they don’t talk about it and it’s absolutely destroying their lives but they could have a good life, you know by releasing things. And that’s what I feel about. Alright, you can take a tablet and things like that but it’s not the answer, you know. The answer is to free yourself from, you know, different things...You know just talk. If something is really, a problem shared is a problem halved. There’s always somebody out there that’s listen to you and help you out.

Implicit in this and other accounts is the idea of treatment with the aim of cure, whereas for many participants ‘symptom’ reduction or remission did not seem to be the main determinant of the group’s perceived value. Instead, several suggested that the emphasis was on group members helping each other ‘cope with things’ (Andrew) and manage their difficulties. For some this occurred through sharing coping strategies, ‘ideas’ (Anne) and ‘tips’ (Anabelle).

> Brian: You can still get your days when you can be paranoid. You can have an anxiety attack or or various different things. Or you can feel anxious sort of thing…But I think it has it has helped the group. I don't know I find it hard to explain that. I don't think, I don't know. I think it has helped quite a lot, really.
>
> Maria: I can cope with it better. Cause the anxiety doesn't go away, the voices don't go away, this and that don't go away. No. It's about coping, managing them.

Relatedly, Pickle, who stated that '(she) hate(s) the word recovery' framed her struggles as something one lives with, as a journey with ups and downs. She went on to explain how the group, which she described as a 'treasure', helped her 'maintain (her) mental health'.

> Pickle: I know I'm gonna crash sooner or later, but I accept that. I accept that with my mental illness it's up and down and it's in and out and it goes in waves but at the moment I'm alright in the tall waves. I appreciate those.

This seemed to be interlinked with the facilitators' approach who did not seem to predetermine a desired direction of change. In contrast to clinical group interventions or more conventional peer support groups, change was not evaluated by changes in 'symptom' rating scales or other types of measures and, as Stanley explained, members' own views of 'outcome' were given priority.

> Stanley: But she (facilitator's name) is good actually, she is good er er levelling the ground, for want of a better expression and helping people realise, myself included, that that we don't have to be necessarily fixed in a particular direction, yeah so she is good.

Other participants more explicitly questioned the assumption that help is or *should* be about change. Often constructed as lacking insight by virtue of group membership, these participants offered insightful and non-totalising accounts regarding the non-therapeutic nature of the group.

For Louise, the validation afforded by the group was experienced as qualitatively different from offers of 'solutions' which, themselves, could be experienced as invalidating and disrespectful. In the extract below, Louise points to the sense of *being with* one's pain and suffering without attempting to intervene, suggesting that doing the latter can sometimes be not what the person needs or asks for. This sense of invalidation through an expectation to 'carry on' and what was described as a fetishisation of change, mirrors Anne's account who compared her experiences in the group to professional support.

> Louise: …with professionals they're more likely to come at you with

> solutions. It depends what professional they are. Therapists don't tend to do that but someone like a CPN or a care co-ordinator … You know, obviously she has a different function to what this group has and her job is completely different erm but I think on the whole with professionals you get a more 'Oh well what can we do to help you?' And it's not really like that here. We are not focusing on solutions, we are not focusing on fixing the person…Erm, warts and all, you know, they 're not trying to say, you know, that they can help, they're not trying to say 'This is the answer' they are just respecting where you're coming from.
>
> Anne: You know, I used to get the feeling that they just want me to carry on with life, go and get strong and carry on with your life.

For Tina, this different approach offered by the group was described as freeing. There was a sense that the idea that one *should* make oneself better during therapy was somewhat tyrannical, even if therapy was ultimately experienced as helpful and 'completely open'. Notably, for Tina the group did indeed lead to healing although this was not perceived as the primary benefit derived from participation, but a 'side-effect'. This suggests that other outcomes are equally if not more important for some participants. This healing was felt to have occurred in a forceless way.

> Tina: Yes, so I receive private therapy at the moment…That's different to here er... She's a therapist and she, we work through things together erm. There's a there's a there's a prerogative, I don't know if that's the right word, of making myself better with that. Erm, not in a forced way, not even, it's completely open…Whereas when I come here…It's not like I come here with the need of, and I sit down 'I'll make myself better now'. Although that's a side-effect of the group. Yeah, it's not the initial sort of gain, I mean and there's no. She's a professional therapist, she gets money for treating me so, yeah. This is not on the NHS, but I used to have psychotherapy sessions on the NHS, and that was similar, which, where there's more CBT.

Moreover, this perceived preoccupation with, or expectation of, change appeared incongruent with some members' sense-making and preferences. For example, Stanley did not see his experiences as a mental health issue—a notion that he questioned—but as part of his 'growth process'. Stanley spoke about his longstanding involvement with New Religious Movements and Indian mysticism and explained that he saw his difficulties through these lenses. Talking about how he perceived the group, Stanley remarked: 'It's just been part of my growth process which is ongoing'. Whilst participants were not directly asked about the content of their beliefs during the interview, some spoke about them

spontaneously. For example, Louise explained that some of her beliefs at times of being 'manic' are empowering and 'wouldn't have gone without them'. Whilst Louise did not romanticise her experiences and reflected on their distressing side, for her, the group was not a space for belief modification.

> Louise: …three-dimensional reality is too harsh you know you want to be open to further dimensions of experience and some of the experiences I've had have been amazing. I wouldn't have gone without them. They are extraordinary and amazing and very pleasant (laughs). You know, I mean it's a great thing to believe that you are a special, chosen person. It's very confidence boosting. Don't get me wrong. When you come down it's horrible because you feel, on top of the fact that you are depressed anyway, you also have the embarrassment of feeling that you made a fool of yourself and did things that were out of character.

'Who decides what's an unusual belief?': Problematising 'delusions'

The notion of 'fixing' or making oneself 'better' is premised on the assumption that something is in need of cure and implies the existence of a normal version of the person. However, some participants questioned some of the taken-for-granted assumptions upon which mainstream conceptualisations of 'delusions' are based. For example, key characteristics of 'delusions', as defined in contemporary diagnostic systems were, either explicitly or implicitly, challenged. This aspect of participants' accounts seemed important for understanding their experiences of the group albeit in a wider sense; and hence, it was developed within the analysis.

Across interviews, the term 'delusion' was only used by one participant, only to highlight its pejorative connotations.

> Louise:…people have different ways of dealing with someone who, who is if you wanna use the term psychotic I don't know…erm delusional, you know all those words are very pejorative and I know this group is trying to bring things out in the open more and have a more accepting approach and be a forum for people to just bring, you know, themselves, you know, their reality.

Louise's assertion that the group was a place for people to bring 'their reality', was supported by other participants who highlighted the group's emphasis on members' subjective experiences from the perspective of the person him or herself. As Pickle remarked: 'I know I'm being paranoid but for me it's real'. For Pickle, this meant that no one's version of reality could claim to be more objective or more accurate.

> Pickle: When I'm, I know it's ridiculous, there's no one in my house watching me, but when I'm doing things I feel like someone's watching me. I know there's no one watching, there's no cameras in my house…And there's no one to notice, I live on my own (laughs). You know what I mean…But it's very real for you. It is it is it is real.

Other participants challenged the notion of a sharp categorical distinction between 'normality' and pathology, suggesting instead that unusual beliefs lie on a continuum with ordinary beliefs. As Tina commented: 'I think the core point though is that it's a spectrum. That mental health is a spectrum and that every single person is on that spectrum'.

> Tina: I-I used to have paranoia and unusual beliefs myself a couple of times in my life. Mm, I still feel a bit paranoid sometimes and I guess I have unusual beliefs and maybe sometimes a little bit as well. Everyone's got, everyone's on, this is a spectrum and and erm.
>
> Louise: There is no obvious cut-off point between someone's beliefs being unusual and them just being an average Joe, you know, or Jane. You know, there is no obvious. It's a very very fine line isn't it? And where do you draw that line? You know, it seems to me that it's inevitable that you're going to get into philosophical territory with this subject…You know, who are these people that are making a judgment? I only know this group works really well for me.

Relatedly, a formal diagnosis of any kind was not a prerequisite for participation in the group. Some explained that group membership was not dependent on diagnostic homogeneity among members and this did not seem to prove problematic. As Mike, referring to his fellow group members, put it: 'some of them have the same illness, some are a bit different but they all can relate in one way or another'.

Participants spoke about, or alluded to, a range of explanations for their experiences. Whereas several drew on culturally dominant frameworks, others seemed to be invoking a patchwork of explanations for their distress. And although references to 'illness' were common across some interviews, it was evident that different perspectives were allowed to co-exist, even within the same group. As Mike, the only participant who made an explicit reference to the dopamine hypothesis of psychosis, commented:

> Mike: I know it's a dopamine increase…but the group doesn't specifically say 'Well, this is happening in your brain at this time'…like doctors say, they don't do that… So for example if somebody says, I don't know, I hear voices a lot, the facilitator won't say 'Well, the part of your brain that produces too much dopamine…'. That doesn't happen.

Yet, whilst no one spoke about the group advocating a specific explanatory framework for members' experiences, there was an assumption underlying several participants' accounts that adverse life experiences are seminal in one's mental health struggles with some talking explicitly and others more implicitly about this.

> Andrew: Erm, as I started, you know, going to the group, I started getting more mellow. You know, and understanding people and where they were coming from. A lot of them was different things, you know, unusual beliefs and things like that. But…now I sort of. I sort of understand where people's coming from...Just having that understanding that not everybody is the same but, you know, we have different ways of coping with what's happened to us.
>
> Tina: Erm some people go through terrible things in their lives, I mean erm I'm not gonna tell say names or, I don't want to talk too much about the people on the group but...Some people have gone through terrible things in their lives and I think it just makes sense that they had, that they have experienced mental health problems.

Taken together, the ideas expressed by some participants problematised key assumptions upon which dominant psychiatric understandings of unusual beliefs are predicated and it appeared that the group offered a space for these construings.

From the 'I' to the 'We'

This theme explores two interlinked 'transitions' that appeared in participants' accounts; namely the shifts from isolation and alienation to connection, and from the personal and individual to the collective.

Although some participants reported having a small number of supportive relationships in their lives, these were, almost invariably, limited to their immediate social circles. For example, participants commented that they felt able to share their struggles only with: 'couple of my friends…And my daughter' (Pickle); 'Mum and my dad and my sister' (Brian); 'my immediate family' (Mike); or 'a couple of other friends' (Anne).

Some spoke about being abandoned by significant people in their lives because of their difficulties, whilst others conveyed a sense of betrayal at being cast aside by those whom they once considered close: 'We were like brothers, we grew up together, done everything sort of thing. And like since he don't want to know me since…' (Brian).

> Andrew: Cause I never was like, you know. I used to just get on, I had lots and lots of friends before my accident and a lot of them disappeared then after my accident. And erm I used to have lots and lots of, you know, knew lots of people. But I suppose…maybe it's that that's what I'm missing. Communication.

For Stanley a loss of vital contact with others seemed to be painfully familiar and characteristic of much of his live: 'I've got so much isolation, lack of relationships'; 'I'm starved of human contact'. Others, like Claire, reported that their attempts to establish a connection with others—even at the most fundamental level—were often met with hostility and indifference.

> Claire: People outside don't listen, but in here, (facilitator's name) group, they listen. People out there, they don't listen... If you, if you talk to them they walk away, outside. And in here, they don't.

A number of participants explained that this pervasive sense of alienation could stem not just from an absence of social contact, but also from a lack of understanding from others. For example, Anabelle articulated her struggle at trying to communicate her experiences to her friends. The extract below illustrates the experiential chasm that seemed to separate Anabelle from important people around her and also hints at the isolation that can be associated with holding distressing beliefs.

> Anabelle:…when I get paranoid my phone rings, I don't answer it, don't answer it. They say I'm being rude, they say I'm being funny to em, but I'm not, but I'm not…these guys here in the group can understand what I am saying. But my other friends without mental health doesn't. So, I've noticed the difference, when it shouldn't be that way, you know.

Yet, some participants saw this disconnection from human relationships as typical of contemporary culture and not merely as a result of ignorance or lack of awareness. Like other participants, Pickle spoke, more broadly, about the dehumanisation of social relationships and what she described as a general societal apathy to the wellbeing of others. Her words seemed to complement those of Louise, who invoked a view of people ('we all', 'everyone') as inherently interdependent beings. In Louise's account, this notion was contrasted with contemporary ways of life, in which persons exist as separate, 'individual' entities.

> Pickle: You know if you're sitting on the bus and…I'm convinced that there's two people behind me and they're laughing, I have to physically stop myself from turning and saying 'What the fuck you're laughing at?'…And it's

> horrible, it's horrible. Yeah so people don't understand it, people don't want to know. **[Why do you think that people don't want to know?]** Because…as long as it doesn't affect them, it's over there, it's yours. Doesn't belong to me, ain't my problem you've got problems.
>
> Louise:…because on some level we all are, you know we are all connected and we all have that, well, I believe we all have a divine spark within us that connects everyone. It's just that a lot of the time we feel unfortunately alone and individual and that's very painful.

Finding a forum to meet, listen to and share their experiences with others seemed to serve as a counterforce to such experiences of isolation and disconnection in a number of ways. Nearly all participants highlighted the importance of coming to realise, some for the first time, that they were not alone in their distress and that their struggles were shared by others.

This recognition seemed to ease participants' sense of isolation and reduce feelings of abnormality which many described as profoundly reassuring, particularly during the early stages of their membership in the group.

> Andrew:…listening to other people's problems and then I say myself well, you know, I thought it was just me, you know, that I was the only one.
>
> Anne: So then I think 'What's different about me?'. We are all human beings, we all get these kind of feelings, and we all get similar problems, you know, cause we all have children, we all have families, we all have friends, we all live in a society, you know.

Over time, strong bonds and a sense of 'camaraderie' (Pickle) formed among members, who were often in contact with each other outside group meeting times. Indeed, the group was described as a 'family', a 'home' or a 'collective' and the determiner 'my' used by several participants attested to their strong affiliation: 'I always call it my support group' (Louise).

> Andrew: How shall I say, it's. Quite a few people that come here is regulars. And it's like a family, you know. You just listen to your, your brothers and sisters within the family talking about different things…and trying to help.

Thus, the group seemed to function not just as a weekly supportive forum, but as an alternative social space wherein a powerful sense of community was fostered. The sharing of intimate experiences, over several months or years, the 'feeling of caring for each other'

(Anne) both within and beyond the group, as well as the lasting friendships that developed among members, all seemed to contribute to the creation and sustenance of this community.

> Mike: There's been members there for several years like me. And I know…their personal lives, they know my personal lives and so we erm we (are) empathetic towards each other and we are comfortable talking about very sensitive things within that group setting.
>
> Louise: These are my friends! (laughs)…I'm someone who socialises online a lot and I'm not very social…I don't have many friends in real life. I have more online stuff. So this is a very, you know, important part of my week cause it's somewhere where I'm with real people talking about things that affect us most. Erm (pause) and, you know, it keeps me in touch with, you know, the social world.

Critically, many participants explained that members were both co-creators and co-owners of this milieu. As Pickle remarked, the group 'will keep going as long as people keep attending'. Thus, being part of this community seemed to be coupled not only with opportunities (e.g., expanding one's social network) but also with responsibilities towards one another. In talking about this aspect of the group, participants seemed to undermine the cultural imperative of individualism, which prioritises self-interest over solidarity and cooperation. And whereas Annabelle explained that she attended the group primarily for her own wellbeing ('It's for you, and you only'; 'I'm there for myself'), the dominant account was that of seeing the good of the one as inseparable from the collective good. A sense of dedication to the welfare of fellow members was evident in several interviews and this seemed to take different forms for different participants.

Some questioned the notion that one 'uses' peer support solely for one's personal benefit. For example, Pickle reported that she attended the group even if things were OK for her hoping to be of help to other members. Pickle went on to explain that she devoted substantial energy to ensure the group's continued existence which was threatened due to funding cuts. This involved assuming additional responsibilities and partaking in consultations at the organisation where the group operated. And as she emphasised, she did this not just for herself: 'I give a lot of my time and a lot of my effort. Because I believe in it. And not just for me.'.

For Andrew, this desire to make a contribution to the lives of others was more directly linked to the running of the group. He explained that during the facilitator's absence, he voluntarily took the 'facilitator' role which he attributed to a strong desire to 'give back'.

> Andrew: Erm, and that's why I want to give back because they were so supportive here. You know and they helped me out, they done everything...And it's something that I want to give back, you know, because I just want to get involved in helping people.

Andrew's words echoed the perspectives of several other participants, like Maria and Anne, who noted that this interest and ethical commitment ('I need to') to the wellbeing of others often extended beyond the temporal and spatial boundaries of the group.

> Maria: Not only expecting help from others…I need to offer help as well. I like helping others, I really do. If I see someone who's upset, I will approach them and ask 'Please don't be upset with my question, I want to know what happened to you'…They may say 'Today I'm not in a good mood'. 'Alright, would you like a cup of tea? I can make some tea for you'. I try, I try.

A number of participants described such small acts of solidarity as personally rewarding and helpful: 'And to see somebody going through the same thing as me, if I can say something that can help them, you know I feel good' (Mike).

> Pickle:…because I know how it feels like to have someone ease a little bit of my pain…if I can give a little bit of that back that means a lot to me. If someone can take something away maybe that I've said…**[And why is that important for you?]** Because it makes me feel good about myself, makes me feel worthwhile, makes me feel useful, and makes me feel wanted…

For others, supportive interactions continued outside the group. For example, Andrew explained that he helped a fellow member who was fearful of using public transport, regardless of the personal cost that this had of him. This 'self-sacrifice', however, had a positive impact on him too. Andrew came to discover that through helping others, he was also helping himself.

> Andrew: I try and help somebody who's terrified getting on the tube. So sometimes I'll go with that person into the town. She goes to big stores, but I <u>hate</u> the big stores. I can't, you know. I used to be terrified, I wouldn't even go to the supermarket...My friend, part of the group, is struggling with erm you know she's terrified to get on the tube or a bus...I go in there, you know, around shops, things like that. But it's helping me too.

Yet, it was clear from participants' accounts that these actions were not taken merely in anticipation of, or in exchange for, a personal gain. On the contrary, the distinction between the one who helps and the one being helped was considered as somewhat redundant. This seemed to mirror the facilitators' egalitarian approach and their willingness to share power.

> Tina:…in the group it just goes hand in hand, erm. I think there's no real offering and receiving happening. We're just ourselves and no one, there's no hierarchy or…And (facilitator) is even, she…has a great way of not not making us feel like she's some sort of erm group initiative person. We talk about our week and she does as well.

And although, as discussed in the subtheme 'It became quite an intimidating environment', new, insidious hierarchies could occasionally emerge, the group was largely described as a community of equals, characterised by horizontal relationships. For Pickle, this lied at the core of the group's ethos: 'that's the whole thing about peer support. Yeah, no one comes in and starts dictating this is what you should be doing, that's what you should be doing…It's a discussion'.

These practices seemed to stand in contrast with the self-centeredness, the fragility of social bonds and the erosion of community life, characteristic of the Western neoliberal order. In the extract below, Tina reflects on how responses to distress have changed over time. She describes how at different times and in different places, more humane and cooperative ways of responding to distress existed. Perhaps, then, the alternative community created by the group carried the traces of a 'remembered' past or those of an imagined—preferred—future.

> Tina: In other cultures and in maybe long ago times, mental health problems were sort of more embedded in culture and, I think…they were more dealt in families and people were living with big extended families, in big houses and mental health problems were just dealt with in different ways. And erm, nowadays there's mental health, the label, and it's being dealt with, with like through medication with psychiatrists, they're like doctors, mechanics, you know they. It's like they they treat it like, there's a factory erm erm factory fitting for for every patient and just like there's for, you know, when you've got a broken leg there's certain procedures.

Chapter 4: Discussion

Chapter summary

This chapter begins by summarising and discussing the study's findings in relation to previous research and relevant theory. Next, the implications of this study will be examined and its strengths and limitations will be considered. Finally, directions for future research will be presented.

Overview of findings

The study aimed at exploring participants' experiences of attending peer support groups for unusual beliefs and the ways in which, if any, the group impacted participants' lives. Following a thematic analysis approach, four themes were developed from the data.

In search of an 'oasis'

The finding that the group functioned as a safe and accepting space is largely in keeping with previous findings documented in the Hearing Voices Network (Oakland & Berry, 2015; Payne et al., 2017) and broader peer support (e.g., Davidson et al., 1999) literature. 'Safety' and 'acceptance' are also widely-researched beneficial processes in group therapy (e.g., Yalom & Leszcz, 2005). Previous IPA studies (e.g., Hendry, 2011; Payne et al., 2017) have drawn on psychological theories to elucidate the ways in which hearing voices groups served as a 'secure base' or created "a safe space through enabling emotional containment" and "cathartic release" (Payne et al., 2017, p. 213). Ian Parker has argued that through concentrating on what is 'inside' individuals, IPA studies "lose sight of how what is 'inside' is dependent on what is 'outside' the individual as the context for the narrative to make sense" (Parker, 2005, p. 75). Similarly, the notion of acceptance is often used in the psychosis literature in order to denote acceptance of 'psychotic' experiences by the person themselves. For instance, a study of a mindfulness group describes how participants became "more self- accepting and more accepting of the diagnosis of bipolar disorder" (Chadwick, Kaur, Swelam, Ross, & Ellett, 2011, p. 281). The role of social acceptance in such analyses is sidestepped, yet it seemed crucial for participants in this study. Here, these notions have been interpreted rather differently.

The term 'safe space' originates in LGBT and feminist activism and refers to "exclusive physical and discursive spaces for sexual minorities or women to come together to talk and

support each other" (Macdonald, 2014, p. 63). Seen from this perspective, the notion of the unusual beliefs group as a safe and accepting haven resonates with the practices of other oppressed and marginalised groups who seek sanctuary. Indeed, the word 'oasis' used by one participant to describe the group, evokes not only a vital place of sanctuary where nourishment is available but also a deserted, and potentially dangerous, outside world.

Experiences of stigma (a term explicitly mentioned by several participants) and overt discrimination were overwhelmingly reported and seemed to permeate all facets of participants' lives. This finding is consistent with a large body of research documenting that such experiences remain highly prevalent (e.g., Gerlinger et al., 2013) and echoes the findings of a recent thematic synthesis which noted the social embeddedness of stigma in psychosis (Wood et al., 2015). As discussed in the Introduction, such experiences can have a profoundly negative impact on multiple life domains and can be more distressing that the experiences of psychosis themselves (Bajorek, Stockmann, & Burton, 2012). Moreover, as previously discussed, experiences of victimisation have been implicated in the development and maintenance of paranoid beliefs and this was evident in some participants' accounts. For example, one participant described how neoliberal attacks on welfare provision and being blamed as a 'scrounger' served to intensify his paranoid thinking. This is in keeping with recent research on the deleterious impact of welfare reform on service users' mental health (Mehta, Taggart, Clifford, & Speed, 2018). Arguably, theories that assume that the causes of distress are to be discovered solely 'inside' people and with no consideration of people's social and material circumstances (The Midlands Psychology Group, 2014) are ill-equipped for understanding such experiences of invalidation.

Notably, some participants reported feeling unable to talk about their experiences to professionals whom they sometimes perceived as patronising or dismissive. This reflects not only the well-documented finding of service users being treated in a disrespectful manner by service providers (e.g., Pinfold, Byrne, Toulmin, 2005; Wahl, 1999) but perhaps also a prevalent fear among professionals that discussing clients' unusual beliefs will make them worse (e.g., Lüllmann, & Lincoln, 2013). For example, a survey of mental health nurses, psychiatrists and clinical psychologists (Aschebrock, Gavey, McCreanor, & Tippett, 2003) found that 38% of respondents felt that exploring the content of a person's 'delusions' could potentially distract them from more important aspects of their work such

as establishing their form (e.g., whether they are ‘grandiose’ or ‘persecutory’). A further 28% expressed a concern that an exploration of content could unwittingly reinforce them.

In contrast to such experiences, the group was positioned as a space where participants could openly share, experience distress and ‘be themselves’, free from judgment and discrimination. This included the sharing of beliefs that would in other contexts be regarded as irrational or pathological. In addition to juxtaposing the group with the unsafety and lack of acceptance so common in their wider social worlds, several participants expressed their anger and indignation at what they saw as unjust treatment. It could be said that this relates to notions such as ‘righteous anger’ (Corrigan, Roe, & Tsang, 2011) and ‘stigma conversion’ (Humphreys, 1972). Corrigan has suggested that members of peer support groups may begin to resist oppression and start to view stigma as illegitimate. As a result, instead of diminished self-worth (a key consequence of internalised stigma) they experience righteous anger. Similarly, for Humphreys (1972), through a process of ‘stigma conversion’, the person no longer sees their difficulties as personal failings but as societal problems. Such transformative processes within user-led spaces may sow the seeds for collective action (Corrigan et al., 2011). Several commentators have argued that just that like the notion of recovery, the meaning of empowerment has been diluted (e.g., Rose, 2019). These important critiques aside, a user- developed measure (Rogers, Chamberlin, Ellison, & Crean, 1997) includes righteous anger as one of the attributes of empowerment. The latter, has been associated with peer support in several studies (e.g., Pitt, Kilbride, Welford, Nothard, & Morrison, 2009) and it may be viewed as relevant here, too.

In addition to exploring what participants felt safe *from*, the first subtheme outlined the features that were found to be conducive to this atmosphere of safety and acceptance. Consistent with other studies in the hearing voices literature (Dos Santos & Beavan, 2015; Payne et al., 2017), the role of facilitators was described as integral and participants spoke about their open and respectful stance. Notably, participants highlighted the importance of the trust that developed over time among members. This suggests that key processes that seemed to matter the most for these participants, such as trusting and being trusted by others, are processes that arguably cannot be captured through randomised trials of peer support. In addition, the importance placed on trust appears somewhat incongruent with the dominant trend in mental health services towards short-term support (Lousada, Weisz,

Hudson, & Swain, 2015), in a seeming attempt to avoid 'service dependency' (Rose, 2014).

Yet, adopting a non-judgmental attitude, a key value of hearing voices and unusual beliefs groups (e.g., Dillon & Hornstein, 2013; May, 2012), was not an effortless act. Some participants spoke about the struggle of remaining non-judgmental, especially when other members' realities were very different from their own. Thus, this acceptance of diverse realities was not necessarily a given, but rather something that was cultivated *through* participants' attendance. It could be said that this different kind of ethical listening that participants referred to, required what Fricker (2007) has termed reflexive critical openness; an openness to what another has to say and, ultimately, to who they are. Much of the self-help/peer support literature to date has emphasised how, through the empathy that *intuitively* stems from members' shared experiences, support groups can be a source of emotional support (e.g., Helgeson & Gottlieb, 2000). Whilst this was undoubtedly true for these participants too, this finding paints a more complex picture.

However, as the subtheme 'It became quite an intimidating environment' highlights, at times, some of the very features that rendered the group a place of refuge, seemed to be jeopardised. Payne et al.'s (2017) study found that conflicting viewpoints and interpersonal struggles were barriers to connecting and that some participants felt unheard in the group. Similarly, in the recent survey by Longden et al. (2018), 34.6 % of participants reported that they occasionally found the hearing voices group distressing. The finding that conflictual situations had a powerful impact upon participants and could be a cause of distress, adds to these previous findings. Moreover, the finding that conflict typically involved new rather than established group members and could be a reason for disengagement has implications for the groups and the work of the network.

Notably, these tensions appeared to remain largely unexplored and unacknowledged. Sociologist Deborah Gould (2009) has observed a similar phenomenon in the context of AIDS activism. She suggests that unacknowledged 'undercurrents' of mistrust, anger and nonrecognition among members of the activist group ACT UP, eroded sentiments of solidarity and, ultimately, helped to fracture the movement. Relatedly, Spandler (2017) has cautioned against the dangers of creating divisive new hierarchies and norms within the service user/survivor movement. Such implicit 'hierarchies' of distress were described in

the present study, with harmful consequences for those involved. This seems to be in diametrical opposition to the ethos and purpose of these groups (e.g., May, 2012) and it highlights how dominant discourses can infiltrate even spaces that are specifically designed to move beyond normative notions of normality and pathology. Whilst this finding has not been previously discussed in the hearing voices literature, it bears similarities to Chassot and Mendes's (2015) observation. In a qualitative study of members of the British service user/survivor movement, these authors found that some people were rejected and seen as less legitimate if they didn't "fit a certain profile-characterised by severe mental distress and treatment in psychiatric hospitals" (Chassot & Mendes, 2015, p. 380-381).

Choice means something different here

The group's voluntary membership and the lack of restrictions around attendance seemed to provide opportunities to exercise agency and control, affirming participants' right to speak and act for themselves. Thus, the term choice here—a term explicitly used by groups such as 'Survivors Speak Out'—reflects these key tenets of the disability rights and service/user movements (e.g., Charlton, 2000) and not a neoliberal notion of a 'free', autonomous chooser.

Participants explained that they could decide for themselves whether the group met their needs and that they were allowed to participate as they deemed appropriate to their situation. For some, this included taking some time off from the group which was described as important. This supports the findings of Oakland and Berry (2015) and Payne et al. (2017), whose participants similarly highlighted group ownership and flexibility around attendance as unique features of the group. In addition to re-positioning members as agentive, this flexibility seemed to be beneficial for different reasons for different participants. For example, one participant explained that he missed group sessions in order to reconnect with his passion for music. Rediscovering areas of interest has been found to facilitate recovery (Roe, 2005) and, arguably, this level of flexibility is typically unavailable in mainstream services where non-attendance policies exist and notions such as 'throughput' are often employed. Moreover, in a group psychotherapy context, the 'underlying meaning' of missing group meetings would most certainly be interpreted (Counselman & Gans, 1999) which further illustrates the difference of this form of support to conventional psychological therapy.

On the other hand, and in contrast to the rhetoric of 'patient choice' and 'control' (e.g., DOH, 2010), interactions with professionals were described as paternalistic and disempowering. Participants noted examples where their wishes and preferences were over-ridden and spoke about being turned away from services, despite their requests for support. This concurs with previous studies (e.g., Stovell, Wearden, Morrison, & Hutton, 2016) and seems to resonate with the idea that we live in an era chiefly characterised by neglect rather than coercion (Spandler, 2016). This finding also highlights that for some participants, the group was not only a valued source of support, but perhaps the *only* source of support available. Indeed, several participants described their disillusionment: waiting for appointments and never hearing back, being discharged from services despite not feeling ready themselves, difficulties in getting consultations with psychiatrists, to name a few of the experiences reported. One wonders, then, whether, in addition to other functions it may serve, peer support has come to fill the gaps of an underfunded mental health system (Docherty & Thornicroft, 2015).

The subtheme 'And slowly slowly I opened up', focused on participants' control over the manner in which their stories were shared in the group. Silence was accepted and participants explained that they didn't have to share if they didn't want to. This seemed to put them at ease. Interestingly, this aspect of the group is in contrast with much of the group therapeutic literature wherein silent members are seen as common 'problem situations' (e.g., Stock Whitaker, 2001). For example, a guidebook on group CBT for psychosis suggests that therapists can address the problem of the 'mute' member by asking them to write on the flip chart, by asking easy questions or by offering positive reinforcements (Lecomte, Leclerc, & Wykes, 2016). The idea of not intervening and accepting the person's silence, as reportedly the unusual beliefs group allowed, is not mentioned as an option.

Relatedly, it seems that the group enabled participants to share their stories at their own pace. This seemed to be facilitated by the longevity of the group and was identified as helpful, especially when it came to the sharing of particularly painful material. This seems to resonate with the suggestion that unlike structured groups, hearing voices groups render possible a more iterative sharing of experiences with members "holding space between the urge to story one's experiences, and the difficulties of so doing" (Woods, Hart, & Spandler, 2019, para. 54). One could argue that having this level of control over one's story is

somewhat incongruent with mainstream clinical practice. For example, in trauma-focused therapies, the clinician has some control over the client's narrative through instructing the person on which memories to focus on (Corrado, 2016). Moreover, one wonders whether this fluid and gradual sharing that participants spoke about is compatible with time-limited, formalised types of peer support. For example, all the peer support groups (primarily manualised self-management interventions) included in the aforementioned Cochrane review (Chien et al., 2019) had a finite number of sessions and 6 out of the 8 groups examined were of a duration of 4 months or less. In the present study, participants were members of their respective groups for much longer, often for a number of years, and it's not hard to imagine the different dynamic that this may create. The importance placed upon the group's longevity is also supported by Oakland and Berry's (2015) study which found that the group's open-endedness enabled people share their experiences in their own time frame without the anxiety that a time limit would impose.

This is peer support, not therapy

This theme explored the group's non-clinical ethos. The ideas captured in the subtheme 'We are not focusing on fixing the person' highlight the group's distinctiveness as a form of support that was not guided by ideas such as outcome, clinical recovery or change.

Underpinning many of the views expressed by the participants was a sense that dominant responses to mental distress are often premised on notions of recovery or change in ways that fail to reflect their experiences and preferences. A clear message was that 'symptom' eradication was not the main indicator of the group's 'success' and the group was described as valuable even in the continued presence of distressing experiences. This concurs with studies in the hearing voices literature demonstrating a range of benefits of group attendance despite no changes in clinical outcomes (e.g., Beavan et al., 2017; Longden et al., 2018).

Instead of placing a focus on 'symptom' reduction, participants described the group as a forum wherein members could, among other things, share and try out ways of coping, with one participant referring to the group as a 'learning platform'. These opportunities, in turn, seemed to enable participants to negotiate a different relationship with their distressing experiences. From a theoretical perspective, this exchange of ideas and feedback could be

conceptualised as a source of informational support which is thought to increase one's sense of mastery and control (Loat, 2011). The notion of discovering personally resonant ways of coping (as opposed to 'curing') is described as central in the theoretical literature on unusual beliefs groups (e.g., Knight, 2009; May, 2012) and the importance attributed to this aspect of the group by participants is consistent with previous qualitative (e.g., Dos Santos & Beavan, 2015; Oakland and Berry, 2015) and quantitative studies (Beavan, et al., 2017) on hearing voices groups.

It could be said that these perspectives are in keeping with service users' conceptualisations of recovery from psychosis. For example, the notion that 'symptom' eradication is not the sole legitimate aim and the emphasis placed on coping are both well-described in the literature on recovery (e.g., Pitt et al., 2007; Wood, Price, Morrison, & Haddock, 2010). Seen from this perspective then, these findings would reiterate the importance of approaches that take a broader focus that extends beyond merely clinical domains, to include, for example, outcomes related to recovery (e.g., Bellamy et al. 2017). It has been argued that, in its current professionalised form, recovery has also come to be closely associated with 'getting better' (Perkins, 2015) and 'outcome' (Campbell & Rose, 2010), whereas these participants seemed to be emphasising something else: the very different foundations upon which therapy and peer support rest.

Participants spoke about the importance of 'being with' one another's pain without attempting to intervene or 'fix'. This echoes Adame and Leitner's observation (2008, p. 148) who describe peer support as a "a mutual…*mode of being*". Based on a bibliography of over 900 'first person narratives of madness', Hornstein (2011) has suggested 4 processes that help in recovery. One of these processes seems pertinent here and refers to the importance of having an empathic witness to one's suffering; having someone bear witness as a fellow human being. Indeed, participants didn't describe the telling and listening that occurred in the group as "instrumental tools mobilised to achieve change, to move…from A to B" (Walker, Hart, & Hanna, 2017, p. 78). On the contrary, they questioned the very idea that healing human encounters and 'improvement' are synonymous. In doing so, they challenge the notion of peer support as a technical means to bring about a (predetermined) end. Relatedly, outcome measures, which are generally disliked by service users (Solstad, Castonguay, & Moltu, 2019) were not used in any of the

groups. These perspectives and practices seem to challenge the "assumption…that improvement in symptoms, functioning, or reports of distress, is all the good we need be concerned about" (Smith, 2009, p. 34)—in other words, the edifice upon which evidence-based practice is based. These findings contribute to contemporary debates around researching peer support and whether studies of peer support are investigating what really matters to service users (e.g., Bellamy et al., 2017; Gillard, 2019). In addition, they support calls for the need to remain cognisant of the fact that peer support was never conceptualised as a substitute to clinical services (Penney, 2018) and preserve its ethos and values (e.g., Faulkner & Basset, 2012a).

The next subtheme, 'Who decides what's an unusual belief?', explored the ways in which participants challenged some of the key assumptions upon which medical conceptualisations of 'delusions' are based. The fact that the term 'delusion' was only used once, and that to highlight its pathologising connotations, is significant in and of itself as it denotes a preference for a non-stigmatising language that doesn't reduce people to 'symptoms' and 'disorders' (BPS, 2013; 2015).

The views expressed by participants contribute to the literature presented in the Introduction highlighting the difficulties inherent in current definitions of 'delusions' (e.g., Harper, 2004; Cromby & Harper, 2009; Georgaca, 2000). They also largely concur with critiques of the medicalisation of distress from both users/survivors and professionals (e.g., Boyle, & Johnstone, 2018). To date, debates around the nature of 'delusions' have largely been theoretical and conceptual. The findings presented here highlight that these are not merely matters of academic discussion but also of direct concern to people holding beliefs others find unusual. The notion of a single objective truth was juxtaposed with the need to honour the reality of the person and there was also a sense that lack of factual verification does not negate the truth of one's feelings. The assumed qualitative difference between 'delusions' and ordinary beliefs was also questioned and the role of past trauma in distress was seen as important. Thus, it seems that the group offered space for these less pathologising perspectives.

Recent years have witnessed a controversy over which perspective or frame of reference is

more ‘valid’ and one might wonder what is at stake (and for whom) in these debates. For example, it is often assumed that people have one and only way of understanding their experiences. Yet, several participants didn’t frame matters in terms of either/or. Interestingly, both medical and nonmedical frames of reference, even within the same interview, were not uncommon. This finding supports anthropological studies suggesting that, more often than not, people have multiple, co-existing explanations (Kirmayer, Corin, & Jarvis, 2004) for their experiences. It also echoes the words of Rufus May’s (2001) who, writing from a personal perspective, notes “I do not have one formulation of my own experiences . . . I have several which lend themselves to different paradigms. The psycho-social, the spiritual and the pathological explanations I consider, at various times, all have strengths and weaknesses” (p. 16). Participants indicated that the group allowed these different construings to co-exist, without an attempt to reduce members’ experiences to a single explanatory system. It could be argued that such an approach opens up rather than shuts down dialogue and may enable a shift from a position of simplicity to one of complexity, in a way that is not typically encountered in many contexts. For example, Kennedy and Humphreys (1994, p. 183) suggest that in groups such as GROW and AA the “wisdom and…the worldview of the group is passed on to its members”. Such self-help groups have a specific philosophy and set of teachings that instruct members how to interpret their difficulties (Kennedy & Humphreys, 1994) which appears almost antithetical to what participants in the present study described.

From the ‘I’ to the ‘We’

Experiences of isolation and loneliness in people with experiences of psychosis are highly prevalent. Their social networks are typically restricted and their access to social support beyond that provided by services is limited (Buchanan, 2004). Stain et al. (2012) found that over 80% of people with experiences of psychosis reported feeling lonely in the past year and a recent systematic review (Wood & Alsawy, 2018), identified social exclusion from community groups as a key barrier to recovery.

Participants described a pervasive sense of isolation and disconnection from human relationships. Meeting others with similar experiences in the context of the group created a sense of universality which was described as transformative. Universality is a well-established healing factor both in therapeutic and mutual support groups (Yalom & Leszcz, 2005), including hearing voices groups (Oakland & Berry, 2015; Payne et al., 2017). This

realisation served to normalise participants' experiences and reduce feelings of isolation.

The deep sense of solidarity and concern for one another captured in this theme has not been previously discussed in the hearing voices literature. The group seemed to function as an alternative social world whose values stood in contrast to dominant sociocultural imperatives. In contrast to the position of a 'passive patient', these participants articulated altruistic reasons for participating, a commitment to the wellbeing of fellow members as well as the importance of having a positive impact on another's life. Helping others was, indeed, described as helpful for the person offering help which resonates with the helper-therapy principle (Riessman, 1965; 1990) discussed in the Introduction.

Strengths and Limitations

Previous research in this area (e.g., Payne et al., 2017) has acknowledged lack of consultation with the Hearing Voices Network as a limitation. A key strength of this study—the first to explore the Hearing Voices Network approach to unusual beliefs—was the substantial input from members of the user-led network especially during the design, planning and recruitment phases. Conversations with several stakeholders (e.g., Trustee of Hearing Voices Network and group facilitators from 6 different locations) shaped the study and this ensured that it was relevant to users' priorities and concerns. Relatedly, 'sensitivity to context' (Yardley, 2017) was maximised through sustained engagement with the activities of the network, such as attendance at quarterly Hearing Voices Network meetings and training events. Cumulatively, these encounters increased the researcher's awareness of the 'culture' within which the groups operated and ensured that the overall approach was respectful to the ethos and values of the groups.

Care was taken to match the study's epistemological and ontological assumptions (as much as possible) to the work of the groups under investigation. This was considered particularly important given the centrality that notions such as 'truth' and 'reality' inevitably have in discussions around 'delusions'. It was felt that an approach that prioritises the subjective realities of participants whilst acknowledging that these realities are shaped by one's historical, social and cultural context (Madill et al., 2000) was best suited for this study. To date, studies in the Hearing Voices Network literature have tended not to make explicit their authors' philosophical positionings and the present study attempted to address this limitation.

The study's sample was diverse in terms of culture, gender and age. This represents an important strength of the present work that can be built upon, as previous investigations have tended to involve predominantly White participants. For example, 82.2% in Longden et al.'s (2018) survey and 75% in the study by Payne et al. (2017) identified as White British.

Whilst the number of participants recruited is in keeping with recommendations in the literature (Braun & Clarke, 2013), it was nevertheless, towards the lower suggested range for the chosen method of analysis. That said, this is clearly an emerging area of study and getting insight into these participants' experiences can still enrich the field.

The study aimed to reach a broad understanding of members' experiences and thus a maximum variation sampling strategy was used. A variety of recruitment strategies were used (e.g., Advertisements for the study in electronic newsletters, giving presentations about the study) and participants from 4 different groups were recruited. As this is a self-selected sample, it may have been limited to those members who found the unusual beliefs group helpful. However, a number of challenging and problematic experiences were shared during the interviews and these seemed to be shared across groups. That said, most members were longstanding members of their respective groups and future studies will benefit from exploring the views of newer group members.

Implications

A noteworthy finding was that, with the exception of one participant (who was unsure), none of the participants had discovered the group through a health care professional. This finding contrasts with the results of earlier studies which found that the majority were introduced to the group by a professional (e.g., Beavan, et al., 2017; Oakland & Berry, 2015). This study suggests that there is a rationale in raising awareness of unusual beliefs groups among practitioners and users of services alike. Moreover, and similarly to the suggestion of Longden et al. (2018), clinicians can draw on the findings of the present study and consider encouraging group attendance for their clients, support existing groups, or help set up new ones alongside experts by experience. Arguably, engaging with service users as a movement (as opposed to as clients in therapy) may open up possibilities for different forms of collaboration (Harper, 2010) and for the forging of new alliances. This, in turn, requires clinicians to use a range of skills beyond their therapeutic ones. The study

has a number of implications for the work of the groups too. Conflict within these groups seem to remain largely unacknowledged, whereas the findings suggest that its impact is long-lasting and, for some, a reason to stop attending.

Future research

Whilst at present there are Hearing Voices Networks in 30 countries with over 1,000 groups globally (Kay, Kendall, & Dark, 2017), it is striking that all studies have been conducted either in the UK or in Australia, primarily by Clinical Psychologists. Moreover, there are no examples of user-controlled research and this would be an interesting avenue given the Network's user-led ethos.

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Appendix A: Recruitment Advert

Peer support groups for unusual beliefs: Exploring members' experiences

My name is Roupen Baronian and I am a Trainee Clinical Psychologist at the University of Essex. I am doing a research study to understand people's experiences of attending peer support groups for paranoid and unusual beliefs.

I am interested in your experiences and views about attending a support group for beliefs. The aim of this study is to help increase awareness of peer support groups and their potential benefits among experts by experience and anyone supporting people with distressing or overwhelming beliefs.

Who can take part in this study?

I am looking to speak with people who are:

•aged 18 and above

•regularly attend a peer support paranoia and beliefs group

What will I be asked to do?

If you decide to take part, I will arrange to meet with you to talk about your experiences of attending the group. Our conversation will take up to one hour. I can offer £20 as acknowledgement of your time and participation in the study.

If you are interested in finding out more or participating in this study, please contact me on **Tel: 07964528179** or **Email: rb16064@essex.ac.uk**

Appendix B: Participant Information Sheet

Participant Information Sheet

Peer support groups for unusual beliefs: Exploring members' experiences

My name is Roupen Baronian and I am a Trainee Clinical Psychologist at the University of Essex. You are being invited in taking part in a study exploring people's experiences of attending peer support groups for paranoid and unusual beliefs. Before you decide whether you would like to participate in this study, it is important that you understand why this this research is being done and what your participation will involve. You can talk to others about the study if you wish. Do not hesitate to ask me anything that is not clear or if you would like more information.

What is the purpose of this study?

The purpose of this study is to explore members' experiences of attending peer support groups for paranoid and unusual beliefs. I hope that this will be useful and informative for individual groups, the work of the London Paranoia & Beliefs Network as well as anyone supporting people with distressing or overwhelming beliefs.

Who can take part?

I would like to speak to people who:

•are aged 18 years or above

•have attended a paranoia and unusual beliefs group at least twice over the last 6 months

•are willing to discuss their experiences during the interview and have this interview audio-recorded

•are able to give written informed consent to participate in the study

•are English-speaking

Do I have to take part?

No. It's up to you if you want to participate or not. If you agree to take part and later change your mind, this is also ok. You are free to withdraw from the study at any stage without giving a reason and this will not have any impact on the services you receive.

What will the study involve?

The study will involve a face-to-face conversation with me, which should take up to 1 hour. I will ask you some questions about your experiences of attending the group and you will be asked to consider how this relates to how you understand your beliefs. Our conversation will take place before or after the group in the same building where the group runs.

Will my information be safe?

I will record our conversation to help me remember what we have discussed. All the information you share with me will be private and confidential within the research team. The recordings will be password-protected and kept in a safe place. The recordings will be kept until the end of the study (April 2019), after which they will be deleted. The interviews will be written up and stored in a password-protected file, so only myself and my supervisors have access to them. If you would like, I can send you a copy of your interview.

Who has reviewed the study?

This study has been reviewed and approved by the University of Essex Research Ethics Committee.

What will happen to the information that I give you?

The results of the study will be written up and submitted to the University of Essex as a thesis document and will be available online. This may include some quotes from the interviews, but I will use pseudonyms and will not include any information that would identify you. In addition, the findings of the study will be directly fed back to individual peer support groups and the London Paranoia & Beliefs Network. Appropriate ways of sharing the findings with a wider audience will be decided by members of the Network, including peer facilitators and group participants. For example, this could include a presentation at the World Hearing Voices Congress.

What are the possible benefits of taking part?

Some people find it helpful to talk about their experiences to someone who is able to listen. Through exploring what members consider helpful or not so helpful about the groups, the study may be useful for paranoia and beliefs support groups as well as the work of the London Paranoia & Beliefs Network. The study could also help increase awareness of the benefits of peer support groups and inform anyone supporting people with beliefs that others consider strange or unusual.

I will be able to offer you £20 to thank you for the time you have taken to participate in this study.

What are the possible risks of taking part?

While I hope that our conversation will be a positive experience for you, it can sometimes be difficult to talk about personal experiences. If at any point during the interview you would like to

take a break, then please let me know. If anything we talk about is difficult for you, it is OK to stop the interview or take a break. How much you tell me is entirely up to you and it is OK to not answer any question that makes you feel uncomfortable. If anything we discuss leaves you feel upset, we can talk about. I will also provide you the details of where you can access additional support.

Who is conducting the research?

I have a longstanding interest in peer-led alternatives to mainstream mental health services and professional models of expertise. I was introduced to the work of the Paranoia Network in 2009, as an organisational member of the European network of (ex)users and survivors of psychiatry and have attended group facilitation training through the London Paranoia & Beliefs Network.

What if there is a problem?

If you have any concerns or complaints about any aspect of the way you have been approached or treated during the course of the study, you can contact me and I will do my best to answer your questions. Alternatively you can contact my research supervisors, Danny Taggart (dtaggart@essex.ac.uk) or Lisa Wood (ljwoodm@essex.ac.uk).

Thank you very much for taking the time to read this information. If you would like to take part or would like to find out more about the study, please contact me on: Tel: 07964528179 or Email: rb16064@essex.ac.uk

Appendix C: Interview Topic Guide

Interview Topic Guide

Introduction:
Thank you very much for agreeing to take part in this study. Our conversation should take up to 1 hour. If at any point during our conversation you would like to take a break, then please let me know. It can sometimes be difficult to talk about personal experiences; if anything we talk about today is difficult for you, it is OK to stop the interview or take a break. How much you tell me is entirely up to you and it is OK to not answer any question that makes you feel uncomfortable. This study is separate to any support you receive from (name of host organisation/group) and taking part does not affect any support you get.

As we discussed, I will record our conversation to help me remember what we have said and I will remove any information that would identify you. You can choose a pseudonym for the study if you like. All the information you share with me is private and confidential within the research team (myself and my supervisors), unless you say something that leads me to think that you or someone else may be at risk of significant harm. Only on those occasions, and as part of my duty of care, I will need to pass on information to a third party (e.g. your GP) to make sure you are safe.

I have some key points here to guide our conversation, but this is flexible to allow us to discuss issues that are relevant to you. As you know, I am interested in your own experience of attending the (name of unusual beliefs) group.

Does that sound OK to you? Is there anything that you would like to ask me before we start?

Demographic information (age, gender, pseudoname, ethnicity, length of attendance, how the participant found out about the group)

Opening question
•What happens in an unusual beliefs group (*Describing the group; similarities and differences compared to other experiences*)

Helpful and unhelpful experiences
•Helpful/Positive experience(s) in the group (*prompt for examples*)
•Not so useful, difficult, or challenging experience(s) in the group (*prompt for examples*)
•Importance/Meaning of being part of a paranoia and beliefs group (A group that specifically focuses on beliefs)

Relating with other members
•Relationships in the group (*How would you describe your own and others' relationships in the group; changes in relationships in the group over time*)
•Thoughts about receiving and offering support to other members (*prompt for any obstacles*)

Impact of the group on you
•Impact of the group on your understanding of your experiences/beliefs
•Positive & negative aspects (*prompt for examples*)
•Other changes in your life as a result of attending the group

History of the group
•Historical origins of the group in the survivor movement (*How much do you know about the history of the Network/the history of the group?*)

•Anything else that you would like to mention
•Thoughts/Reflections on the experience of being interviewed

Appendix D: Examples of extracts of data collated for three codes

An 'antidote' to isolation	My wellbeing, your wellbeing?	An individualised world
before I never used to really mix a lot with people, before. I always sort of used to isolate and things. (P6, 155-156) It gets me out of the house, it improves my life because I'm associating with people. At home I would've been all alone (pause). (P2, 742-745) quite often I found that I felt nourished myself, actually. From just being with other people. Cause I spend my life in isolation. So it does something for me like that. (P7, 163-168) I 've changed, I kind of mix more with people now coming lot to (service). I come out my shell more if you know what I mean. [Coming out of your shell.] I'd say I seem a bit more like happier sort of thing since I've been coming here. (P6, 852-857) Camaraderie, belonging to something, erm having something special in my life. It's a treasure to me, yeah it's right up there. (P9, 873-875) What's helpful is, I used to be extremely isolated and just being in a group where I can talk about personal problems. (P5, 69-70) Yeah, friends. Friends that we share things with, you know talk if we see each other out in the street, have a chat you know, things like that. (P10, 523-525) Coming to the groups can be very helpful. Cause you're meeting people, you're talking with people. It's sort of socialising, ain't it really? Whereas otherwise I'd been at home all the time probably (P6, 208-211)	I'd like to see a person just getting on with their, you know, you know have a good life. And if I can help them I'll help them, you know. And just to be happy in life and enjoy life. That's why we're here on earth. Just get on with our life and not to be miserable all the time, feel sorry for ourselves. (P10, 508-514) I give a lot of my time and a lot of my effort. Because I believe in it. And not just for me and my, they call it...I hate the word recovery. (P9, 926-929) It's for you, and you only, you know. (P4, 276-277) in the group it just goes hand in hand, erm. I think there's no real offering and receiving happening. We're just ourselves and no one, there's no hierarchy or. (P8, 443-445) So sometimes I'll go with that person into the town. She goes to big stores but I hate the big stores. I can't, you know. I used to be terrified, I wouldn't even go to the supermarket...My friend, part of the group is struggling with erm you know she's terrified to get on the tube or a bus...I go in there, you know, around shops, things like that. But it's helping me too (P10, 527-534) Not only expecting help from others…I need to offer help as well. I like helping others, I really do. If I someone who's upset, I will approach them and ask 'Please don't be upset with my question, I want to know what happened to you'…They may say 'Today I'm not in a good mood'. Alright, 'Would you like a cup of tea? I can make some tea for you'. I try, I try. (P11, 224-233) Because, we are on the same boat, we know how life hard can life be when you deal with the symptoms so it's like almost like you wanna help somebody that's in the same boat, having the same problems. (P5, 575-580)	because I think the other thing is also erm when mum was alive we, sister, brother used to meet in mum's house, you know, every now and then, fortnightly whatever…and that has all stopped. (P2, 204-210) Well, we chat, and we're friends, and erm …but one thing I really value in this group as well is is that I probably wouldn't have met these people otherwise. If it wouldn't be for this group…we all socialise and interact within our own bubble don't we all? Do you know what I mean? Bubble of people that we interact with. (P8, 321-330) Alright, you can take a tablet and things like that but it's not the answer, you know. The answer is to free yourself from, you know, different things...You know just talk. (P10, 384-387) You know because on some level we all are, you know we are all connected and we all have that, well, I believe we all have a divine spark within us that connects everyone. It's just that a lot of the time we feel unfortunately alone and individual and that's very painful. (P1, 237-244) And it's horrible, it's horrible, yeah so people don't understand it, people don't want to know. [Why do you think that people don't want to know?] Because it doesn't, as long as it doesn't affect them, it's over there it's yours. Doesn't belong to me, ain't my problem you 've got problems. (P9, 98-107)

Appendix E: Ethical Approval

University of Essex

07 November 2017

MR ROUPEN BARONIAN
FLAT 3
19 LYDFORD ROAD
LONDON
NW2 5QY

Dear Roupen,

Re: Ethical Approval Application (Ref 17002)

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by the School Ethics Representative on behalf of the Faculty Ethics Committee.

Yours sincerely,

Lisa McKee
Ethics Administrator
School of Health and Human Sciences

cc. Research Governance and Planning Manager, REO
Supervisor

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Resources in the event of distress

Should you feel distressed either as a result of taking part in this study or in the future, the following resources may be useful:

- Your GP

- The Samaritans offer a listening service 24 hours a day, 365 days a year

www.samaritans.org

National freephone number: 116 123

- SANEline offers emotional support and information between 4:30pm and 10:30 pm every evening

- MIND Information Line offers mental health information from 9:00am to 18:00 pm during weekdays. Tel. 0800 123 3393, text 86463

email info@mind.org.uk

If you are experiencing a mental health emergency, you are urged to seek support through:

- Calling or texting a friend or family member

- Going to your local Accident and Emergency department or calling 999 if you need an ambulance

- Booking an emergency appointment with your GP

- Contacting your crisis team, if you already have one

Appendix G: Receipt of Payment

Receipt

I hereby confirm that I have received £_____for my participation in the study '*Peer support groups for unusual beliefs: A qualitative analysis of members' experiences'.*

Name:

Signature:

Date: